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The wellbeing of family members of children on the Autism Spectrum

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Contents

Chapter 1: Literature Review

Understanding of minds: implications for siblings of children on the Autism Spectrum

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Chapter 2: Empirical Paper

Factors associated with the wellbeing of parents of children on the Autism Spectrum

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Chapter 3: Reflective Paper

Conducting research with families with children on the Autism Spectrum: methodological, ethical and personal reflections

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Page number

List of Appendices

List of Tables

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Finally, to my parents, my sister Eve, and to Celt, it is your confidence in me that makes everything possible. Thank you.

Declaration

This thesis was carried out under the supervision of Dr Sarah Kent, Dr Camilla Watters and Ms Jacky Knibbs. Authorship of published papers will be shared with the above. Ideas for this research were my own, and followed discussions with Dr Sarah Kent, Dr Camilla Watters and Ms Jacky Knibbs. Apart from the above collaborations, all of the material presented within this thesis is my own work. This thesis has not been submitted for a degree to any other university.

Ethical approval was obtained from Coventry University Research Ethics Committee and from Coventry Local Research Ethics Committee.

Summary

This thesis consists of three papers, a literature review, an empirical paper and a reflective paper. The main focus of the literature review is on ‘understanding of minds’ and the development of this ability in siblings of children with a diagnosis on the autism spectrum (DAS). Evidence from clinical and non-clinical populations suggests that this group may be particularly vulnerable with regard to developing difficulties associated with an understanding of minds. Methodological issues are discussed and the findings are summarised with particular reference to clinical and ethical implications.

The empirical paper reports on a study of factors associated with the wellbeing of parents of children with DAS. Measures of parental competence, child difficulties, family cohesion, relationship satisfaction and the impact of the child with DAS on the parental relationship and siblings, were all obtained from parents of school age children with DAS. Parental competence, depression in the other partner, and family and relationship variables were found to be associated with parental wellbeing. Parental stress was predicted by child pro-social behaviour. Differences were found between mothers and fathers on a number of variables. In addition to pro-social behaviour, maternal stress was further predicted by child behaviour problems. Maternal depression was predicted by age, the impact of the child on the parental relationship and the impact of the child on siblings. Results were considered within the context of a number of methodological issues. Implications for clinical interventions for families of children with DAS were discussed.

The thesis concludes with reflective material drawn from observations made whilst recruiting participants, collecting data and by contact with research participants. The paper summarizes with an account of the areas of learning arising from these reflections.

Chapter 1

Literature Review

Understanding of minds: implications for siblings of children on the Autism Spectrum

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To be submitted to Child Development

1.1 Abstract

The aim of this paper is to explore existing literature pertaining to a specific group of individuals, namely those with a sibling or siblings with a diagnosis on the autism spectrum (DAS)[1]. There will be a particular focus on the ability termed in this paper as ‘understanding of minds’ and the development of this ability in siblings of individuals with DAS. A full understanding of minds refers to the ability to attribute mental states to oneself and others, and to understand that others have mental states different from one’s own.

At present, there exists a debate as to how the knowledge associated with an understanding of minds is acquired. A recurring theme within current arguments is the issue of disentangling environmental and genetic influences on the development of this ability. It is proposed that these discussions have particular relevance to siblings of children with DAS.

Before focussing on siblings, research exploring how children both with and without DAS demonstrate an understanding of minds are considered. Two distinct, yet related sets of literature are then reviewed. First, evidence from the wider sibling research field highlights the role of siblings’ learning experiences and the particular family environment in which they are raised in the development of an understanding of minds. Second, research with siblings of individuals with DAS implies that these children may experience added difficulties with an understanding of minds due to a genetically based predisposition. In short, this combination of environmental and genetic influences may render siblings of children with DAS vulnerable with regard to

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[1] The term ‘diagnosis on the autism spectrum (DAS)’ will be used throughout this paper and should be considered interchangeable with the term pervasive developmental disorders (see DSM-IV) and represent individuals with autism (both with and without formal diagnosis of autistic disorder), Asperger’s syndrome and pervasive developmental disorder not otherwise specified (PDDOS).

developing difficulties with understanding minds and as a consequence, worthy of particular attention. Findings are considered in the context of a number of methodological limitations. Finally, clinical and ethical implications are discussed.

1.2. Literature search strategies

Three search strategies were used to collate the literature included in this review. First, three databases were searched, Web of Science, SCOPUS, and PsycINFO. Searches were carried out in August/September 2008 and January 2009. The following search terms were used: *Asperger*, autism, ASD, pervasive developmental disorder, theory of mind, central coherence, false belief, understanding mind*, broad* autism phenotype, sibling**. Only peer reviewed publications in English were included. Second, reference lists of relevant publications identified through this process were checked for search terms. This process was repeated for every new publication identified thereon. Finally, all past issues of *Journal of Autism & Developmental Disorders* were searched for relevant publications.

1.3 Understanding minds

To acquire a mature understanding of minds, one must be able to infer the full range of mental states that cause action (Baron-Cohen, 2001). These mental states include beliefs, perceptions, memories, cognitions, desires, intentions, imagination and emotions. Importantly, possessing this ability is to be able to attribute mental states to oneself and others, and is fundamental to understanding the social world.

Many researchers subscribe to the term 'theory of mind[2]' (ToM; Premack & Woodruff, 1978) as a means of defining this ability.

As work in this field has developed, researchers have posed a number of theoretical questions regarding the origins, nature and representation of an understanding of minds (e.g., Carruthers & Smith, 1996; Garfield, Peterson, & Perry, 2001). In contrast to these ongoing and often conflicting debates (see Hughes & Leekam, 2004 for a review), there is wide consensus regarding the presentation of typical and atypical development pathways associated with an understanding of minds. The following section will attempt to provide a brief overview of this development, as observed in both typical development and in individuals with DAS.

1.4. The development of an understanding of mind

In their classic study, Baron-Cohen, Leslie, and Frith (1985), discovered that, compared to typically developing children or children with Down Syndrome, children with autism demonstrate significantly poorer comprehension of the behavioural consequences of a person's entertaining of an objectively false belief. Entertaining false belief is to recognize that others can have beliefs about the world that are wrong. To do this, one must be aware that people's beliefs are based on their knowledge, and

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[2] It has been proposed that a number of skills observed in infancy (e.g., joint attention, eye gaze monitoring, imitation, pretend play, communicative gestures and vocalisations) are indicative of developmental precursors of 'theory of mind' acquisition (e.g., Baldwin & Moses, 1994; Bates, 1979; Dunn, 1996; Meltzhoff, Gopnik & Repacholi, 1999; Tomasello, 1995). Specifically, it is suggested that these behaviours are directed at achieving a connection with another mind. Without an appreciation of the mental states of others, such behaviours would be unlikely to occur, as their purpose would not be comprehended (Travis & Sigman, 1998). The current paper will use the wider term 'understanding of minds' as well as the term 'theory of mind' to encompass these 'fledgling' skills.

For the purposes of this paper, the adoption of the terms 'understanding of minds' and 'ToM' is associated with a neutral position among the current debates regarding the aetiology of this knowledge and how it might be acquired and represented.

have an understanding of the conditions under which a belief is formed. In addition, one must also understand that mental states can differ from reality and that another's behaviour can be predicted by their mental states.

Research following Baron-Cohen et al. (1985) has conclusively demonstrated that individuals with autism show an impaired ability to postulate the existence of mental states, thus, making it difficult for these individuals to explain and predict anothers' behaviour. As a consequence of this work and others, an impaired ability to understand minds is often cited as one of the core deficits of autism and is presumed to explain the problems these individuals encounter with regard to social functioning and communication (Yirimiya, Erel, Shaked, & Solomonica-Levi, 1998). Before the nature of this impairment is explored in more detail, an outline as to how an understanding of minds typically develops will be provided. This will then be compared against empirical observations of understanding of minds in individuals with DAS.

1.4.1 Typical development

Considerable evidence has emerged that an understanding of minds, or at least some essential component(s) of it, usually develops early on in childhood and seems relatively set in terms of sequence. Although there is some disagreement as to whether this process is culturally universal (see Vinden, 1996; 1999), the relatively fixed nature of the process is perhaps the strongest support for a modular account of the development of an understanding of minds (e.g., Leslie, 1994; Baron-Cohen, 1995; Baron-Cohen, & Sweetenham, 1996). Key behaviours assumed to be associated with this ability include joint attention behaviours and pretend play. At around a year old, children demonstrate joint attention behaviours such as monitoring eye gaze (Baron-

Cohen, 1995; Butterworth & Jarrett, 1991) and can direct another person (e.g., by pointing) to attend to something of interest (Bates, Benigni, Bretherton, Camaioni, & Volterra, 1979). Gaze checking is often assumed to indicate that the child is aware of the other's mental state (Tomasello, 1999). By fourteen months, pretend play is also evident in typically developing children (Bretherton, 1984) and by the age of two, children understand that people have subjective experiences such as desires and emotions (e.g., Bartsch & Wellman, 1995; Repacholi & Gopnik, 1997). They are able to report their own desires, attribute desires and emotions to others, and can associate desires and behaviours (Gopnik & Slaughter, 1991). By the age of three, children understand and use propositional attitude expressions (de Villiers & de Villiers, 1999). It is proposed that these early understandings and observations reflect the developmental precursors of a knowledge of persons as intentional experiencers of inner states (e.g., beliefs, hope, desires), and an awareness that these states can be used to predict and explain behaviour.

The understanding of false belief is thought to mark an important step in the acquisition of ToM (Astington, Harris, & Olson, 1988; Perner, 1991). A large body of work consistently demonstrates that children are usually able to pass tests of false belief[3] by the age of four (e.g., Karmiloff-Smith, 1992; Lewis & Mitchell, 1994; Light, 1993) and it is generally accepted that ToM is usually empirically demonstrated between the ages of 3 and 5 years (Flavell, 2000).

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[3] A typical test of false belief (for e.g., see Baron-Cohen et al., 1985) involves the child under study being privy to information that a doll character or an actor does not have. As a consequence, the doll or actor holds a false belief about where a particular item is located. To pass the test, the child must correctly infer where the doll or actor might search for the item on the basis of their false belief.

1.4.2 Individuals with DAS

A small number of studies suggest that, in children with DAS, an impaired understanding of minds may be apparent as early as one year old (Baron-Cohen, 2001). Indeed, children around 18-months who show reduced, or lack joint attention and pretend play behaviours, have been shown to be at higher risk for acquiring a later DAS (Baron-Cohen, Allen, & Gillberg, 1992; Charman, Swettenham, Baron-Cohen, et al., 1998; Wong, Hui, Lee, et al., 2004).

As a diagnosis is unlikely to be made before the age of three years (Gillberg, Ehlers, Schaumann, et al., 1990), the majority of research in this area has been conducted with school age children and young people. Unlike typically developing children, individuals with autism usually fail tests of false belief task well beyond four years. Children with intellectual disability indicative of a lower mental age, but without DAS, usually pass the same tasks (e.g., Baron-Cohen et al., 1985). This has led to the assumption that the difficulties children with DAS demonstrate cannot be explained in terms of general cognitive deficits (e.g., Baron-Cohen et al., 1985; Happé, 1995; Perner, Frith, Leslie, & Leekam, 1989). Double dissociations of ToM from social and general intelligence have also been cited as compelling evidence for understanding of mind modules (Garfield et al., 2001).

Children with DAS also show impaired production and comprehension of joint attention (see Charman, 1997, 1998 for reviews) and produce less pretend play compared to mental age matched or chronological age matched comparison groups (see Jarrold, Boucher, & Smith, 1993, for a review). They also experience problems in understanding intention (Phillips, Baron-Cohen & Rutter, 1998), complex emotion (Baron-Cohen, Spitz, & Cross, 1993), knowledge (Leslie & Frith, 1988), and are impaired with regard to empathic responses to distress (Sigman, Kasari, Kwon, & Yirimiya, 1992).

A number of other studies have reported associations between an understanding of mind and aspects of social understanding. Findings report significant relationships between DAS and ToM impairments in understanding jokes and lies (Leekam & Prior, 1994), deception (Sodian, 1991) and irony, double bluff and white lies (Happé, 1994).

1.5 Aims of review

It is accepted that difficulties associated with an impaired ability to understand minds are likely to pose a number of challenges for individuals with DAS. However, in addition to those studies exploring the effects of DAS on the individual, other work has explored the effects of DAS on family members such as parents (e.g., Rodrigue, Morgan & Geffken, 1990; 1992). The current review aims to extend this work by focussing on the siblings of individuals with DAS. This group have received significant research interest over the years, mainly focussed on the identification of factors associated with adjustment (e.g., Benson & Karlof, 2008). Despite this, there is a surprisingly limited amount of attention devoted to the development of an understanding of minds in this group. Findings from two distinct, yet related sets of literature suggest that this issue is a potentially important one and this proposition forms the rationale for the current paper.

Findings from the wider sibling literature and the autism literature will be reviewed. By drawing these two sets of literature together, the current paper aims to illustrate that having a sibling with DAS could place the individual in a uniquely vulnerable position with regard difficulties in understanding of mind development.

First, literature relating to understanding of mind development in siblings of typically developing children will be discussed. This work explores the importance of sibling variables as predictive candidates of individual variation in the acquisition of an understanding of minds. The following section will attempt to review this research in detail with an aim to determine the interpersonal impact of siblings on developing an understanding of minds. If sibling presence is found to be influential in the development of an understanding of minds in the absence of autism, this may have important implications for those individuals who do have a sibling with DAS.

1.6 Siblings of typically developing children

Studies have found that the presence of siblings can have a beneficial effect on the age at which children acquire ToM (e.g., McAlister & Peterson, 2007; Perner, Ruffman, & Leekam 1994). Perner et al. reported a linear effect, in that children with 2 to 3 siblings were almost twice as likely to pass tests of false belief than only children. In fact, the sibling advantage was comparable to the age advantage of 4-year olds over 3-year olds (the age associated with greatest improvement in ToM performance). Additionally, children with one sibling did not show any advantage of whether that sibling was older or younger in facilitating earlier understanding of false belief.

Following Perner et al., Jenkins and Astington (1996) conclude that it is the number of siblings, rather than birth order, which is important for the development of false belief understanding, even after controlling for verbal mental age and chronological age.

Ruffman, Perner, Naito, Parkin, and Clements (1998) claimed that both Perner et al. (1994) and Jenkins and Astington (1996) may have underestimated the degree of efficacy of birth order on false belief understanding. Indeed, the earlier effect Perner et al. (1994) report for total number of siblings could have solely been accounted for by older rather than younger siblings. Perner et al. (1994) compared the performance of children with only one older sibling with children with only one younger sibling, irrespective of how many older versus how many younger siblings there were. Given the linear nature of the sibling effect, it is possible that degree of sibling influence was underestimated in this analysis.

Ruffman et al. (1998) sought to address these issues by directly exploring the influence of younger versus older siblings on false belief understanding. Ruffman et al. reported a clear advantageous impact on false belief understanding for older, but not younger siblings. The authors also reported that this effect was restricted to children 3 years 3 months and above.

Lewis, Freedman, Kyriakidou, Maridaki-Kassotaki, and Berridge (1996) also report the older sibling advantage. In their sample, middle children displayed the highest levels of performance on false belief tasks with four variables jointly best predicting performance (age, the number of adult kin living in close proximity, the number of younger, and the number of older siblings of the child). Lewis et al. also reported that families that were large due to the presence of other family members, had an equally beneficial effect on ToM development as families that were large due to more siblings. In short, they argued that there was a ‘general apprenticeship’ provided by interacting with family members that could explain ToM enhancement, rather than a specific sibling effect.

In contrast, Peterson (2000) reported that neither overall family size nor birth order were significant predictors of ToM development. In her study, the presence of a younger sibling or a twin was found to be just as effective as an older sibling in enhancing ToM. Children whose sibling constellation was the most varied demonstrated the best performance. Specifically, these were middle children with a larger number of siblings within specified age boundaries. For a sibling effect to occur, the sibling(s) had to be aged between 1- to 12- years. This age boundary effect was replicated in two later studies. McAlister and Peterson (2006) showed the effect using a broader range of ToM tasks, whereas Wright-Cassidy, Fineberg, Brown & Perkins, (2005) demonstrated the effect with twins, but only those who had one or more siblings either older or younger than themselves. Wright-Cassidy et al. (2005) also observed that children with opposite sex siblings outperformed children with same sex siblings.

Other studies report null effects associated with the presence of siblings and performance on ToM tasks. Cutting and Dunn (1999) sampled children from low income families that comprised a high proportion of stepparents, single parents, stepsiblings and other adults. Although the analysis did not test the effect of siblings as a separate category, no significant effects of family size were reported. Cole and Mitchell (2000) confirmed this null effect and also demonstrated the predictive value of socio-economic status. Cole and Mitchell proposed that the level of socio-economic disadvantage in their sample had a ‘contaminating influence’ (p.279) on the sibling advantage. In accordance with these results, Hughes and Ensor (2005) similarly failed to observe any association between sibling numbers and scores on ToM tests. However, these authors also recruited families from economically disadvantaged backgrounds. Finally, a study by Peterson and Slaughter (2003) also failed to report the sibling effect. However, this result was attributed to a lack of variety among the sibling constellations in their sample.

1.6.1 Summary

Although the research suggests that siblings may confer some advantage on understanding of mind ability, current evidence is mixed. It is possible that null effects may be due to the failure of some studies to consider sibling age, (Peterson, 2000), or due to the use of twins (Wright-Cassidy et al., 2005). Furthermore, the sibling effect may only apply to siblings within a certain age range and/or constellation (McAlister & Peterson, 2007; Peterson, 2000; Ruffman et al., 1998), gender (Wright-Cassidy, 2005), or from particular social backgrounds (Cole & Mitchell, 2000). If we accept that siblings do seem to benefit understanding of mind development, what might constitute the nature of the sibling effect? The following section aims to consider some possibilities that have arisen from studies in this area.

1.7 The nature of the sibling effect

Children with child age siblings are known to spend large amounts of time together (Dunn & Kendrick, 1982). Indeed, Dunn (1988) suggested that the sibling relationship provides the most intensive social experience for children aged around 2 and 3 years. It is assumed that this provides children with the opportunity to continually share experiences and activities that could enhance social-cognitive development.

A child who has one or more siblings will differ from an only child in a number of ways. These children may be more exposed to mental state discourse in their families, giving them more opportunity to master the meanings of words related to mental states and the mind (Jenkins, Turrell, Kogushi, et al., 2003). Furthermore, siblings may generate specific kinds of conversations that facilitate understanding of mind abilities. Dunn, Bretherton and Munn (1987) observed that conflict between siblings tended to elicit the most conversation from mothers about feeling states. Conflict may also generate discussion around affective perspective taking and negotiation (Dunn, 1996).

Play has been associated with the use of internal state language (Brown, Donelan-McCall, & Dunn, 1996) and requires cooperation and competition (Cole & Mitchell, 2000). Play also requires children to suspend reality, a skill relevant to simulation theories of understanding of mind development (e.g., Harris, 1992).

Cole and Mitchell (2000) postulated that siblings might accelerate the development of executive abilities, and that this may in turn, accelerate the development of ToM. However, their study failed to find a beneficial effect of siblings upon executive abilities. McAlister and Peterson (2006) reported that, alongside sibling interaction opportunity and language ability, scores on tests of executive functioning were found to predict scores on ToM tasks. However, the role of executive ability as a mediator for the sibling effect on ToM tasks was not found.

Verbal ability has also been associated with enhanced understanding of mind. The sibling relationship may offer increased opportunity for verbal interaction thus raising a child’s level of verbal ability. However, Wright-Cassidy et al. (2005) revealed that sibling benefit transcends more verbal ability, suggesting the involvement of other factors. Finally, Hughes and Ensor (2005) found that the affective quality of the sibling relationship predicted enhanced ToM even after controlling for executive functioning, verbal ability, age and quality of the parent-child relationship. They suggest that the variance in ToM seen in their sample may be the result of, or a precursor of, affectionate communication and play among siblings.

In summary, it is likely that continuing sibling and family based social experiences could plausibly benefit the child's understanding of other minds. If so, what implications does this have for siblings of children with DAS? It is possible that having a sibling with an atypical or less than optimal understanding of minds, may leave siblings vulnerable to developing difficulties with understanding minds and as a consequence, social relationships. Furthermore, in addition to environmental factors, findings from the autism literature suggest that heritability factors may also add to the vulnerability of this group of individuals. This research is reviewed in the following sections.

1.8 Siblings of children with DAS

One source of evidence suggesting that siblings of individuals with DAS may display vulnerability in terms of an understanding of minds deficit is taken from heritability studies which provide support for a strong genetic basis for autism (e.g., Szatmari, Jones, Zwaigenbaum, & MacLean, 1998). Increased concordance rates in monozygotic twins compared to dizygotic twins has consistently been found (Bailey, Le Couteur, Gottesman, et al., 1995; Folstein & Rutter, 1977; Ritvo, Freeman, & Mason-Brothers, 1985; Steffenberg, Gillberg, Hellgren, et al., 1989; Veenstra-VanderWeel, & Cook, 2003). Smalley, Asarnow, and Spence (1988) report a range of sibling risk rates for autism from 2.8% to 7%, figures substantially higher than those recorded in the general population.

Related literature has shown that heritability may not manifest as the full clinical presentation of autism, but may resemble milder features or one or more of the cognitive and/or behavioural characteristics. These have been found in both parents and siblings of children with DAS (e.g., Bailey et al., 1995; Baker, Piven, Schwartz, & Patil, 1994; Landa & Garrett-Mayer, 2006; Nayrayan, Moyes, & Wolff, 1990; Zwaigenbaum, Bryson, Rogers, et al., 2005). This type of presentation has been termed the broad autism phenotype (BAP) (Folstein & Rutter, 1977; Piven, 1999; Rutter, 2000).

At present there is no consensus as to the exact nature of what is inherited, although a number of studies suggest that the profile of the BAP involves deficits in understanding of mind skills (Bailey, Goode, et al., 1996; Baron-Cohen, Bolton, Wheelwright, et al., 1998; Hughes, Plumet & Leboyer, 1999; LeCouteur, Piven & Palmer, 1997; Piven, Wzorak, Landa, et al., 1994; Wolff, Narayan, & Moyes, 1988). Research addressing this proposal has yielded mixed findings, and a detailed exploration of this work is provided below.

1.8.1 Understanding of minds in siblings of children with DAS

1.8.1.1 Joint attention

A reduced propensity to engage the attention of others and respond to another's bid for attention may contribute to deficits in the ability to understand the mental states of others. A number of studies have reported that siblings of individuals with DAS demonstrate differences in these early indicators of an understanding of minds (e.g., Bryson, Zwaigenbaum, Brian et al., 2007; Sullivan, Finelli, Marvin, Garrett-Mayer, et al., 2007; Toth, Dawson, Meltzoff, Greenson, & Fein, 2007).

Using a prospective approach, Bryson et al. (2007) followed nine younger siblings of children with autism, from 6-months to 36-months of age. All children showed varying degrees of impaired social communicative development (as indicated by limited/lack of: social referencing, self-initiated contact with others, giving or sharing of interest in object/event, distal pointing, imitation, etc). According to maternal reports, some also showed a loss of emotional connectedness over time. All children went on to receive a DAS at 36 months. In a second prospective study, Sullivan, et al. (2007) examined joint attention skills in 51 younger siblings of children with autism at aged 14- and 24- months. The authors report that joint attention deficits were present at 14- and 24- months for these children. Outcome data at 36- months of age indicated that 16 children met both diagnostic criteria and clinical judgement for a DAS, and a further 8 met criteria for the BAP (based on a language delay or on a clinical judgement of social/behavioural/communication difficulties). For the purposes of the present paper it would have been helpful to have compared performance of those children who did not receive a DAS or who were not classed as BAP with siblings of typically developing children. Together, however, these studies suggest that siblings of children with autism who later develop DAS themselves may show deficits in an understanding of minds as early as 14 months of age.

Whereas some prospective studies have focussed on younger siblings who received a DAS, other studies have concentrated on younger siblings who do not have a diagnosis (e.g., Cassel, Messinger, Ibanez, et al., 2007; Goldberg, Jarvis, Osann et al., 2005). This is either because the children included have been too young to determine outcome, or have included children who do not meet diagnostic criteria.

Cassel et al., (2007) used the Still Face procedure[4] to compare social-communicative abilities in 12, 6-month old younger siblings of children with DAS and 19 matched siblings of typically developing children. Cassel et al. retested these infants at regular intervals up to age 18-months using the Early Social Communication Scales (ESCS; Mundy, Hogan, & Doehring, 1996). Taking into account the small and varied number of ESCS measures collected at each time point, and mindful of the multiple comparison procedure, it can be tentatively accepted that siblings of children with DAS initiated fewer joint attention bids (e.g., using gestures and gaze to declaratively/proto-declaratively communicate about an object/event in the environment) than comparison siblings at 15 months.

This finding is supported by previous work by Goldberg et al. (2005) who also used the ESCS to assess a sample of children under 3 years. Although small sample sizes were used (8 in the DAS sibling group and 9 in the comparison group), Goldberg et al. reported that younger siblings of children with DAS in their study showed deficits in initiating joint attention which did not differ from their older affected siblings, but differed significantly from a third group of typically developing children. In contrast, Yirmiya, Gamliel, Pilowsky et al. (2006) found no deficits in their larger sample of 21 siblings of children with autism with regard initiating joint attention at 14 months of age when compared to siblings of typically developing children (as assessed by the ESCS). At 4- months old, these infants had been observed with their mothers during a free play interaction period. It was reported that siblings

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[4] In this paradigm, the mother engages the infant by smiling, talking and making eye contact, for a predetermined period. She then presents the ‘‘Still Face’’, i.e., looking at the infant while displaying a blank, neutral expression. Reciprocal interaction is then resumed. The pre- and post- interaction episodes are used to assess the social capabilities of the infant and the Still Face episode is used to observe how the infant reacts to socially induced anxiety.

of children with autism and their mothers were observed to be less synchronous during interactions led by the infant. Synchrony has been associated with impairments in both joint attention and ToM (e.g., Leekam, Baron-Cohen, Perret, Milders, & Brown, 1997; Yirmiya et al., 1998). However, it is possible that maternal factors may also affect synchrony in mother-infant interactions. This issue is discussed in section 1.8.2.2.

With regard to observations of responses to joint attention bids using the ESCS (e.g., following pointing behaviour), inconsistent findings are similarly reported, with some studies reporting differences between the siblings of typically developing children and siblings of children with DAS (Cassel et al, 2007), and others finding no difference (Goldberg et al., 2005; Yirmiya et al., 2006).

Other research indicates that siblings of children with autism have more difficulty locating the target of an adult’s attention, than do siblings of typically developing children (Cassel et al., 2007; Presmanes, Walden, Stone, & Yoder, 2007). Presmanes et al. used 10 different types of attention-specifying prompts and found that responding to joint attention was particularly difficult for siblings of children with autism when prompts involved directing verbalisations combined with gaze shifts. Interestingly, in this study, siblings of children with autism did not show lower rates of disengaging attention from toys and looking toward the experimenter. However, this observation has been reported for siblings of children with autism who later receive a diagnosis (Zwaigenbaum, Bryson, Rogers, et al., 2005).

In summary so far, it appears that findings are highly varied with regard differences in joint attention behaviours between siblings of children with DAS and siblings of typically developing children. Some studies report initiating joint attention differences between these groups (e.g., Cassel et al., 2007; Goldberg, et al., 2005), whereas others report no difference (e.g., Toth, et al., 2007; Yirmiya, et al., 2006). Further inconsistencies are reported with regard responding to joint attention bids; again, some studies reporting differences between sibling groups (e.g., Cassel et al., 2007; Presmanes et al., 2007) and others finding no difference (e.g., Goldberg, et al., 2005; Toth et al., 2007; Yirmiya, et al., 2006). In light of these mixed reports, it may be useful to consider other early indicators of an understanding of minds.

1.8.1.2 Play, imitation and other indicators

In addition to joint attention bids, play and imitative behaviours have also been implicated as precursors to an understanding of minds. Toth et al. (2007) explored a range of early social communication, imitation, play, and language abilities in 42 18- to 27- month old siblings of children with autism. Results were compared with those of 20 children with no family history of autism. Siblings of children with autism obtained lower scores on parent report measures of symbolic behaviour (including symbolic object use during play). According to their developmental histories, these children were also reported to have more social difficulties compared to typically developing children.

In a sample of 64 siblings of children with DAS and 42 siblings of typically developing children, Stone, McMahon, Yoder, and Walder (2007) assessed play, requesting, directing attention, and imitation using the activity based Screening Tool for Autism in Two-Year Olds (STAT; Stone, Coonrod, Turner, & Pozdol, 2004). Children were aged between 12- and 23- months. Weaker performance was revealed for siblings of children with DAS. Lower social-communicative performance as measured by an assessment of social engagement behaviours (e.g., turn taking, referential eye contact) was also reported by the parents of these children.

In addition to the work conducted with pre-school children, a number of studies include samples of older siblings. Bolton, Macdonald, Pickles, Rios, Goode, et al. (1994) interviewed parents of 99 individuals with autism and 36 individuals with Down syndrome. One aspect of the interview schedule was designed to examine reciprocal social interaction and included measures of affective reciprocity, social play and friendship in all first degree relatives over the age of 8 years. Analysis revealed an increased rate of deficits in these areas for the 137 siblings of individuals with autism compared to the siblings of individuals with Down syndrome. Szatmari, Jones, Tuff, Bartolucci, Fisman, et al. (1993) used the same family history method as Bolton et al. (1994) and included siblings between 6- and 18- years. However, Szatmari et al. reported no differences with regard rates of social play between their samples of 84 siblings of children with DAS and 55 siblings of children with Down syndrome or low birth weight. Similarly, Folstein, Santangelo, Gilman, Piven, Landa et al. (1999) reported no differences between siblings of children with autism and siblings of children with Down syndrome on measures of friendship (specifically intimacy and reciprocity).

1.8.1.3 Theory of mind

There are a small number of studies that directly focus on the mature acquisition of an understanding of minds in family members of individuals with DAS.

Baron-Cohen and Hammer (1997) recruited 30 parents of children with DAS and 30 parent controls. Groups were compared on performance on an adult test of ToM, termed the Reading of Mind in the Eyes Test[5] (Baron-Cohen, Jolliffe,

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[5] Participants are shown pairs of eyes and presented with a time limited, forced choice between 2 mental state terms. They are then required to indicate which term they believe best describes the mental state depicted by the eyes.

Mortimore, & Robertson, 1997). Baron-Cohen and Hammer (1997) reported that parents of children with DAS demonstrated poorer performance compared to the control group. Dorris, Espie, Knott, and Salt (2004) replicated this study using a sample of siblings of children with DAS. Twenty-seven siblings of children with DAS participated, with an age range of 7 to 17 years. Their performance on the Eyes Test was compared with that of a matched group of siblings of typically developing children. Findings indicated that siblings of children with DAS performed significantly less well than the siblings of typically developing children.

Conversely, other studies that have directly explored an understanding of minds in siblings of individuals with DAS have reported null effects. Ozonoff, Rogers, Farnham, and Pennington (1993) compared 18 siblings of individuals with DAS and 18 siblings of individuals with intellectual disability. Performance on tasks of executive function and ToM were assessed. In terms of ToM assessment, participants were required to complete a second-order belief attribution task[6]. They were then required to read a fable and modify the language so that it might be understood by a young child. Finally, participants were presented with pictures and asked to narrate the story it illustrated from another's point of view. Ozonoff et al. found no group differences on the ToM variables, however, they concede that lack of power may have influenced results. Furthermore, participants in this study were aged between 8- and 18- years, with a median age of 11.8 in the siblings of individuals with DAS group and a median age of 12.5 in the group of siblings of individuals with a learning disability. As children typically pass ToM tasks by around age 4, it is possible that any group differences in the Ozonoff et al. (1993) study may have been concealed by age variability and older median ages. Consequently, Shaked, Gamliel,

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[6] Second-order tests involve considering embedded mental states (i.e., one person's mental states about other mental states) (e.g., Baron-Cohen, 1989).

and Yirmiya (2006) investigated ToM in a sample of younger children with a tighter age range of 4- to 5- years. Twenty-four participants comprised siblings of children with DAS and 24 were siblings of typically developing children. A false belief task and a strange story task (where the participant must justify why a person in a story has said something they do not literally mean) were administered as measures of ToM. No differences were reported between the two groups. However, despite the common observation that children typically pass tests of false belief at this age, it is of note that only half the children in each group passed both trials. Although this is not a floor effect, it may suggest some dissimilarity between this particular false belief test compared to others.

Briskman, Happé, and Frith (2001) theorized as to the social characteristics that may relate to ToM ability. Briskman et al. generated a list of items regarding social competence; including diplomacy and sociability, enjoyment of the company of others and a tendency to adopt the interests of peers (considered to require the ability to represent others' thoughts and feelings). These questions aimed to collect information relating to real-life social and non social preferences in 8- to 18- year old siblings of individuals with autism, as rated by their parents. Responses were compared to those of siblings of individuals with dyslexia, and siblings of typically developing children. Briskman et al. reported no differences between groups.

To summarize, it appears that there is no firm conclusion as to the degree of risk associated with having a sibling with DAS on understanding of mind development. The heterogeneity of results in this area may be associated with a number of methodological issues, which are reviewed in the following section.

1.8.2 Limitations

1.8.2.1 Sampling issues

A limitation of many of the studies presented is small sample size. This is potentially important with regard group comparisons, as the sample requires enough power to detect a difference between groups if such a difference exists.

In some cases, studies have failed to use an appropriate comparison group. Matched comparison groups are important to control for potential confounding variables and minimize potential sources of bias. When differences emerge, it is important to establish whether difficulties in an understanding of mind are specific to siblings of children with DAS or whether they are associated with other diagnoses, for example language delay and/or other developmental delay.

Many studies have employed siblings of children with Down Syndrome as comparison groups (e.g., Baron-Cohen et al., 1985; Bolton et al., 1994; Szatmari et al., 1993). However, like individuals with DAS, individuals with Down Syndrome may not be a homogenous group in terms of their developmental profile. Indeed, research has shown notable variability in the cognitive and adaptive profiles of children with Down Syndrome (e.g., Dykens, Hodapp & Evans, 1994; Tsao & Kindelberger, 2009). This finding may question the suitability of siblings of children with Down syndrome as an appropriate comparison group. In addition to disorder specificity, matching comparison groups are also important to reduce potential confounds such as age, gender, and birth order (Shaked & Yirmya, 2004).

Another issue relates to exclusion and inclusion criteria. Some studies have excluded siblings of children from various diagnostic groups (e.g., Asperger's syndrome). Therefore, there may be a difference between sibling groups of different studies regarding their relative chance of genetic risk for the BAP.

Method of recruitment may also require consideration. It is possible that parents may participate in studies only after becoming concerned about an aspect of their child's development. This may elevate the chances of difference between siblings of children with DAS and typically developing sibling groups. Conversely, parents may enrol to confirm that there are no developmental issues with their child. Many studies have recruited the siblings of children with DAS through their older, affected sibling. It would be interesting to explore whether similar effects are reported for multiple siblings or siblings who are older than the affected child.

1.8.2.2 Familial factors

In comparison studies, matching familial factors such as education, socioeconomic status and family composition may need to be considered. This information is not included in many of the studies presented here.

Characteristics of the child in the family with DAS may also be important when studying their siblings. Issues such as severity and level of function may influence the parental perceptions of risk and also their likelihood of participating.

Many of the studies presented are characterised by a lack of clinical information regarding the parents of the children recruited to participate. This is particularly relevant for those studies that observe sibling-parent interaction (e.g., Yirmiya et al., 2006). Differences in maternal stress or other characteristics are often not reported. This is important as parents of children with intellectual disabilities reporting high levels of stress may exhibit different parenting behaviour that in turn, may influence child outcomes. For example, parents who are suffering from depression have been observed to interact very differently with their children (Downey & Coyne, 1990). Furthermore, parents with an older child with DAS may have less experience with regard reacting to initiative expressions in their younger children as these were presumably reduced or even absent in interactions with the affected child.

The stress associated with parenting a child with special needs is an important factor to consider in this work. This issue will be returned to later in this thesis and will form the rationale for the Empirical Paper in Chapter 2.

1.8.2.3 Data collection

Parent report has been used as an efficient means of collecting information regarding early history, however, there are a number of limitations of this approach. Parent report may be influenced by poor recall and/or biases toward under or over sensitivity to developmental differences. For example, parental ratings of siblings may be an underestimation of level of impairment as a result of implicit comparison with the child with DAS. Another source of parental bias may originate from BAP confounds. Heritability studies (e.g., Bailey et al., 1995) indicate the increased likelihood of autistic features in parents of children with DAS. It is possible that BAP characteristics in the parents themselves may influence parental report in some way.

There may also be researcher bias, in that lack of blindness to both the status of the sibling and the study hypothesis may result in an over-identification of impairments in the siblings of children with DAS or underestimates of the rates in comparison group siblings. Furthermore, the use of single reports is limiting, as it is not possible to obtain corroborating information from other sources. It is likely that some aspects of difficulties in an understanding of minds would be apparent in particular contexts and under a range of facilitating or interfering conditions that may not be replicated in a research setting. Future work would benefit from obtaining data from as many informants as possible in addition to observation.

1.8.2.4 Measures

The number of times within the study period children are assessed may also be an issue. In the case of typically developing children, there are critical periods of development in which certain behaviours (e.g., joint attention skills) are established (Corkum & Moore, 1998). Multiple assessments during such periods may be required in order to determine any impairment. Furthermore, multiple assessments would establish whether or not any observed delay or impairment at any one time was transient, as in some studies (e.g., Gamliel, Yirmiya, & Sigman, 2007), or stable and robust over time.

Consideration must also be given to the type of assessment tools used. For example, Yirmiya and Ozonoff (2007) point out that some diagnostic instruments used in sibling studies have been standardised with children with DAS and other delays and not necessarily with typically developing children. It is possible that some typically developing children may score close to the cut off criteria on such measures due to difficulties other than DAS related (e.g., anxiety).

The question of how an understanding of minds is best assessed is also worthy of attention. Understanding of minds is a complex concept, presumably involving a number of critical social-perceptual and metacognitive skills that can only be partially assessed by the measures implemented in the studies presented here. Although some tasks are able to reveal robust differences between groups (e.g., Dorris et al., 2004), they may only roughly encapsulate the complex processes which may be compromised in siblings of individuals with DAS. In addition, it is possible that the linguistic content of tests of ToM may contribute variance into the measure, thus serving as a confounding observation of ToM processes.

The false belief test is one of the classic methods in ToM. However, it has been suggested that success at these tasks rests on verbal ability and such success is not the same as false belief understanding (Lewis & Osborne, 1990). Presumably, in addition to verbal ability, successful performance on such tasks also relies on other abilities, such as executive functioning. This is important as in addition to impaired ToM, individuals with DAS can also experience weak central coherence and executive dysfunction (Russell, 1997). Furthermore, Leudall, Costall, and Francis (2004) point out that testing children's ability to represent the intentions of others in laboratory settings rather than observing their intentionality in spontaneous social interactions, may yield very different results.

The methodological issues associated with assessing ToM in individuals with DAS further complicate the interpretations of results of comparison studies. It is therefore important to develop further means of assessing these abilities in future work.

1.8.2.5 Outcome diagnoses

The aim of many of these studies was to directly explore early markers of autism and/or examine features of the BAP. The majority of this work includes infants. Given the strong genetic basis of autism, it is highly likely that a proportion of these children will go on to receive a DAS themselves. As a consequence, one would *expect* to see early markers of ToM difficulties in this group of children, as reported in many of these studies. Therefore, a significant issue regarding the findings of these studies is the lack of stable outcome diagnoses. As a consequence it is uncertain as to whether the group differences reported will remain consistent once the siblings are further divided as a function of outcome. Some findings therefore, may change with time. Children who go on to receive a diagnosis may differ from those children who go on to present aspects of the BAP, and in turn, these children may differ from those who go on to show typical development. In addition, the difficulties observed in some children may resolve over time. On the other hand, it is possible that early differences in social communicative behaviour may influence exposure to crucial social input and have developmental consequences (Mundy & Neal, 2001). Longitudinal, prospective studies are needed to address this issue.

A related issue is how the BAP and its characteristics are defined across studies. Some of the studies presented that involve infants have used a priori definitions taken from the criteria typically used for older children and adults (e.g., performance of a given standard deviation from the mean on standardised assessment tools) (e.g., Sullivan et al., 2007). However, others have developed empirically driven definitions once the outcome diagnosis is known later in childhood (e.g., Bolton et al., 1994). It would be useful for future work to establish a definitive description of the BAP in infancy.

1.8.3 Summary

As discussed, studies of typically developing children suggest that environmental factors may contribute to the vulnerability of this group of individuals. This research implicates the role of the child’s learning experiences and the particular family environment in which they are raised in understanding of minds development. Research drawn from the autism field suggests that siblings of individuals with DAS may possess an added vulnerability to experiencing difficulty with understanding minds due to a genetically based predisposition. Indeed, research from this area suggests that these children do display difficulties with an understanding of minds. In short, it is proposed that through both environmental and genetic influences, the sibling relationship may confer a double disadvantage with regard developing difficulty around an understanding of minds. The following section considers the implications of this proposal.

1.9 Implications

The combination of genetic and environmental influences may affect sibling understanding of mind development in a number of ways. Firstly, having a sibling whose own ability to understand minds is limited may have a direct effect on the typically developing sibling experiencing difficulties. At the very least, one would expect that fewer opportunities exist for siblings of children with DAS regarding the types of communication and interactions described above. Parental factors may also be influential in this regard. For example, parents may divert their attention disproportionately to the child with DAS, thus reducing their availability to communicate with the sibling(s). It is possible that interactions with family members of children with DAS may also be qualitatively different. It is suggested that further research is required in order to explore some of these factors.

1.9.1 Clinical and ethical issues

The research presented in this paper presents both clinical and ethical considerations. In order to conduct this research, investigators must ensure to take both a clinically sensitive and yet rigorous approach to eliciting the concerns of parents. Finding a balance that does not raise undue parental anxiety is highly important. Although one could argue that intervention may be required for siblings, it is important to consider existing stress within the family that may be associated with the child with DAS.

It is difficult to determine the youngest age at which children should be identified as exhibiting characteristics which warrant concern so that intervention can be offered. Assuming that the genetic predisposition is weaker for siblings and that they are more receptive to certain environmental influences, it is possible that they would be ideal candidates for intervention around supporting understanding of mind development. Indeed, research suggests that children with DAS who receive early and intensive intervention have better outcomes than those who undergo treatment later on (e.g., Kazdin & Weisz, 2003). This may also apply to the siblings of children with DAS. These issues raise a number of ethical questions.

Highlighting potential difficulties in subsequent children may not be helpful until more is known about the developmental trajectories of siblings of children with DAS. So how might researchers respond to any concerns of parents that arise out of their work? Worries must be acknowledged with seriousness and sensitivity, even if implications are currently unknown. Also, how might researchers communicate any concerns they might have following their assessments? Clinical expertise is required to interpret assessment findings and provide families with feedback. It is proposed that clinical psychologists may have a critical role in this area. Furthermore, if a sibling seems to be at a high risk of autism, Zwaigenbaum, Thurm, Stone, et al. (2007) ask at what point is there an ethical obligation to share this information with families? On the other hand, in the case of infant participants, potential errors of classification should also be considered. It is possible that some children recruited in these studies may not exhibit stable aspects of DAS. It is proposed that all these issues should be carefully considered in the ongoing development and design of studies in this area.

1.10 Summary

Evidence from the wider sibling research field implicates the role of siblings' learning experiences and the particular family environment in which they are raised in understanding of mind development. In addition, findings from autism studies suggest that these children may experience added difficulties with an understanding of minds due to a genetically based predisposition. These two distinct, yet related sets of literature come together to suggest that siblings of children with DAS may experience a particular vulnerability with regard an understanding of minds. Although this proposition must be considered in the context of a number of methodological issues, its clinical and ethical implications are important issues for clinical psychologists working with families of children with DAS.

This paper has identified one factor (understanding minds) that may be associated with the wellbeing of siblings of children with DAS. Findings of studies of parents and studies of siblings have suggested that family members experience the effects of having a relative with DAS differently (e.g., Rodrigue et al, 1990; 1992; Rodrigue, Geffken & Morgan, 1993). Therefore, the following chapter turns to factors that may be associated with the wellbeing of parents of children with DAS.

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Chapter 2

Empirical Paper

Factors associated with the wellbeing of parents of children on the Autism Spectrum

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2.1 Abstract

Previous research has suggested that mothers and fathers of children with a diagnosis on the autism spectrum (DAS) experience stress differently. The majority of research in this area has identified child behaviour problems as being associated with the wellbeing of these parents. However, recent studies have highlighted the importance of psychological process variables and inter-relationships between family members and their association with parental wellbeing. The current study investigates a number of these variables and their association with stress and mental health symptomatology in parents of children with DAS. Specifically, parent wellbeing, parent competence, child difficulties, family cohesion, relationship satisfaction and impact of the child on the relationship and siblings were all explored in 42 parents (20 parent dyads and 2 mothers) of children with DAS. Correlational analyses revealed that parental competence, depression in the other partner, and family and relationship variables were all associated with parental wellbeing. Parental stress was predicted by child pro-social behaviour. Maternal stress was further predicted by child behaviour problems. Maternal depression was predicted by age, the impact of the child on the parental relationship, and the impact of the child on siblings. Results were considered within the context of a number of methodological issues. Implications for clinical interventions for families of children with DAS were discussed.

2.2 Introduction

Parents of children with DAS report significantly more stress than parents of typically developing children and often more than parents of children with other learning disabilities such as Down syndrome (e.g., Dumas, Wolf, Fisman & Culligan, 1991; Rodrigue, Morgan & Geffken, 1990; 1992; Sanders & Morgan, 1997). Parenting a child with DAS has been associated with high levels of emotional distress including depression, anxiety, and anger (Gray, 1994; Gray & Holden, 1992; Olsson & Hwang, 2001). In short, a number of studies exploring the relationship between parenting a child with DAS and stress have concluded that children with DAS affect parental wellbeing[7] (e.g., Bebko, Konstantareas, & Springer, 1987; Hastings & Brown, 2002; Hastings & Johnston, 2001; Koegal, Schriebman, Loos, et al., 1992). Despite these findings, not all parents of children with disabilities report significant distress. Evidence suggests that there exists significant variability in the levels of parental stress and coping, and this variability has been associated with a range of factors (e.g., Baxter, Cummins, & Yiolitis, 2000).

2.2.1 Differences between mothers and fathers

In addition to variability across families, there also appears to be some variability within families of children with DAS. Findings of studies of parents and studies of siblings have suggested that family members experience the effects of

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[7] In line with previous studies on this topic (e.g., Hastings, 2003; Hastings et al., 2005; Lloyd & Hastings, 2008), the current study defines parental wellbeing as level of parenting stress and mental health symptoms (anxiety and depression).

having a relative with DAS differently (e.g., Bägenholm & Gillberg, 1991; Fisman, Wolf, Ellison, et al., 1996; Gold, 1993; Rodrigue, Geffken, & Morgan, 1993). Mothers of children with DAS typically report more stress than fathers (e.g., Bristol, Gallagher, & Shopler, 1988; Brobst, Clopton, & Hendrick, 2009; Donenberg & Baker, 1993; Gray, 1994; Gray & Holden, 1992; Hastings & Brown, 2002; Rodrigue et al., 1990). However, other studies have not found differences in stress levels between mothers and fathers (Bebko, et al., 1987; Factor, Perry, & Freeman, 1990; Hastings, 2003a; Hastings, Kovshoff, Ward, et al., 2005; Ornstein-Davis & Carter, 2008; Wolf, Noh, Fisman, & Speechly, 1989).

Mothers of children with DAS have also been found to report more anxiety (Hastings, 2003a) and depression (Hastings et al., 2005; Olsson & Hwang, 2002; Ornstein & Carter, 2008; Wolf et al., 1989) than fathers. However, differences in depression (Hastings 2003a; Hastings & Brown, 2002) and anxiety (Ornstein & Carter, 2008) between mother and fathers have not always been reported.

Despite conflicting findings, the importance of the role of both parents as care providers for children with DAS should not be underestimated**.** Societal changes (e.g., more women in employment, increased divorce rate, etc.) have necessitated parental role changes. Namely, fathers now assume more responsibility for child-care than in previous decades (Rodrigue, Morgan, & Geffken, 1992).

Much of the literature to date in this area identifies variables that have been directly associated with wellbeing in parents of children with DAS (e.g., behaviour problems, child age, diagnosis, etc.). One idea is that parenting stress is associated with the breadth and frequency of the child's behavioural problems (e.g., Tomanik, Harris, & Hawkins, 2004). Moreover, studies have consistently found that behaviour problems in children with DAS can predict levels of maternal stress (e.g., Hastings, Daley, Burns, & Beck, 2006; Lecavalier, Leone, & Wiltz, 2006), and are more strongly associated with maternal stress than paternal stress (Hastings 2002; Hastings, 2003a).

Ornstein-Davis and Carter (2008) identified a number of child characteristics that were associated with stress in mothers and fathers of pre-school children with DAS. Specifically, regulatory problems were found to be associated with maternal stress, whereas externalizing behaviours were associated with paternal stress. Delays and/or deficits in social relatedness (e.g., social interactional skills) were also found to be inversely related to parenting stress for both parents.

It has been proposed that mothers are more affected by behaviour problems than fathers, because mothers report increased involvement in the care of their child with DAS (e.g., Konstantareas & Homatidis, 1992). Indeed, observational studies of families of children with Down syndrome indicate that fathers interact less with their child with a disability when the mother is also present (Stoneman, Brody, & Abbott, 1983).

2.2.2 Systemic approaches to DAS and parental wellbeing

The rationale of the current paper is based on a systemic approach to DAS in families. Systemic approaches move away from linear causality and understanding of problems as objective, to a postmodern understanding of reality as socially constructed. Rather than analyzing causes of problems, systemic methods seek instead to identify patterns of behavior in groups of people such as families, and address those patterns directly. To this end, systemic theory emphasizes family relationships as an important factor in psychological health and wellbeing (Dallos & Draper, 2005).

In line with systemic thinking, the current paper proposes that parental wellbeing may not be exclusively a function of the child with DAS. Indeed, more recent studies have begun to explore psychological process variables such as parental competence and systemic factors such as inter-relationships between family members in terms of their association with parental wellbeing (e.g., Hastings, et al., 2005; Lloyd & Hastings, 2008). Focussing on these variables in parental adjustment and DAS may prove to be more clinically useful with regard intervention compared to those variables that have been previously associated with parental distress and yet not amenable to change (e.g., child age, diagnosis, etc.).

The aim of the current study is to extend this work by using measure that explore a number of psychological process and systemic variables in mothers and fathers of school-age children with DAS. A brief overview of the relevant literature exploring some of the systemic factors that have been associated with parental wellbeing will be provided in the following section. Although evidence from the wider intellectual disability literature is highly relevant, the breadth of this material is wider than can be accommodated here. As a consequence, the following discussion will focus mainly on work specific to children with DAS and their families.

2.2.2.1 Efficacy and satisfaction

Perceived parenting self-efficacy is defined as feelings of competence in the caretaking role. Efficacy is one concept that has been found to relate to child difficulties and parental wellbeing, in families of children with DAS (Hastings & Brown, 2002). In their sample of 26 mothers and 20 fathers of school age children with DAS, Hastings and Brown (2002) reported that having a child with high levels of behaviour problems reduced mothers' feelings of efficacy which in turn, predicted maternal depression. In short, maternal feelings of efficacy were able to explain how behavioural problems impacted upon depressive symptoms. For fathers, the pattern of results revealed an interaction effect. At higher levels of child behavioural problems, fathers with lower self efficacy reported more anxiety. However, efficacy had no influence at lower levels of behavioural problems.

Kuhn and Carter (2006) conducted a cross-sectional survey on the internet of 170 mothers of children with DAS. Kuhn and Carter investigated associations between efficacy, agency, level of autism knowledge, feelings of guilt, and wellbeing. They reported that maternal efficacy was negatively associated with maternal stress, depression, and guilt. In turn, these variables were found to predict maternal efficacy.

Parenting satisfaction is defined as feeling satisfied with the parenting role and is considered to reflect an affective dimension of parenting (Johnston & Mash, 1989). Using the Parenting Sense of Competence Scale (PSCS; Johnston & Mash, 1989), Hassall, Rose, and McDonald (2005) assessed efficacy and satisfaction of a sample of mothers with children with intellectual disability. Hassall et al. found that sense of satisfaction with parenting and to a lesser extent, parental self efficacy, were inversely correlated with parenting stress. Donenberg and Baker (1993) report contrasting findings using this measure. Donenberg and Baker compared children with autism, children with externalizing behaviour, and typically developing children, on parent ratings of a number of measures, including the PSCS. All children were pre-school age. No differences between ratings on the PSCS for the three groups were reported. However, the measures in this study were sent to participants to be completed by the ‘primary caregiver’. Therefore, it is unclear as to what proportion of the data was obtained by mothers relative to fathers and whether any difference in responses existed between parents.

Using the PSCS, the current study will aim to further explore the association between parental wellbeing and parenting satisfaction and efficacy in parents of school age children with DAS.

2.2.2.2 Parent and partner mental health

A number of studies have explored the idea that parental wellbeing may not only be a function of the child with DAS but also the mental health of their partner. Hastings (2003a) recruited 18 parent dyads of school age children with DAS to report on their stress and symptoms of anxiety and depression. Partial correlational analyses revealed that teacher rated child behaviour problems and fathers' anxiety and depression, were associated with mothers' stress. However, neither child behaviour problems or mothers' anxiety were associated with fathers' stress. A small association was found between maternal depression and paternal stress. This finding was later extended by Hastings et al. (2005). In their sample of 48 mothers and 41 fathers of pre-school children with DAS, Hastings et al. report that maternal stress was related to child behaviour problems and their partner's depression. However, paternal stress was not related to child behavioural problems but was predicted by their partner's depression. Hastings et al. found no difference between the stress levels of mothers and fathers. However, they report that mothers had more depressive symptoms overall than fathers. Finally, Hastings et al. explored positive perceptions of the child with DAS in their sample. Mothers had higher levels of positive perceptions than fathers. In addition, maternal depression was found to predict paternal stress and paternal positive perceptions of the child. The authors also reported that stress and positive perceptions were related for fathers but not for mothers.

These findings indicate that parental wellbeing is not only related to having a child with DAS but also the psychological wellbeing of their partner. This further emphasises the importance of the psychological wellbeing of the family system, when considering adjustment of any one family member to having a relative with DAS.

2.2.2.3 Family factors: siblings, parental relationship, and family cohesion

Research suggests that increasing complexity of DAS is associated with a greater risk of poor psychological adjustment within the family (Rodrigue, Geffken, & Morgan, 1993). Despite this, there appears to be a relatively limited amount of evidence exploring the impact of a child with DAS on siblings (Gray, 1998; Kaminsky & Dewey, 2002; Macks & Reeve, 2007). Available research suggests that siblings of children with DAS may have additional problems when compared with control groups or other groups of siblings of children with disabilities (e.g., Bägenholm & Gillberg, 1991; Fisman, et al., 1996; Gold, 1993; Hastings, 2003b). However, other studies have reported findings inconsistent with this (e.g., Mates, 1990). In an interview study with parents of children with DAS, the majority of parents expressed significant concerns for the wellbeing of their other children (Gray, 1994). Furthermore, Donenberg and Baker (1993) reported that the impact of a child with DAS on his/her siblings was related to parenting stress, marital satisfaction, and parenting satisfaction. The current study aims to explore mothers' and fathers' perceptions of the impact of a child with DAS on his/her siblings, and any associations of this variable with parental wellbeing.

In addition to partner mental health, Hastings (2003a) suggests the likelihood of further variables that account for stress between mothers and fathers. It is possible that the quality of the spousal relationship could be a potential candidate in explaining this (Floyd & Zmich, 1991). In addition, it is proposed that characteristics of the family, such as level of cohesion, may also be associated with parental wellbeing (Rodrigue, Morgan, & Geffken, 1990). There are few studies that explore factors associated with the family and the parental relationship in families of children with DAS.

Rodrigue et al. (1990) compared mothers of 20 children with DAS, 20 children with Down syndrome, and 20 typically developing children. Mothers of children with DAS reported less parenting competence, less marital satisfaction, more family cohesion, and less family adaptability than mothers in the other two groups. In a later study, Rodrigue et al. (1992) also compared fathers of 20 children with DAS, 20 children with Down syndrome, and 20 typically developing children. Fathers of children with DAS and Down syndrome, reported more disruption in planning family activities and increased financial burden because of their child. Rodrigue, et al. (1992) also found that fathers of children with DAS used information seeking and wish fulfilling fantasy as coping strategies more frequently than fathers of typically developing children. Moderate levels of family cohesion and adaptability were reported for fathers of children with DAS. However, unlike the mothers in the earlier study, fathers' levels of perceived parenting competence, marital satisfaction, and social support were comparable to those reported by fathers of typically developing children. In contrast to the findings of Rodrigue et al. (1990, 1992), Donenberg and Baker (1993) found no difference in measures of marital functioning between groups of parents, in their sample of parents of children with autism, children with externalizing behaviour, and typically developing children. However, as previously discussed, it was not apparent which parent contributed to the data in this study.

Toth, Dawson, Meltzoff, Green, and Fein (2007) examined cognitive, adaptive, imitation, play, and language abilities in 20 pre school siblings of children with autism and 42 siblings of typically developing children. Although the focus of the study was not parental wellbeing, Toth et al. also measured parental stress, mental health, and marital satisfaction. Toth et al. reported no differences between parent groups on these measures. However, as the study was essentially focussed on the children, no parent details were provided. In addition, as no statistical comparisons were made within parent dyads, it is unclear as to whether there were any differences between mothers and fathers with regard wellbeing or relationship satisfaction.

In contrast to Toth et al.'s findings, Brobst, et al. (2009) found that parents of children with DAS experienced greater parenting stress, more intense child behaviour problems, and lower marital satisfaction than parents of typically developing children. Brobst et al. compared 25 couples with children with DAS and 20 couples of typically developing children (ages 2 to 12 years). For parents of children with DAS, parental stress was positively related to the intensity but not the number of child behavioural problems. For mothers of children with DAS, parental stress was negatively related to marital satisfaction; however this was not reported for fathers. To extend this work, the current study will investigate relationship satisfaction alongside parental perceptions of the impact of the child with DAS on the relationship.

Based on studies exploring family and relationship factors, it is proposed that mothers and fathers may perceive the degree of relationship satisfaction and the level of family cohesion differently. This in turn may be associated with variations in parental wellbeing observed in parents of children with DAS. Therefore, the final focus of this study will be to explore the wellbeing of parents of children with DAS in the context of their family relationships. It is anticipated that parental stress may be associated with perceptions of family cohesion, relationship satisfaction and factors related to impact of the child on the relationship and the impact of the child on his/her siblings.

2.2.3 Summary and aims

The purpose of the current study was to aid in the consolidation and broadening of the investigation of psychological variables and their association with parental wellbeing in parents of school age children with DAS. Based on previous findings in the literature, it is anticipated that there may be differences between mothers and fathers of children with DAS on levels of parental wellbeing. It is also proposed that there may be parental differences with regard the relative association of wellbeing with child, parent, partner, relationship and family variables. In short, it is anticipated that the set of variables that predicts parental wellbeing may differ for mothers and fathers. This may have important clinical implications for families of children with DAS.

2.3 Method

2.3.1 Recruitment

Children with DAS were identified through Child and Adolescent Mental Health Services (CAMHS) within an NHS Trust in the UK. It was anticipated that these children would represent the population of children with DAS in this area. For these children, a multi disciplinary team would have typically made the diagnosis.

Eighty-nine parent dyads (178 parents) were sent letters inviting them to receive more information about the study. Forty-two parent dyads (84 parents), indicated their willingness to be contacted to receive more information by returning a tear off slip included in the letter. These parents were contacted by telephone and all agreed to receive an information sheet and consent form. Questionnaire packs were sent out to the 46 parents that returned consent forms. Those parents that returned questionnaire packs were included as participants in the study.

2.3.2 Participants

Participants were 42 parents (22 mothers and 20 fathers) of school-age children with DAS. All of the children had received a diagnosis from a multi disciplinary diagnostic clinic.

The mothers' mean age was 41.11 years (*SD* = 6.92), 27% were educated to degree level. The fathers' mean age was 44.11 years (*SD* = 8.2), 32% were educated to degree level. Fifty percent of families had an annual income of over £40 000. All 22 families in the sample were intact, and comprised 20 married couples and 2 couples who were living together. All parents described their ethnicity as white.

The children with DAS had a mean age of 11.01 years (*SD* = 4.19, range 4.0 – 16.92 years), 18 children were male and 4 were female. In terms of specific diagnoses provided by the parents, 3 children had a diagnosis of 'autism', 10 children had a diagnosis of 'autism spectrum disorder', 8 children had a diagnosis of 'Asperger's syndrome' and 1 child was diagnosed as 'severely autistic'. The mean age of receiving diagnosis was 5.56 years (*SD* = 3.17, range 2.5 – 13.8 years). Eighteen of the children were educated in mainstream school and the remaining 2 children were educated at schools for children with special educational needs. All 22 children lived in the family home, with their parents.

Eighteen of the children had a total of 22 siblings between them. Siblings had a mean age of 10.54 years (SD = 4.7, range 2.17 – 18.08 years). Fifteen siblings were male and 7 were female. In terms of birth order, 8 of the children with DAS had a younger sibling and 7 had an older sibling. One child had both an older and a younger sibling and one had 2 younger siblings. Two children also had siblings of the same age. All siblings lived within the family home and with the child with DAS.

2.3.4 Measures

Seven measures were included in the present study. A brief demographic questionnaire was used to record a number of details including: parent age; ethnicity; education; household income; relationship status; child age; sex; education; specific diagnosis; time since diagnosis; residential status and the age, sex and residential status of siblings.

Of the remaining measures (described below), all were completed by both mothers and fathers.

2.3.4.1 Parenting Stress Index – Short Form, 3rd Ed (PSI-SF; Abidin, 1995*).*

Abidin (1995) suggests that parental stress can be defined as a function of salient child characteristics, parent characteristics, and situational variables related to the role of being a parent. The 36 item Short Form of the PSI (PSI-SF) was used as the dependent variable in the current study. This measure yields a total score for parenting stress and three subscales (parental distress, parent-child dysfunctional interaction, and difficult child). Items are endorsed using a 5 point agreement scale. Test-retest reliability and internal reliability for the PSI-SF have been reported at .84

and .91 for total stress respectively (Abidin, 1995). In the present sample, Cronbach's alphas were .92 for both mothers and fathers for the total stress score.

2.3.4.2 Hospital Anxiety & Depression Scale (HADS; Zigmond & Snaith, 1983).

The HADS comprises 14 items, 7 of which assess depression and 7 assessing anxiety. This measure has demonstrated good reliability when used within populations of both mothers and fathers of children with DAS (Hastings, 2003a; Hastings & Brown, 2002). Scores on the anxiety and depression subscales of the HADS were used as dependent variables in the current study. Following the findings of Hastings (2003) and Hastings et al. (2005), scores on the HADS were also assigned as possible predictors for stress as measured by the PSI-SF. Cronbach's alphas for mothers were .77 (anxiety subscale) and .84 (depression subscale). Cronbach's alphas for fathers were .87 (anxiety subscale) and .93 (depression subscale).

2.3.4.3 Strengths & Difficulties Questionnaire (SDQ; Goodman, 2001*).*

The SDQ comprises 25 items on 4 subscales (emotional symptoms, conduct problems, hyperactivity and peer problems) which provide a total difficulties score when summed. A separate 5-item scale is summed separately and assesses the pro-social behaviour of the child. Each item is rated on a 3 point Likert scale (not true, somewhat true, certainly true). This scale has been used with children with intellectual disabilities (e.g., Beck, Hastings, Daley & Stevenson, 2004; Lloyd & Hastings, 2008) and is often completed routinely by CAMHS in the UK (CAMHS Outcome Research Consortium; CORC, 2007). In the present sample, Cronbach's alpha scores of .79 for mothers and .81 for fathers were obtained.

2.3.4.4 Family Impact Questionnaire (FIQ; Donenberg & Baker, 1993*).*

This measure was developed in order to directly explore parental perceptions of the impact of children on their families. Items are scored on a four point scale of endorsement. The initial version used a sample comprising 118 parents of preschool aged children including 20 parents of children with DAS. Analysis yielded a 50 item measure, comprising 6 subscales (scale reliability values ranged from .83 - .92). Two subscales of the FIQ will be used in the present study. The first explores negative impact of the child with DAS on the parental relationship (7 items), and the second explores negative impact of the child with DAS on siblings (8 items)[8]. Cronbach's alpha coefficients for the relationship subscale were .91 and .89 for mothers and fathers respectively. Cronbach's alpha coefficients for the siblings subscale were .74 and .75 for mothers and fathers respectively.

2.3.4.5 Parenting Sense of Competence Scale (PSCS; Gibaud-Wallston & Wandersman, 1978; Johnston & Mash, 1989*).*

The PSCS has 17 items each arranged on a six point scale of level of agreement. Johnston and Mash (1989) revised and validated this measure to reflect two dimensions of parenting self-esteem. The first assesses the extent to which parents believe they have the skills and knowledge to be good parents (efficacy scale). The second explores the level to which parents feel frustrated, anxious and poorly motivated in the parenting role (satisfaction scale). The scale has good internal consistency (.79) and predicts both internalizing and externalizing behaviour in children (Johnston & Mash, 1989). This scale has been used successfully in research

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[8] The original scale has a total of 9 items. However, it was felt that ambiguity in the wording of the first item ('the other children in the family help take care of him/her more') would make scoring this item as having a positive impact on sibling(s) or a negative impact on sibling(s) difficult. Therefore, this item was removed.

with parents of children with intellectual disability (Hassell, et al., 2005). In the current sample, Cronbach’s alphas for mothers were .92 (efficiency subscale) and .81 (satisfaction subscale). Cronbach’s alphas for fathers were .84 (efficiency subscale) and .82 (satisfaction subscale).

*2.3.4.6 Dyadic Adjustment Scale (*Spanier, 1976*).*

This measure comprises 32 items that aim to assess marital functioning (overall reliability .96). Four subscales include: cohesion, dyadic satisfaction, consensus, and affectional expression. Internal consistency for the subscales is acceptable (range .73 - .94). There are a number of short form versions of the Dyadic Adjustment Scale. Hunsley, Pinsent, Lefebvre, James-Tanner, and Vito (1995) explored which of these conserved the construct validity of the full scale. Hunsley et al. (1995) proposed that the 10-item dyadic satisfaction scale (reliability .94) could be used as a reliable short form substitute for the full Dyadic Adjustment Scale. In the current sample, Cronbach’s alphas of .85 for mothers and .83 for fathers were obtained for the satisfaction subscale.

2.3.4.7 Family Cohesion Scale (taken from the Family Adaptability and Cohesion Evaluation Scales IV – FACES, Olson, Gorall, & Tiesel, 2007*).*

The complete FACES-IV measure comprises 62 items designed to assess family cohesion and family flexibility. The family cohesion subscale is used in the present study. This comprises 7 items rated on a 4 point scale (strongly disagree – strongly agree). Cronbach’s alphas for mothers and fathers were .94 and .92, respectively.

2.3.4.8 Parent reflections

At the end of the questionnaire, parents were given space to record any comments they might have regarding the subject matter of the study, their participation, or anything else they felt was important to add.

2.4 Results

Before the main statistical analyses were conducted, all of the main child and parent variables were tested for normality of distributions using the Kolmogorov-Smirnov one-sample test. In all cases, results were non-significant indicating that variables were normally distributed. As a consequence, parametric analyses were used.

Associations between demographic variables and measures of parental wellbeing were also explored using t-tests (for dichotomous variables, such as sex of child) and Pearson's correlations (for continuous variables, such as parental age).

Correlations revealed a significant relationship between parent age and level of parenting stress and mental health scores. Older parents reported more parenting stress ($r_{(20)}$ = .46, p<.05 for mothers; $r_{(18)}$ = .45, p<.05 for fathers), and more depressive symptoms, ($r_{(20)}$ = .51, p<0.05 for mothers; $r_{(18)}$ = .49, p<.05 for fathers). The age of the child was also related to parent mental health, with mothers with older children reporting more depressive symptoms ($r_{(20)}$ = .54, p <.05), and fathers of older children reporting more anxious symptoms, ($r_{(18)}$ = .45, p<.05). Thus, parent age and child age were retained as variables for later analyses.

Three analysis strategies will be used. First, parental differences on all measures will be explored. Second, associations between child, mother and father variables will be investigated using correlations. Third, variables that are found to associate significantly with stress and mental health measures will be included in regression analyses to test possible predictors of parental wellbeing.

2.4.1 Parental differences

The means and standard deviations for the measures used in this study are shown in Table 1. A series of repeated measures t-tests was performed on these variables. Results of this analysis are also reported in Table 1. Significant differences were found between mothers and fathers on measures of wellbeing. Mothers reported more depressive symptoms and higher levels of stress than fathers. Differences were also reported between child difficulties and relationship satisfaction. Mothers reported more child difficulties than fathers and lower levels of relationship satisfaction.

Table 1: Means and standard deviations for mothers and fathers on all measures.

Measure	Mothers (n=20)		Fathers (n=20)			
	Mean	SD	Mean	SD	t	*p*
Anxiety symptoms	8.45	3.95	6.65	4.29	1.57	.13
Depression symptoms*	8.00	4.63	5.10	4.77	3.14	.00
Parenting stress*	104.85	22.79	89.90	18.88	4.05	.00
Parenting satisfaction	36.05	8.10	38.90	7.49	-1.65	.12
Parenting efficacy	29.55	7.65	29.20	5.64	.17	.87
Child difficulties*	19.60	4.86	16.55	5.57	3.35	.00
Child pro-social behaviour	4.00	2.27	5.00	2.66	-1.93	.07
Negative impact on relationship	9.00	6.42	7.80	5.17	1.03	.32
Negative impact on siblings	6.88	3.76	6.40	4.09	.696	.49
Relationship satisfaction*	32.00	6.31	34.35	5.57	-2.27	.04
Family cohesion	26.70	6.16	27.65	5.59	-.84	.41

*significant difference reported

According to scores on the anxiety subscale of the HADS, 22% of mothers' and 26% of fathers' scores fell within the 'normal' clinical range. 11% of mothers scores and 7% of fathers scores fell within the 'mild' range, and 15% of mothers scores and 9% of fathers' scores fell within the 'moderately' anxious range. Finally, 2% of both mothers and fathers fell within the 'severely' anxious range. With regard scores on the depression subscale, 20% of mothers and 33% of fathers were in the 'normal' range. 17% of mothers and 2% of fathers were found to be 'mildly' depressed and 9% of mothers and 9% of fathers were found to be 'moderately' depressed. An additional 2% of mothers were reportedly 'severely' depressed.

2.4.2 Correlational analyses

Associations between ratings of the child measures and parent measures were explored using Pearson's correlations. As described above, ages of parents and children were also entered into the analysis as they were found to have significant associations with parental wellbeing scores. The results of these analyses for mothers and fathers are summarised in Tables 2 and 3 respectively[9].

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[9] As guided by previous research, Table 2 presents relationships between the key variables under study. Results of the entire correlational analysis are provided in Appendix 15.

Table 2: Correlations between Child and Maternal variables (n=22)

Variable$^{\phi}$	1.	2.	3.	4.	5.	6.	7.	8.	9.	10.	11.	12.
1. Mothers age	-											
2. Child age	.73**	-										
3. Parenting satisfaction	-.29	-29	-									
4. Parenting efficacy	-.41	-.29	.74**	-								
5. Anxiety symptoms	-.02	.05	-.59**	-.28	-							
6. Depression symptoms	.54**	.51*	-.81**	-.71**	.45*	-						
7. Parenting Stress	.46*	.37	-.79**	-.67**	.32	.77**	-					
8. Child difficulties	.09	.09	-.46*	-.42	.17	.37	.76**	-				
9. Child pro-social behaviour	-.18	-.03	.47*	-.45	.17	-.58**	-.75**	-.51*	-			
10. Impact on relationship	.17	.24	-.17	-.32	.38	.48*	.28	.26	-.13	-		
11. Impact on siblings	.06	.01	-.71**	-.58*	.45	.50*	.75**	.67**	-.64**	.29	-	
12. Marital satisfaction	-.13	-.01	.48*	.44*	-.38	-.61**	-.39	-.33	.46*	-.34	-.36	-
13. Family cohesion	-.03	.07	.26	.25	-.19	-.53*	-.42*	-.33	.64**	-.32	-.39	.78**

Table 3: Correlations between Child and Paternal variables (n=20)

Variable$^{\phi}$	1.	2.	3.	4.	5.	6.	7.	8.	9.	10.	11.	12.
1. Fathers age	-											
2. Child age	.69**	-										
3. Parenting satisfaction	-.44	-.10	-									
4. Parenting efficacy	-.26	-.09	.45*	-								
5. Anxiety symptoms	.38	.45*	-.61**	-.34	-							
6. Depression symptoms	.49*	.32	-.66**	-.46*	.63**	-						
7. Parenting Stress	.45*	.14	-.78**	-.39	.47*	.69**	-					
8. Child difficulties	0.5	-.19	-.33	-.39	.10	.32	.47*	-				
9. Child pro-social behaviour	-.11	.13	.37	.18	-.03	-.25	-.59**	-.17	-			
10. Impact on relationship	.18	.39	-.39	-.22	.33	.08	.28	.02	-.08	-		
11. Impact on siblings	.55*	.31	-.58*	.02	.65**	.48	.61*	.26	-.41	.20	-	
12. Marital satisfaction	-.09	-.16	.39	.33	-.44	-.45*	-.46*	-.60**	.15	-.52*	-.44	
13. Family cohesion	.21	-.08	.32	-.45*	-.40	-.30	-.33	-.29	.13	-.46*	-.15	.52*

*** = p<0.05; ** = p<0.01**

$^{\phi}$3 & 4 = measured by the Parenting Sense of Competence Scale; 5 & 6= measured by the Hospital Anxiety & Depression Scale; 9 = measured by the Parenting Stress Index-Short Form; 10 & 11 = measured by the Strengths & Difficulties Questionnaire; 12 & 13 = measured by the Family Impact Questionnaire; 14 = as measured by the Dyadic Adjustment Scale Satisfaction Subscale; 15 = measured by the Family Adaptation & Cohesion Evaluation Scale Cohesion Subscale.

Parental stress was positively related to child difficulties ($r_{(20)} = .76$, $p<0.01$ for mothers; $r_{(18)} = .47$, $p<0.05$ for fathers), symptoms of depression ($r_{(20)} = .77$, $p<0.01$ for mothers; $r_{(18)} = .69$, $p<0.01$ for fathers), parent age ($r_{(20)} = .46$, $p<0.05$ for mothers; $r_{(18)} = .45$, $p<0.05$ for fathers), and impact on siblings ($r_{(16)} = .75$, $p<0.01$ for mothers; $r_{(15)} = .61$, $p<0.01$ for fathers). Parental stress was also negatively related to parenting satisfaction ($r_{(20)} = -.76$, $p<0.01$ for mothers; $r_{(18)} = -.78$, $p<0.01$ for fathers) and the level of child pro-social behaviours (as assessed by the SDQ) ($r_{(20)} = -.75$, $p<0.01$ for mothers; $r_{(18)} = -.59$, $p<0.01$ for fathers). Associations between parenting stress and mental health in the other partner were also explored. Parenting stress for both mothers and fathers was found to be positively related to levels of depression in the other partner ($r_{(18)} = .47$, $p<0.05$ for mothers; $r_{(18)} = .56$, $p<0.05$ for fathers).

For parenting stress, there were differences found concerning the relationships between variables for mothers and fathers. For mothers, parenting stress was negatively related to both parenting efficiency ($r_{(20)} = -.67$, $p<.01$) and level of family cohesion ($r_{(20)} = -.42$, $p<.05$), however, these associations were not found for fathers. For fathers, parenting stress was positively related to symptoms of anxiety ($r_{(18)} = .47$, $p<.05$) and negatively related to relationship satisfaction ($r_{(18)} = -.46$, $p < .05$). These associations did not approach significance for mothers.

Other than maternal depression, no variables were found to be related to maternal anxiety. However, for fathers, child age ($r_{(18)} = .45$, $p<.05$), parenting satisfaction ($r_{(18)} = -.61$, $p<.05$) and impact on siblings ($r_{(15)} = .65$, $p<.01$) were all associated with paternal anxiety.

For mothers and fathers, age ($r_{(20)} = .54$, $p<.01$ for mothers; $r_{(18)} = .49$, $p<.05$ for fathers) and depression levels in the other partner ($r_{(18)} = .62$, $p<.01$) were positively related to depression. A number of variables were also negatively associated with depression. These included: parenting satisfaction ($r_{(20)}$ = -.81, p<.01 for mothers; $r_{(18)}$ = -.66, p<.01 for fathers) and efficacy ($r_{(20)}$ = -.71, p<.01 for mothers; $r_{(18)}$ = -.46 for fathers), and relationship satisfaction ($r_{(20)}$ = -.61, p<.01 for mothers; $r_{(18)}$ = -.45, p<.05 for fathers).

For mothers, there were additional variables found to be associated with depression that were not present for fathers. Child age ($r_{(20)}$ = .51, p<.05) and negative impact on relationship ($r_{(20)}$ = .48, p<.05) and siblings ($r_{(16)}$ = .50, p<.05) were also all positively associated with maternal depression. In addition, child pro-social behaviours ($r_{(20)}$ = -.58, p<.01), and family cohesion ($r_{(20)}$ = -.53, p<.05) were negatively associated with maternal depression.

2.4.3 Predicting parental wellbeing

All variables that showed significant correlations with parental wellbeing at the level of p<.05 were entered into multiple regression analyses for depression, anxiety and stress for mothers and fathers. Maternal anxiety was not analysed further as only one initial correlation (with maternal depression) was found. Those variables that accounted for a significant amount of variance are shown in Table 4.

Table 4: Regression analyses of parental wellbeing.

Dependent variable	**Predictor variable**	**Beta**	***p***
Maternal stress[1]	Child difficulties	.374	.028
	Child pro-social behaviour	-.349	.048
Paternal stress[2]	Child pro-social behaviour	-.405	.017
Maternal depression[3]	Age of mother	.755	.019
	Child impact on relationship	.539	.023
	Child impact on siblings	.415	.045
Paternal depression[4]	*No significant predictors found*		
Paternal anxiety[5]	*No significant predictors found*		

[1] $R^2 = .960$, $F_{(9,16)} = 18.439$, $p<0.001$
[2] $R^2 = .918$, $F_{(9,16)} = 8.654$, $p<0.01$
[3] $R^2 = .972$, $F_{(10,16)} = 10.358$, $p<0.01$
[4] $R^2 = .573$, $F_{(5,19)} = 3.753$, $p<0.05$
[5] $R^2 = .811$, $F_{(4,16)} = 5.762$, $p<0.01$

For maternal stress, a significant percentage in scores was explained by the regression model. Child difficulties and child pro-social behaviour were found to be significant predictors. For paternal stress, a significant percentage of the variance was explained. However, only child pro-social behaviour was found to be a significant independent predictor of stress for fathers. For maternal depression, a significant amount of the variance was also explained by the model. Age of mother, child impact on relationship and child impact on siblings were all found to be significant predictors of depression scores. Finally, a significant percentage of the variance in both depression and anxiety scores for fathers was explained by the respective regression models. However, no significant predictors were found for either of these variables.

2.4.4 Parent reflections

Fifteen parents chose to leave comments at the end of the questionnaire. Responses were varied and themes included: positive affect toward child, DAS as rewarding, ways parents have found to cope/adapt to DAS, fears for the child's future, impact of DAS on relationship with partner, impact of DAS on siblings, conflicting attitude of partner toward DAS, importance of child age, family balance, attitudes of extended family, effect of receiving diagnosis on family and gender specific parental roles. Other parents had general feedback on the questionnaire itself. Further discussion of parent reflections is provided in Chapter 3. All parent reflections can be found in Appendix 16.

2.5 Discussion

This study aimed to consolidate and extend past research by exploring systemic factors associated with the wellbeing of parents of children with DAS. Maternal and paternal wellbeing was explored in terms of associations with a number of variables including competence, partner mental health, and family relationships and cohesion.

2.5.1 Review of results

In line with previous research (e.g., Bristol, et al., 1988; Brobst, et al., 2009; Donenberg & Baker, 1993; Gray, 1994; Gray & Holden, 1992; Hastings & Brown, 2002; Hastings et al., 2005; Olsson & Hwang, 2002; Wolf et al., 1989; Rodrigue et al., 1990), mothers in the current study were reportedly more stressed and more depressed than fathers. However, there was little difference in the current study between anxiety levels of mothers and fathers.

Mothers reported more child behaviour problems than fathers and, in accordance with other work (e.g., Hastings et al., 2006; Lecavalier, et al., 2006), the child's behaviour problems were a predictor of maternal stress. However, unlike some previous findings (e.g., Hastings, 2003a; Hastings et al., 2005), fathers' stress in the current study was also associated with child behaviour problems. This finding may reflect societal changes, in that over more recent years, fathers have significantly increased the time they spend with their children (Bianchi, 2000). Fathers today are viewed as more than just economic providers for their children and many fathers assume equal partnership with mothers regarding childrearing and parenting (e.g., Pleck & Pleck, 1997). However, this proposition is yet to be tested in families of children with DAS.

Older parents in the current sample reported more stress than younger parents, and maternal age was found to be a positive predictor of maternal depression. Parents with older children also reported more mental health symptoms than parents with younger children. Many previous studies include parents of pre-school children or children of pre-teen age. However, a number of parents in the current study had adolescent children with DAS. Some researchers have reported that adolescent children with autism are viewed by their parents as more stressful than younger children with autism (Bristol & Schopler, 1984). This may explain the associations between wellbeing and age reported in the current study.

Associations of parental competence with parental wellbeing were demonstrated in the present results. Both parenting stress and mental health symptoms were strongly inversely correlated with parenting satisfaction. This suggests that parents with greater levels of parenting satisfaction experience greater wellbeing. This finding is consistent with previous research with mothers (Hassell et al., 2005) and the current study can extend this finding to fathers of children with DAS. The other PSCS dimension reflected parents' sense of efficacy in parenting. This appeared to have a greater importance for mothers' wellbeing over fathers'. As shown in other studies (Hastings & Brown, 2002; Kuhn & Carter, 2006), efficacy demonstrated significant correlations with maternal parenting stress and maternal depression. The current study also found efficacy to be weakly associated with depression in fathers.

Past research has found that the mental health of the partners of parents of children with DAS can be important with regard parental wellbeing (Hastings, 2003a; Hastings et al., 2005) and to concur, the current study found that parental stress was positively associated with levels of depression in the other partner. Despite the strong associations reported between psychological process variables and wellbeing in the current study, none were found to be predictors of parental stress and mental health. In addition, none of the variables in the current study were able to account for significant variance in paternal mental health. These issues will be addressed further in later discussion of methodological limitations.

The final focus of the current study concerned the importance of interrelationships between family members and the associations of these factors with parental wellbeing. Parental stress was found to be positively related to the impact of the child on siblings. This suggests that parents were more stressed when they perceived the child with DAS to have a greater negative impact on his/her sibling(s) than if the child did not have DAS. Associations with parental mental health and impact on siblings were also reported. Interestingly, child impact on siblings was a positive predictor of maternal depression.

There is evidence to suggest that compared to control groups, siblings of children with DAS present with more psychological problems (e.g., Fisman et al., 1996), problem behaviours (e.g., Rodrigue, et al., 1993) and peer relationship difficulties (e.g., Bägenholm & Gillberg, 1991; Hastings, 2003b). The processes by which these problems occur remain unclear. However, findings of the current study suggest that taking into account all relationships within the family may be important. It is possible that the responses of siblings to a child with DAS might in turn affect parental wellbeing. Furthermore, it is suggested that a bi-directional effect may operate, in that parents experiencing high levels of stress may engage in different parenting behaviour that may affect the outcomes of all children in the family. Indeed, Downey & Coyne (1990) report that parents react very differently to their children when suffering from depression. Furthermore, Floyd and Phillippe (1993) found that self-rated depression in parents' of children with an intellectual disability predicted their attempts to actively manage the child's behaviour. In terms of parental functioning, it is proposed that more research is needed to explore associations with sibling factors and perhaps members of the extended family. This would broaden knowledge around sources of parental stress in families of children with DAS.

Past research reports mixed findings with regard the role of relationship satisfaction in the wellbeing of parents of children with DAS. Brobst et al. (2009) found that stress was related to marital satisfaction for mothers but not fathers. However, the current study reports the contrary result; fathers' parenting stress was inversely correlated with relationship satisfaction but this effect was not found for mothers. Furthermore, relationship satisfaction was related to depression in both parents. Although causal relationships between variables cannot be established on the basis of significant correlations, parenting stress was greater for some fathers and depression higher in parents overall when relationship satisfaction was lower.

A related finding was the perceived impact of the child with DAS on the parental relationship. This appeared to be more pertinent for mothers than fathers, in that the impact of the child on the relationship was a positive predictor of maternal depression. In addition, family cohesion also appeared to be more strongly related to mothers' wellbeing compared to fathers' wellbeing. Both maternal stress and depression was associated with mothers' perceptions of the cohesiveness of the family system.

An unexpected finding was that parents' perceptions of child pro-social behaviour explained variance in stress scores for both mothers and fathers. Some studies have investigated factors related to positive perceptions specific to raising a child with a disability (e.g., Hastings, Allen, McDermott, & Still, 2002). In addition, a number of studies have investigated the contribution of the child's core autism behaviours to parents' stress, including deficits in social reciprocity and communication (e.g., Bebko et al., 1987; Hastings & Johnston, 2001; Ornstein-Davis & Carter, 2008). However, as far as we know, no studies have explicitly explored the association between parental wellbeing and the presence of general, pro-social behaviour in school age children with DAS. As a consequence, no predictions were made regarding this issue in the current study.

Kasari and Sigman (1997) reported that preschool children with DAS who were more responsive in interactions with the experimenter had caregivers who reported lower levels of parenting stress. The current study found that when pro-social behaviour was observed by parents as occurring more frequently, parental stress levels and maternal depression were reportedly lower. Again it is difficult to determine the directionality of this process. Parents who recognise and respond to pro-social behaviour may increase the likelihood of these behaviours occurring, which may in turn have an influence on parental wellbeing. Importantly, these findings suggest that interrelationships between parental wellbeing and family member perceptions of child positive behaviour are set for further research.

2.5.2 Methodological limitations

There are a number of methodological issues relevant to the current study that must be emphasised. First, the samples of mothers and fathers were small. Sample size influences both the power of significant tests and the stability and validity of regression coefficients over repeated sampling. This is particularly important given the number of variables that were included in the study. Increasing the sample size would permit more confidence in the results obtained. In light of this, results of the regression analyses should be interpreted with caution.

Despite the small sample size, strong relationships between variables were found. For example, strong associations were reported between child difficulties and maternal stress. However, the aim of the present study was to identify psychological process variables that may be associated with wellbeing. With a larger sample, it is possible that process variables identified as being associated with wellbeing in the current study could be enough to emerge as significant predictors of the variance in wellbeing.

A second methodological issue also relates to the sample. It is possible that the parents in the current study may not be representative of parents of children with DAS for a number of reasons. The response rate of parental participation in the study was small (around 25%). Furthermore, the parents in the current study were all white, were relatively highly educated and had relatively high incomes. It is likely that low income families and single parents may experience more parenting stress than reported by the participants in the current study. Indeed, there is evidence to suggest that income may predict parenting stress in families of children with disabilities (Smith, Oliver, & Innocenti, 2001). In addition, lower rates of maternal wellbeing are reported for mothers who are single parents (e.g., Cairney, Boyle, Offord, & Racine, 2003). As participants were approached through CAMHS, it is likely that they received more professional input and may have had access to more resources than parents of children with DAS not associated with this service. It is proposed that the results need to be replicated with larger and in socioeconomically and ethnically diverse samples of parents.

There was also limited information about the siblings of the child with DAS. Siblings of children with DAS may have an increased genetic vulnerability to developing autism or milder features or one or more of the cognitive and/or behavioural DAS characteristics (Baker, Piven, Schwartz, & Patil, 1994; Landa & Garrett-Mayer, 2006). It is unclear as to how wellbeing in parents with more than one child with features of DAS may be affected. Collecting richer information about siblings in the current study would have been useful to address this issue.

A significant limitation relates to child diagnosis. The diagnosis of children in the sample was reported by parents and was not verified by direct assessment. Furthermore, there are currently no common structured child diagnostic procedures used across the regions from which the participants were recruited. Therefore, it would have been helpful to confirm diagnosis and/or have some measure of level of severity of autism.

A final methodological issue relates to the measures used in the current study. Given the unusually high R values obtained, it is possible that there may have been some measurement overlap, particularly in relation to the PSI and the SDQ. In addition, strong relationships were reported between mental health symptoms and on efficacy and satisfaction. Indeed, Hastings and Brown (2002) point out that self concept is a key dimension of anxiety and depression. Following Hastings and Brown, it is argued that the items for these variables in the current study are sufficiently unlike one another in the sense that they focus on a different level of measurement (e.g., feelings toward parenting vs. day to day mental health symptoms). Nevertheless, it would be useful for future studies to obtain an independent assessment of mental health symptomatology. Finally, it must be emphasized that causal relationships between the variables measured in this study cannot be established on the basis of significant relationships.

2.5.3 Clinical implications

Despite its limitations, it is proposed that results of the present study have a number of potentially useful clinical implications. Current clinical interventions that are successful at reducing problem behaviours of children with DAS seem to benefit parental wellbeing (Hastings & Beck, 2004). The current study points to the potential buffering effects of parents recognising pro-social behaviour of the child with DAS on wellbeing. While further research is necessary to determine the nature of this effect, it is possible that promoting the recognition of the positive behaviour exhibited by children with DAS may prove useful with regard supporting stressed parents.

Although the focus of this study was on variables that may be amenable to change through clinical intervention, it is important to consider the finding that the age of the parent and/or child in the current sample was associated with parental wellbeing. The present results suggest that older parents, particularly mothers, and parents with older children with DAS may benefit from additional help and support with regard to managing stress.

Findings also emphasize the importance of interrelationships between family members. Specifically, the potential inter-dependence of the wellbeing of all family members is likely to be an important factor in the development of intervention and support services for those living with a child with DAS. Furthermore, from the position of the child with DAS, it is possible that the psychological functioning of other family members affects the expression of both positive and negative behaviours. Hastings (2002) suggests that one mechanism for this may be via different interactional or parenting styles that might be adopted under stress. In addition, increasing levels of stress may affect relationships with the child.

With respect to specific relationships, results suggest that support groups for parents of DAS might benefit from emphasis on sustaining the couples' relationships during times of stress. Encouraging both fathers and mothers, and possibly even siblings, to attend support groups may be important in facilitating family cohesion.

In light of the current findings, it is suggested that the child with DAS cannot be viewed as the sole source of a reduction in parental wellbeing and further research should attempt further investigation of the components of the wellbeing of parents raising a child with DAS. It is anticipated that ongoing focus on the family system through research will increase understanding of the dynamics of the wellbeing of families of children with DAS.

2.6 Summary

The present study aimed to consolidate and extend the current research exploring the variables associated with wellbeing in parents of children with DAS. Past research has tended to identify the child as the source of stress in the family. Moving away from this idea, the current study aimed to investigate the role of psychological process variables and systemic factors in affecting parental wellbeing. As these variables are more amenable to change, it was proposed that this approach was more likely to identify potential loci of intervention.

Correlational analyses revealed that parental competence, depression in the other partner, and family and relationship variables were all associated with parental wellbeing. Parental stress was predicted by child pro-social behaviour. Maternal stress was further predicted by child behaviour problems. Maternal depression was predicted by age, and the impact of the child on the parental relationship and siblings.

Although these findings were considered in the context of a number of methodological issues, it was proposed that results have a number of clinical implications that could prove useful for intervention packages aimed at supporting families of children with DAS.

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Chapter 3

Reflective Paper

Conducting research with families with children on the Autism Spectrum: methodological, ethical and personal reflections

Word count: 3021

3.1 Introduction

In this paper I aim to reflect on the process of completing the research that has been presented in Chapters 1 and 2. The reflective material has been developed from observations specific to the process of recruitment, data collection and through contact with research participants. These experiences have increased my awareness of a number of issues related to research in the context of clinical psychology practice. I feel I have gained a number of insights into my professional development as a scientist-practitioner, ethical issues associated with research and my general learning as a clinician.

The first section of this paper will attempt to describe my developing interest in the area of autism and families. I will then reflect on personal experiences specific to my research journey. I aim to summarise with an account of the areas of learning I feel have arisen from my reflections.

3.2 Background and interest

I first became interested in child psychology whilst on placement within Child & Adolescent Mental Health Services (CAMHS). I found the requirement to creatively adapt and modify psychological approaches, so that they might be accessible to children, to be both challenging and rewarding. I also particularly enjoyed the opportunity to work with family members. One experience on placement involved facilitating a Social Skills Group for children with DAS. Through attending teaching on autism and reading around the subject, I had gained some understanding as to the difficulties that individuals with DAS might experience. However, facilitating the group allowed me to hear first hand some of the challenges that face children with DAS and their families. The parents and often the siblings of the children would wait in an adjoining room for the duration of each group session. As a consequence, I was in a privileged position to hear family members share their experiences of living with a child with DAS together as an informal group.

At around the same time on this placement, I became involved with the Family Therapy Team. The team adopted primarily systemic ways of working and up to that time, I had had very limited exposure to this approach. I was immediately enthusiastic about systemic theorizing and began to use some aspects of systemic thinking in my wider practice. I particularly liked social constructionist ideas around shifting the emphasis from the individual toward the way constructs are created through interaction. I found techniques such as externalising, and a focus on moving away from 'problem saturated thinking' (de Shazer, 1982; George, Iveson, & Ratner, 1992) particularly appealing.

The experiences of talking to families of children in the group, alongside a general exposure to systemic thinking influenced me to develop research ideas about the wellbeing of family members of children with DAS. However, as I began to research the literature in this area, I felt increasingly daunted by the breadth of material already published. I was concerned that I had chosen a topic too unwieldy to be explored in the limited time I had available. I was further alarmed by the discovery that the papers I had began to collate and study for my original literature review (adjustment in siblings of children with DAS) had very recently been reviewed elsewhere. I was anxious at the prospect of having to start over and form an alternative focus for my literature review. I remember struggling to find another topic that caught my enthusiasm to the same extent, yet I felt a pressure to make a decision.

My supervisors encouraged me not to compromise my interest in siblings of children with DAS, and supported me to focus my ideas around formulating a clear and manageable approach to this literature.

For the majority of research I conducted prior to my training, I used quantitative approaches to data collection and analysis. Although in the past I had also used qualitative approaches, I did not feel as confident with this methodology. As a consequence, I opted for quantitative methods for this thesis. However, during the process of this research, I developed a growing interest in the qualitative aspects of my participants' experiences. Interestingly, I found that this issue is linked to a number of my reflections in the remainder of this paper.

3.3 Contacting participants

As described in Chapter 2, parents indicated their interest in participating in the study by returning a reply slip on which they agreed to be contacted by telephone and/or post. The purpose of telephone contact was to introduce myself and the study, ascertain verbal consent to post out written material and address any questions or concerns parents might have regarding participation. As I began making phone calls, I realised that the responses of parents with whom I spoke were interesting in their own right. Although not prompted to do so, many parents spontaneously talked about a number of their experiences, including raising a child with DAS, views of services and thoughts about participating in research. I began to record some of the recurring themes arising out of these conversations in my research notes.

3.3.1 Researcher-practitioner conflict

I often found that introducing the topic of the research (as stress and wellbeing in families of children with DAS) prompted many of the parents to begin to talk about their own stress. I remember one conversation with a mother who was currently experiencing significant anxiety. I heard that her son had been diagnosed with autism at an early age and until recently, the family had managed well and had been discharged from services. However, I heard that since this time, the boy had recently entered puberty and the changes this had brought for him were proving to be extremely distressing. The family were finding it difficult to manage this new challenge and the mother I spoke to was eager to access support. I felt an urge to step into 'therapist mode' and respond as I would in a session and simply advising her to contact CAMHS felt somewhat remiss. Afterwards, I found myself experiencing a degree of discomfort and this feeling persisted every time I heard similarly stressful family stories.

Although I believe I responded to parents' stories appropriately and with empathy, I could not ignore a lingering sense of helplessness and constraint in the face of their worry. I realised that my feelings may have partly been due to the fact that we were communicating via the telephone rather than in person. However, I also reflected on whether these feelings were associated with how I positioned myself, relative to how I was positioned by the parents I spoke to. I considered whether I was experiencing a struggle between where my role as a psychologist ended and where my researcher role began. The status of the scientist-practitioner model in clinical psychology is well advocated (Kennedy & Llewelyn, 2001), and I had always believed that the two roles were synonymous in practice. However, in my role as a scientist, I felt I had to let go of myself as a practitioner and this felt uncomfortable.

Although I had not worked therapeutically with any of the families I contacted, my introduction to the parents through CAMHS may have increased the likelihood of them positioning me as a practitioner rather than a researcher.

3.3.2 Conducting research as a trainee

At around this time, many fellow trainees were in the process of collecting data. I found that others shared similar experiences of having to find ways to reconcile the role change from therapist to researcher, particularly those who were listening to client experiences of distress whilst conducting interviews. Reflecting with trainees on the uncomfortable feelings that remained with me after speaking with parents proved helpful. I considered whether the wider system had a role in our experiences. Personally, I wondered whether the conflict I felt was influenced in some way by the mandatory nature of conducting research as part of a degree. I think that concerns about time, meeting deadlines and worrying about writing a passable thesis meant that I had lost sight of the more important reasons to conduct psychological research. Just as one aim of therapy is to alleviate psychological distress in the here and now, research can be seen as way of alleviating distress in the future through changes in service delivery or informing practice. Reminding myself of why my research is important to the client has been helpful in facilitating my development as a scientist-practitioner.

3.4 Collecting data

Once I had spoken to parents and obtained consent, I no longer had open contact with my participants. Following guidance around confidentiality, I had to rely on participants to return their questionnaires anonymously in the post. Aside from concerns around obtaining enough data, I hoped, and to some degree expected, that from then on the data collection process would be mostly straightforward and uneventful. As from this point on, all parent contact was anonymised, I felt that my relationship with my participants had come to a close. However, as the questionnaires began to arrive, I began to feel differently.

At the end of the questionnaire, parents were invited to add anything they felt important. On receiving the questionnaires back, I was really pleased that I included the opportunity for parents to comment. Reflecting on their responses highlighted issues around ethics and methodology which are considered below.

3.4.1 Ethical issues

In Chapter 1, I considered the ethical issues associated with researchers identifying potential difficulties in siblings of children with DAS and the question of who is best placed, if at all, to communicate these concerns to parents. I was reminded of this issue both when reflecting on the conflict I felt between my roles as researcher and a therapist, and when receiving some of the written feedback from parents. Comments from one parent in particular were influential in my views on this subject. She wrote:

> *"I feel life is very stressful, and that I carry it all. I work full time because husband can't cope with full time work. I feel I have missed out on 'being at the school gates' for kids. I have to organise everything and sometimes feel desperate, especially if I am not coping well with son's behaviour".*

My immediate reaction to this excerpt was to want to help this mother in person. Obviously this was not possible; however, this led me to again consider the issue of clinical intervention alongside research. One could argue that aside from situations where risk arises, psychologists should not be obliged to intervene clinically when they do research. Nevertheless, I experienced a feeling of duty in response to the comments of this participant and yet I was unable to take action. Again, reiterating to myself the ultimate aim of my research was somewhat helpful in alleviating these difficult feelings. It was some consolation to hope that my research might ultimately inform interventions designed to alleviate precisely the difficulties this mother seemed to be experiencing.

3.4.2 Methodological approach

Although telephone contact with parents had sometimes left me feeling uncomfortable, I had also felt really encouraged by the content of some of our conversations. Themes such as the impact of autism on siblings, spousal cohesion and challenges associated with the age of the child with DAS had all arisen spontaneously in telephone discussions with parents. As a result I felt optimistic about the focus of my research; in that the potential participants seemed to share my beliefs that the variables under study were important ones to explore. However, I felt my optimism diminish somewhat on receipt of the questionnaires themselves. Perhaps for the first time I really became aware that due to the nature of quantitative methodology, the rich material I had heard through speaking to parents would be absent in my results. Although the questionnaires allowed me to obtain a quantitative estimate of parental stress and wellbeing, I felt I had neglected the experiential aspects of these phenomena. At this time, I had also begun a specialist placement at a systemic family therapy service. Here I was able to gain a greater awareness as to how families and individuals construct meaning through language. Using qualitative methodology, such as interviewing, would have allowed me to explore in detail how parents of children with DAS construct and define their individual sense of stress and wellbeing.

Reading the responses from parents prompted me to consider a number of other systemic ideas utilized when working with families. I was reminded of the systemic idea of constructing narratives (Gergen & Gergen, 1983; White & Epston, 1990). The task of a therapist using this approach is to seek out examples of resources and resourcefulness within the narratives of family members and build upon them, and Walsh (1996) identifies the process of building new narratives to be an element of family resilience. A related idea that is also making important contributions to the systemic field focuses on the clients' problem solving strategy (Hoyt, 1994). I discovered that examples of family resourcefulness, resilience and problem solving strategies were very apparent in the written feedback from parents. Excerpts from four participants are provided below:

> *"We have chosen to focus on the progress, however small, achieved from one day to the next rather than to worry about a future, which we do not know what holds".*

> *"We feel humour is very important, it's helped in changes - i.e. 'silly mommy forgot to tell you' - gets us through a lot of tricky situations".*

> *"Embracing strengths and 'appropriate' obsessions/interest allows for all family members to be valued. Making sure everyone is treated fairly and is valued is extremely important".*

> *"Having a child with special needs is very stressful but it's also very rewarding and has changed my whole outlook on life. I think if families pull together it can make a massive difference and parents try and stay positive. It's not our fault and we can only do what we can do".*

As the question that had elicited these responses had been worded very generally, I was surprised as to the number of parents who had chosen to comment on family strengths and resources and I wondered why. One parent commented that she felt that items in some of the questionnaires were *"very negative and 'leading' – not making allowance for those parents who 'accepted' their children"*. I considered whether other parents had felt this way too and maybe this had prompted them to include experiences of progress and resourcefulness. I also wondered whether, for some parents, thinking about 'stress' meant reflecting on positive elements of family resilience and problem solving, rather than focussing on difficulties or negative impact of the child with DAS. Lastly, the written responses helped me to appreciate that the impact of the child should be placed in context and that this will be different for each family. As a consequence it became harder for me to see how context and difference could be adequately encompassed using questionnaires. For these reasons I believe that exploring qualitatively the relationship between parental stress/wellbeing with narratives that contain stories of families as progressive and resilient may be an interesting starting point for future research in this area.

3.5 Managing stress and promoting wellbeing

I felt I could not write a reflective account of studying stress without commenting on my own experience of stress throughout this research process. Although I have had previous research experience, I was under no illusions that planning, carrying out and writing up this study would not be stressful. Inevitably, at various stages of this study there were a number of occasions where I felt my stress levels increasing. As previously mentioned, deciding on a focussed and manageable topic for my literature review was the first occasion when I felt stressed. Since that time, worries about meeting deadlines, recruiting enough participants, analysing my data appropriately and completing on time have all been personal sources of stress. For the purposes of this paper, I have considered the factors that have helped me to manage these concerns.

In contrast to research carried out as part of my clinical training, conducting previous research before training was a far more solitary experience. Sharing the research experience with other trainees has been invaluable in helping me to contain the anxiety that I have felt along the way. Listening to others' experiences and helping each other out practically has been such a source of support. Furthermore, knowing that other trainees have had to overcome far bigger personal and professional obstacles than those I have been faced with has helped to put my own worries into perspective. As a consequence, and with regard to anxiety about this research, I am reminded of a quote that we were given early on in our training in a workshop about stress:

“Rule number 1 is: ‘don’t sweat the small stuff”.

“Rule number 2 is: ‘it’s all small stuff. And if you can’t fight and you can’t flee, flow”

(Robert Eliot, Cardiologist. On How to Cope with Stress).

As I approach the end of training, I feel I am now more able to accept this as useful advice compared to when I first read it two years ago (although it still seems more easily said than done). An understanding and accepting support network, coupled with an increased awareness of the importance of considering my worries in the context of others, has been invaluable in this process.

3.6 Summary: learning through reflection

Initially, I feared that conducting a postal questionnaire study might mean that I had a comparatively limited amount of material to reflect upon and inform my learning and professional development. However, I have been surprised by the breadth of learning I have taken from this process. Specifically, I believe that reflecting on the research process has influenced both my ideas around working as a scientist-practitioner, raised my awareness of ethics in research, and added to my clinical professional learning, particularly in the area of systemic working. I have briefly summarised these key areas of personal learning below.

From a clinical perspective, I have made a number of observations in this paper that draw on ideas from the systemic literature. For example, I have increased awareness as to the value of narrative in understanding personal experience. Re-framing difficulties in order to focus on personal strengths and taking a non-pathologising approach to family stories have also been ideas I have found useful in influencing my learning.

Over the course of training I have become increasingly interested in the use of systemic thinking in therapy. The reflections described in this paper have raised my awareness of systemic issues operating in non-therapeutic contexts. This has facilitated my enthusiasm for this way of working and I am further able to see the usefulness of this approach within clinical psychology research, in addition to practice.

As a practitioner, I am increasingly aware of ethical issues, particularly in relation to working with children. However, during the course of this study, I have been challenged to think about ethical issues in the context of research. Considering the question of if or how, clinical concerns arising out of research might be dealt with has been an interesting issue and one I feel worthy of ongoing reflection.

Finally, through exploring factors associated with stress in others I have been encouraged to think about my own stress. Through this process I have gained an appreciation as to how valuable it has been to draw upon the positive and understanding support network that I have been privileged to be part of as a consequence of my training.

3.7 References

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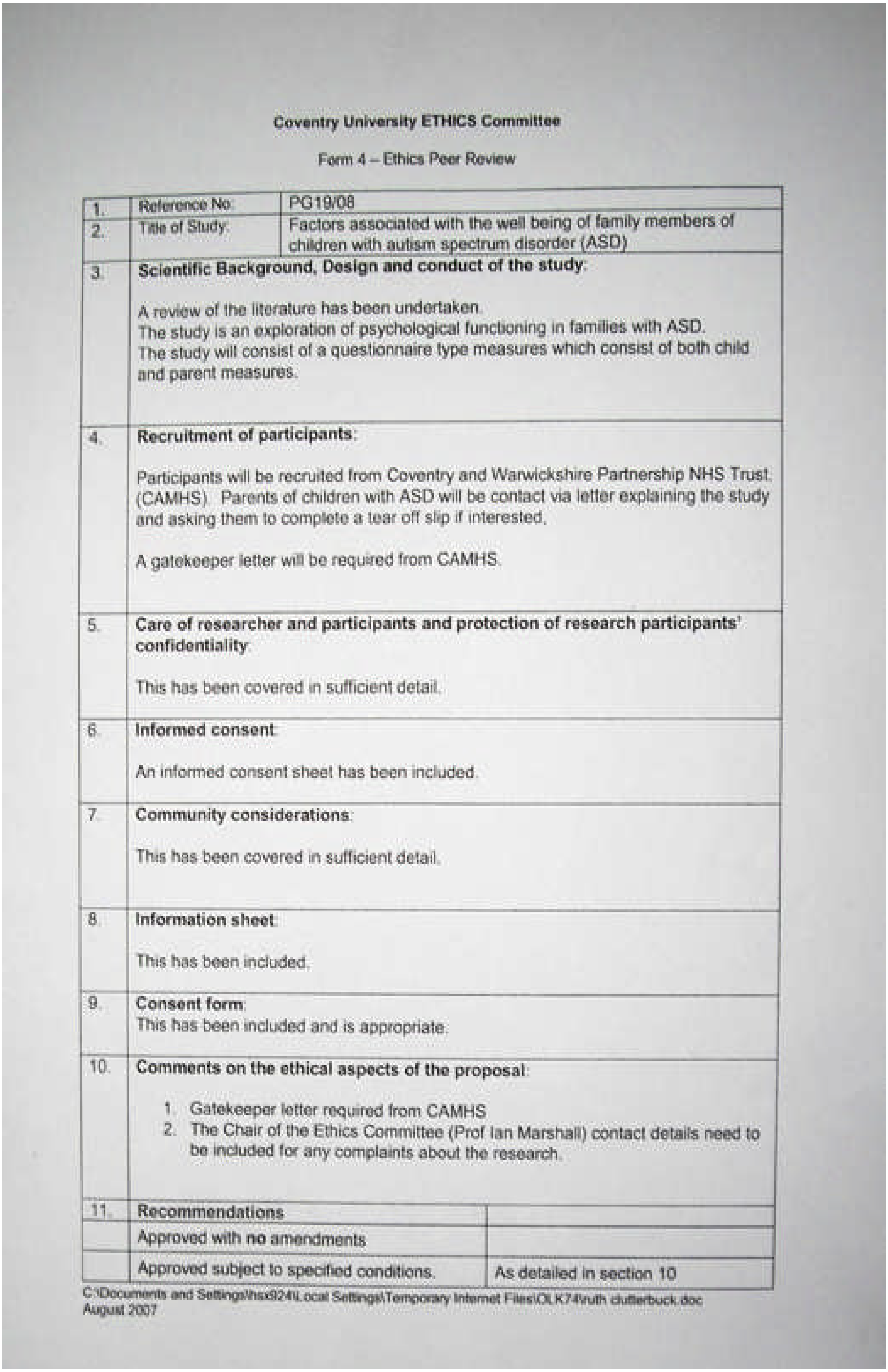
Appendix 1: Ethical approval



Coventry University ETHICS Committee

Form 4 – Ethics Peer Review

1.	Reference No:	PG19/08
2.	Title of Study:	Factors associated with the well being of family members of children with autism spectrum disorder (ASD)

3. **Scientific Background, Design and conduct of the study:**

A review of the literature has been undertaken.
The study is an exploration of psychological functioning in families with ASD.
The study will consist of a questionnaire type measures which consist of both child and parent measures.

4. **Recruitment of participants:**

Participants will be recruited from Coventry and Warwickshire Partnership NHS Trust (CAMHS). Parents of children with ASD will be contact via letter explaining the study and asking them to complete a tear off slip if interested.

A gatekeeper letter will be required from CAMHS.

5. **Care of researcher and participants and protection of research participants' confidentiality:**

This has been covered in sufficient detail.

6. **Informed consent:**

An informed consent sheet has been included.

7. **Community considerations:**

This has been covered in sufficient detail.

8. **Information sheet:**

This has been included.

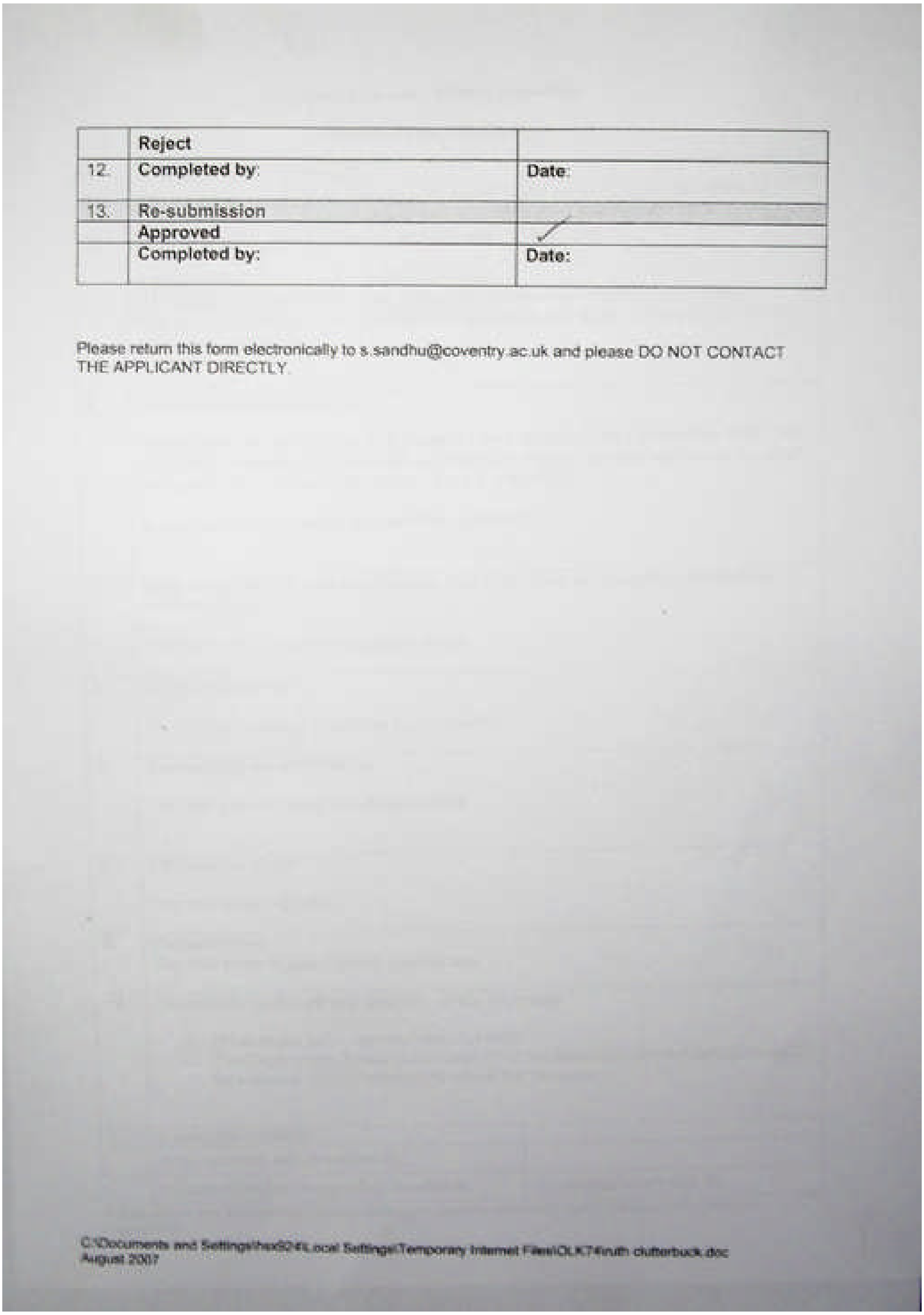
9. **Consent form:**
This has been included and is appropriate.

10. **Comments on the ethical aspects of the proposal:**

1. Gatekeeper letter required from CAMHS
2. The Chair of the Ethics Committee (Prof Ian Marshall) contact details need to be included for any complaints about the research.

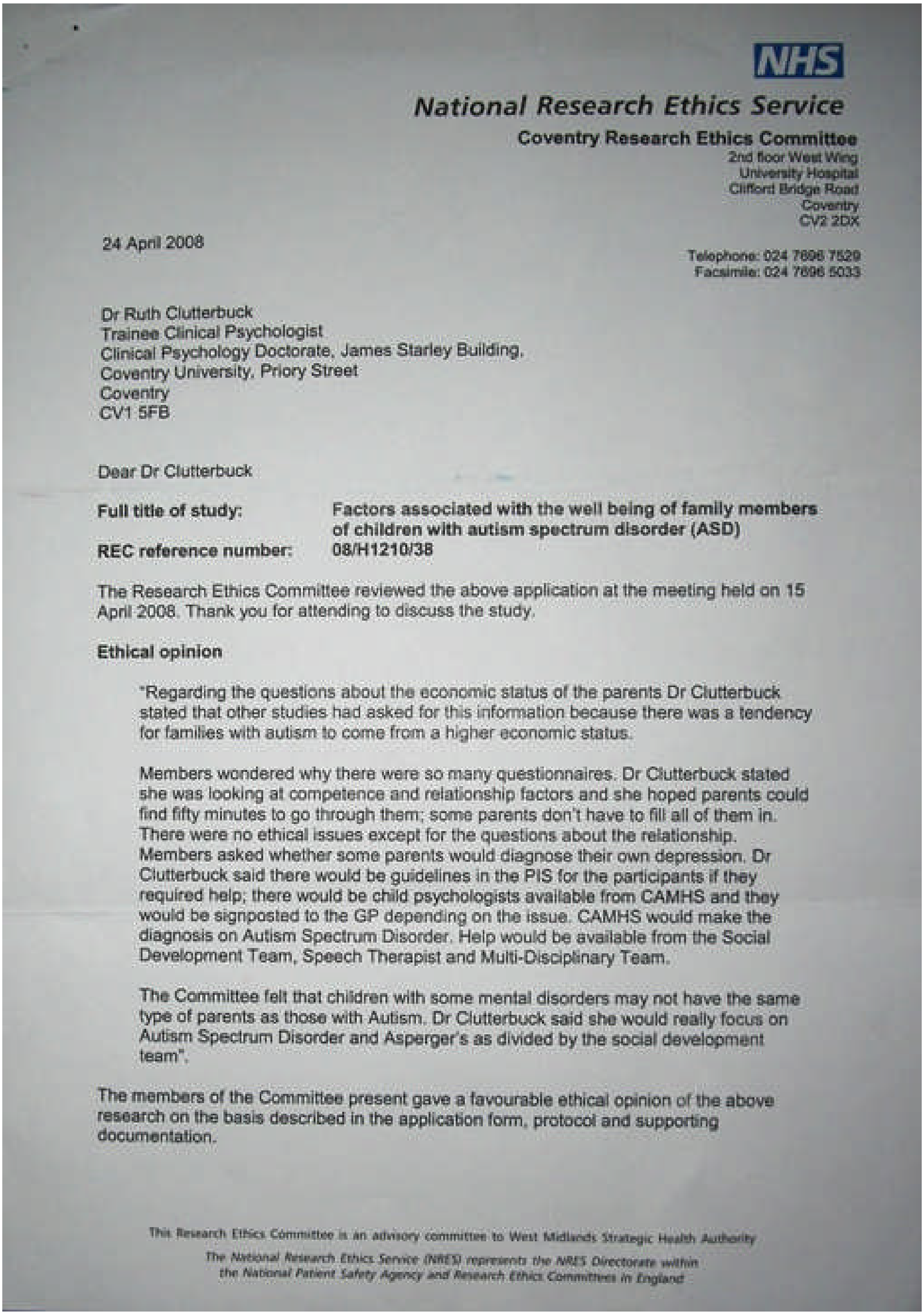
11.	**Recommendations**	
	Approved with **no** amendments	
	Approved subject to specified conditions.	As detailed in section 10

C:\Documents and Settings\hsx924\Local Settings\Temporary Internet Files\OLK74\ruth clutterbuck.doc
August 2007



	Reject	
12.	**Completed by:**	**Date:**
13.	**Re-submission**	
	Approved	✓
	Completed by:	**Date:**

Please return this form electronically to s.sandhu@coventry.ac.uk and please DO NOT CONTACT THE APPLICANT DIRECTLY.



NHS

National Research Ethics Service

Coventry Research Ethics Committee
2nd floor West Wing
University Hospital
Clifford Bridge Road
Coventry
CV2 2DX

Telephone: 024 7696 7529
Facsimile: 024 7696 5033

24 April 2008

Dr Ruth Clutterbuck
Trainee Clinical Psychologist
Clinical Psychology Doctorate, James Starley Building,
Coventry University, Priory Street
Coventry
CV1 5FB

Dear Dr Clutterbuck

Full title of study:	**Factors associated with the well being of family members of children with autism spectrum disorder (ASD)**
REC reference number:	**08/H1210/38**

The Research Ethics Committee reviewed the above application at the meeting held on 15 April 2008. Thank you for attending to discuss the study.

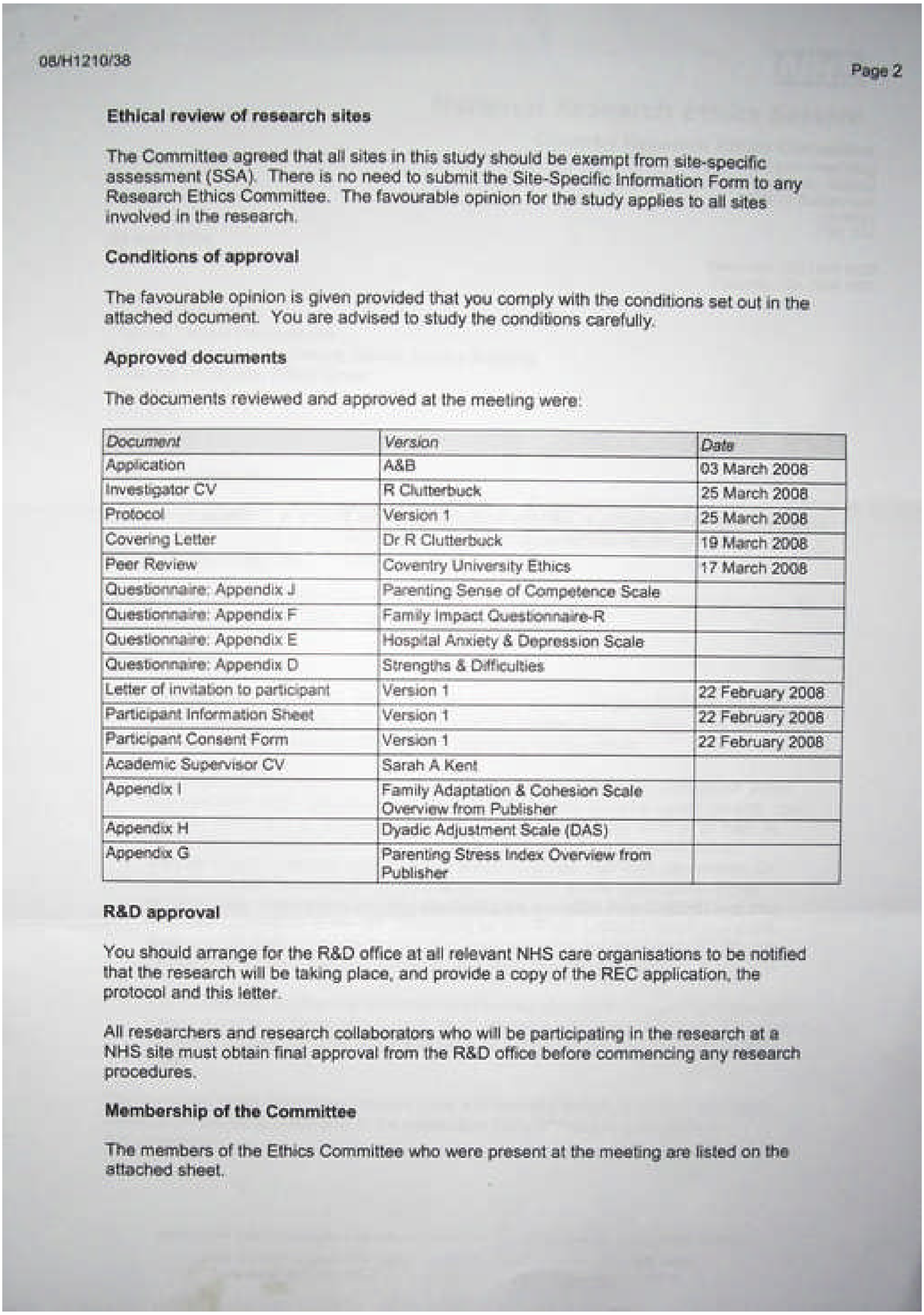
Ethical opinion

> "Regarding the questions about the economic status of the parents Dr Clutterbuck stated that other studies had asked for this information because there was a tendency for families with autism to come from a higher economic status.
>
> Members wondered why there were so many questionnaires. Dr Clutterbuck stated she was looking at competence and relationship factors and she hoped parents could find fifty minutes to go through them; some parents don't have to fill all of them in. There were no ethical issues except for the questions about the relationship. Members asked whether some parents would diagnose their own depression. Dr Clutterbuck said there would be guidelines in the PIS for the participants if they required help; there would be child psychologists available from CAMHS and they would be signposted to the GP depending on the issue. CAMHS would make the diagnosis on Autism Spectrum Disorder. Help would be available from the Social Development Team, Speech Therapist and Multi-Disciplinary Team.
>
> The Committee felt that children with some mental disorders may not have the same type of parents as those with Autism. Dr Clutterbuck said she would really focus on Autism Spectrum Disorder and Asperger's as divided by the social development team".

The members of the Committee present gave a favourable ethical opinion of the above research on the basis described in the application form, protocol and supporting documentation.

This Research Ethics Committee is an advisory committee to West Midlands Strategic Health Authority

The National Research Ethics Service (NRES) represents the NRES Directorate within the National Patient Safety Agency and Research Ethics Committees in England



08/H1210/38

Page 2

Ethical review of research sites

The Committee agreed that all sites in this study should be exempt from site-specific assessment (SSA). There is no need to submit the Site-Specific Information Form to any Research Ethics Committee. The favourable opinion for the study applies to all sites involved in the research.

Conditions of approval

The favourable opinion is given provided that you comply with the conditions set out in the attached document. You are advised to study the conditions carefully.

Approved documents

The documents reviewed and approved at the meeting were:

Document	*Version*	*Date*
Application	A&B	03 March 2008
Investigator CV	R Clutterbuck	25 March 2008
Protocol	Version 1	25 March 2008
Covering Letter	Dr R Clutterbuck	19 March 2008
Peer Review	Coventry University Ethics	17 March 2008
Questionnaire: Appendix J	Parenting Sense of Competence Scale	
Questionnaire: Appendix F	Family Impact Questionnaire-R	
Questionnaire: Appendix E	Hospital Anxiety & Depression Scale	
Questionnaire: Appendix D	Strengths & Difficulties	
Letter of invitation to participant	Version 1	22 February 2008
Participant Information Sheet	Version 1	22 February 2008
Participant Consent Form	Version 1	22 February 2008
Academic Supervisor CV	Sarah A Kent	
Appendix I	Family Adaptation & Cohesion Scale Overview from Publisher	
Appendix H	Dyadic Adjustment Scale (DAS)	
Appendix G	Parenting Stress Index Overview from Publisher	

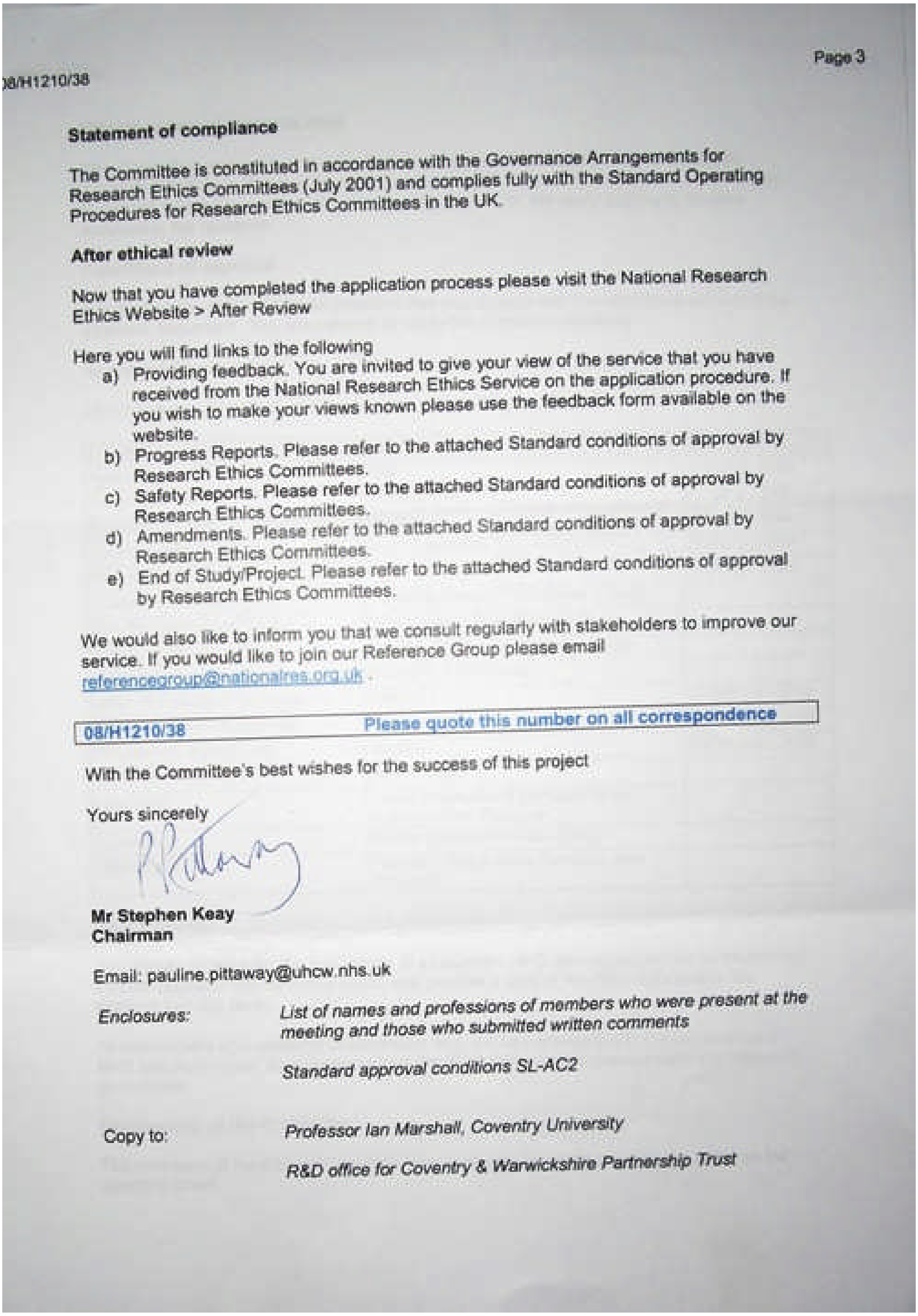
R&D approval

You should arrange for the R&D office at all relevant NHS care organisations to be notified that the research will be taking place, and provide a copy of the REC application, the protocol and this letter.

All researchers and research collaborators who will be participating in the research at a NHS site must obtain final approval from the R&D office before commencing any research procedures.

Membership of the Committee

The members of the Ethics Committee who were present at the meeting are listed on the attached sheet.



08/H1210/38

Page 3

Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees (July 2001) and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

After ethical review

Now that you have completed the application process please visit the National Research Ethics Website > After Review

Here you will find links to the following

a) Providing feedback. You are invited to give your view of the service that you have received from the National Research Ethics Service on the application procedure. If you wish to make your views known please use the feedback form available on the website.

b) Progress Reports. Please refer to the attached Standard conditions of approval by Research Ethics Committees.

c) Safety Reports. Please refer to the attached Standard conditions of approval by Research Ethics Committees.

d) Amendments. Please refer to the attached Standard conditions of approval by Research Ethics Committees.

e) End of Study/Project. Please refer to the attached Standard conditions of approval by Research Ethics Committees.

We would also like to inform you that we consult regularly with stakeholders to improve our service. If you would like to join our Reference Group please email referencegroup@nationalres.org.uk .

08/H1210/38	**Please quote this number on all correspondence**

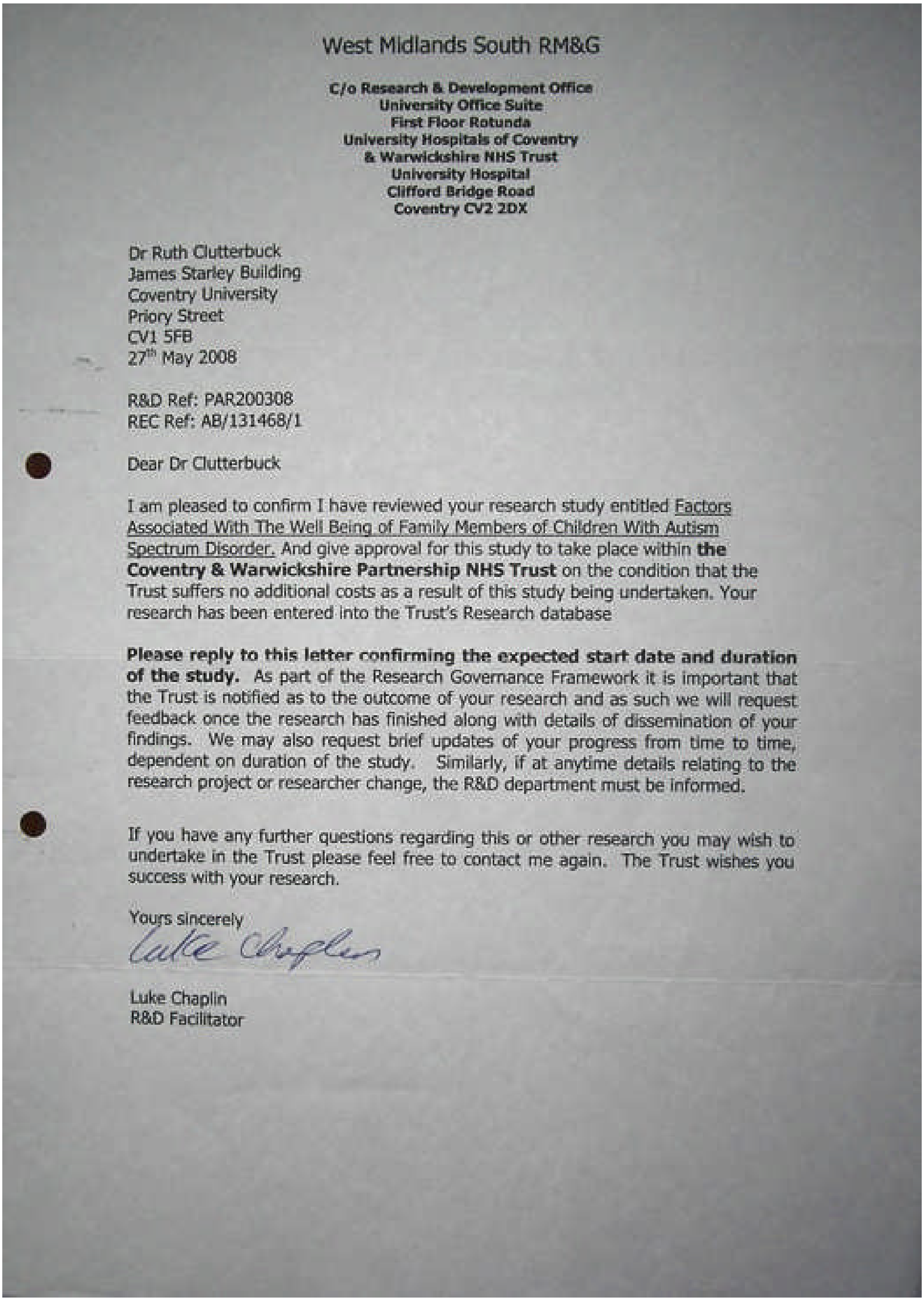
With the Committee's best wishes for the success of this project

Yours sincerely

Mr Stephen Keay
Chairman

Email: pauline.pittaway@uhcw.nhs.uk

Enclosures:	*List of names and professions of members who were present at the meeting and those who submitted written comments*
	Standard approval conditions SL-AC2
Copy to:	*Professor Ian Marshall, Coventry University*
	R&D office for Coventry & Warwickshire Partnership Trust



West Midlands South RM&G

C/o Research & Development Office
University Office Suite
First Floor Rotunda
University Hospitals of Coventry
& Warwickshire NHS Trust
University Hospital
Clifford Bridge Road
Coventry CV2 2DX

Dr Ruth Clutterbuck
James Starley Building
Coventry University
Priory Street
CV1 5FB
27th May 2008

R&D Ref: PAR200308
REC Ref: AB/131468/1

Dear Dr Clutterbuck

I am pleased to confirm I have reviewed your research study entitled Factors Associated With The Well Being of Family Members of Children With Autism Spectrum Disorder. And give approval for this study to take place within **the Coventry & Warwickshire Partnership NHS Trust** on the condition that the Trust suffers no additional costs as a result of this study being undertaken. Your research has been entered into the Trust's Research database

Please reply to this letter confirming the expected start date and duration of the study. As part of the Research Governance Framework it is important that the Trust is notified as to the outcome of your research and as such we will request feedback once the research has finished along with details of dissemination of your findings. We may also request brief updates of your progress from time to time, dependent on duration of the study. Similarly, if at anytime details relating to the research project or researcher change, the R&D department must be informed.

If you have any further questions regarding this or other research you may wish to undertake in the Trust please feel free to contact me again. The Trust wishes you success with your research.

Yours sincerely

Luke Chaplin

Luke Chaplin
R&D Facilitator

Appendix 2: Example of parents’ letter of invitation to participate in the research

Coventry and Warwickshire NHS
Partnership Trust

CHILD & ADOLESCENT MENTAL HEALTH SERVICES
Whitestone Centre
Magyar Cresent
Nuneaton
Warwickshire
CV11 4SG

Tel: 024 7664 1799
Fax: 024 7632 0305

10 July 2008

Dear Parents

Study title: Factors associated with the well being of family members of children with autism spectrum disorder (ASD).

I am writing to inform you of a research project that is currently taking place within our service. Ruth Clutterbuck (Trainee Clinical Psychologist) is currently carrying out a study exploring the factors associated with the well being of family members of children with autism spectrum disorder (ASD). She is hoping to recruit mothers and fathers of children with ASD to take part in this study.
If you are interested in finding out more about this study, please indicate your willingness to be contacted by Ruth by returning the slip below in the envelope provided. Please note that returning the slip does not mean that you have agreed to participate in the study.

Yours sincerely

Dr Claire Rowbury
Consultant Clinical Psychologist (CAMHS)

Study title: Factors associated with the well being of family members of children with autism spectrum disorder (ASD).

We are interested in learning more about the above study and agree to be contacted by telephone/email.

Name & address of parents:

....

....

....

....

Telephone number of parents: ....

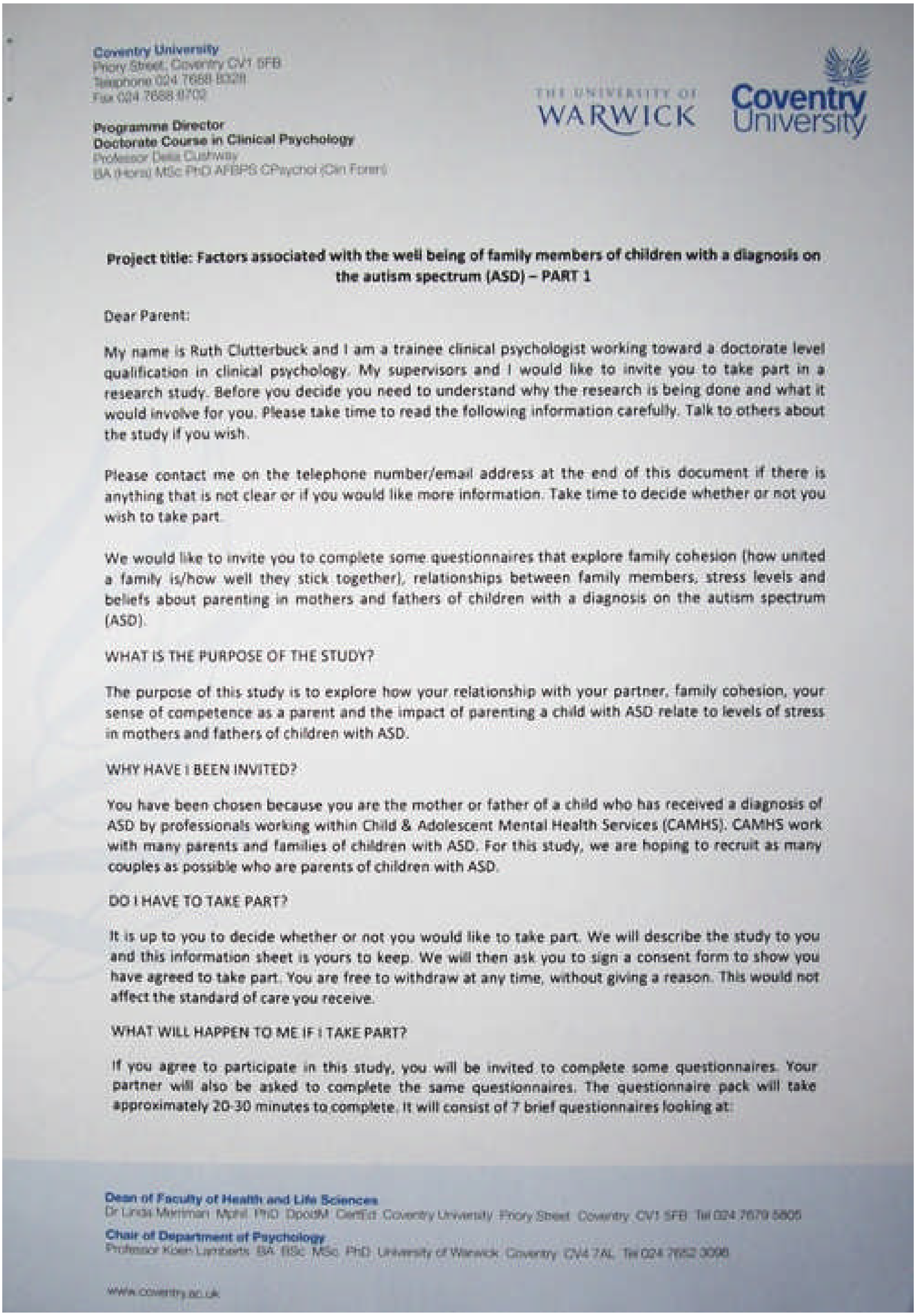
Email addresses of parents: ....

Karamjit Singh - Chairman
Sandy Taylor - Chief Executive

Coventry and Warwickshire Partnership Trust
The Caludon Centre, Clifford Bridge Road, Walsgrave, Coventry CV2 2TE
Tel: (024) 7696 8020 Fax: (024) 7696 7890
www.covwarkpt.nhs.uk

In partnership with:
Coventry City Council
Warwickshire County Council

Appendix 3: Participant information sheet



Coventry University
Priory Street, Coventry CV1 5FB
Telephone 024 7688 8328
Fax 024 7688 8702

Programme Director
Doctorate Course in Clinical Psychology
Professor Delia Cushway
BA (Hons) MSc PhD AFBPS CPsychol (Clin Foren)

Project title: Factors associated with the well being of family members of children with a diagnosis on the autism spectrum (ASD) – PART 1

Dear Parent:

My name is Ruth Clutterbuck and I am a trainee clinical psychologist working toward a doctorate level qualification in clinical psychology. My supervisors and I would like to invite you to take part in a research study. Before you decide you need to understand why the research is being done and what it would involve for you. Please take time to read the following information carefully. Talk to others about the study if you wish.

Please contact me on the telephone number/email address at the end of this document if there is anything that is not clear or if you would like more information. Take time to decide whether or not you wish to take part.

We would like to invite you to complete some questionnaires that explore family cohesion (how united a family is/how well they stick together), relationships between family members, stress levels and beliefs about parenting in mothers and fathers of children with a diagnosis on the autism spectrum (ASD).

WHAT IS THE PURPOSE OF THE STUDY?

The purpose of this study is to explore how your relationship with your partner, family cohesion, your sense of competence as a parent and the impact of parenting a child with ASD relate to levels of stress in mothers and fathers of children with ASD.

WHY HAVE I BEEN INVITED?

You have been chosen because you are the mother or father of a child who has received a diagnosis of ASD by professionals working within Child & Adolescent Mental Health Services (CAMHS). CAMHS work with many parents and families of children with ASD. For this study, we are hoping to recruit as many couples as possible who are parents of children with ASD.

DO I HAVE TO TAKE PART?

It is up to you to decide whether or not you would like to take part. We will describe the study to you and this information sheet is yours to keep. We will then ask you to sign a consent form to show you have agreed to take part. You are free to withdraw at any time, without giving a reason. This would not affect the standard of care you receive.

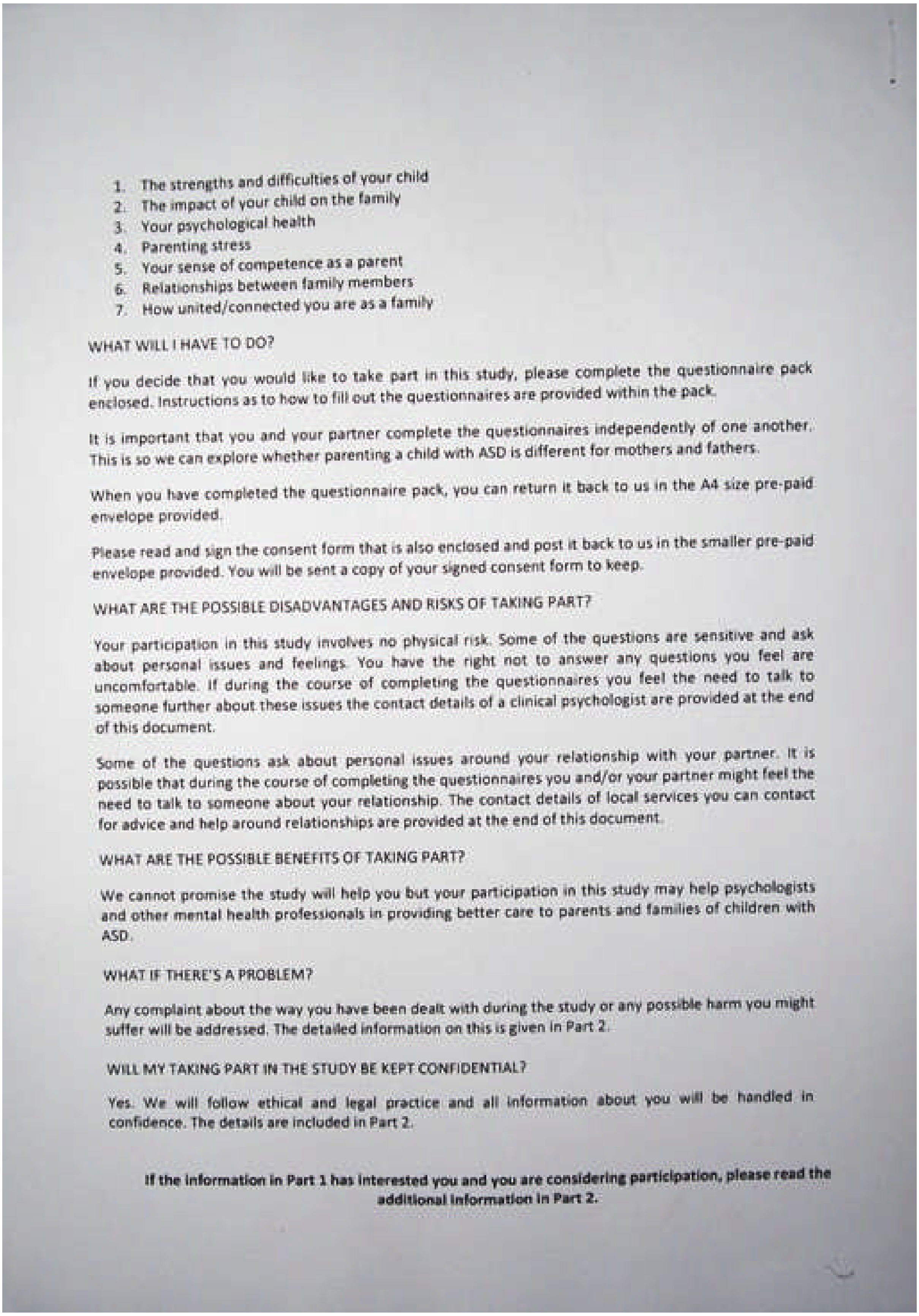
WHAT WILL HAPPEN TO ME IF I TAKE PART?

If you agree to participate in this study, you will be invited to complete some questionnaires. Your partner will also be asked to complete the same questionnaires. The questionnaire pack will take approximately 20-30 minutes to complete. It will consist of 7 brief questionnaires looking at:

Dean of Faculty of Health and Life Sciences
Dr Linda Merriman MPhil PhD DPodM CertEd Coventry University Priory Street Coventry CV1 5FB Tel 024 7679 5805

Chair of Department of Psychology
Professor Koen Lamberts BA BSc MSc PhD University of Warwick Coventry CV4 7AL Tel 024 7652 3096

www.coventry.ac.uk



1. The strengths and difficulties of your child
2. The impact of your child on the family
3. Your psychological health
4. Parenting stress
5. Your sense of competence as a parent
6. Relationships between family members
7. How united/connected you are as a family

WHAT WILL I HAVE TO DO?

If you decide that you would like to take part in this study, please complete the questionnaire pack enclosed. Instructions as to how to fill out the questionnaires are provided within the pack.

It is important that you and your partner complete the questionnaires independently of one another. This is so we can explore whether parenting a child with ASD is different for mothers and fathers.

When you have completed the questionnaire pack, you can return it back to us in the A4 size pre-paid envelope provided.

Please read and sign the consent form that is also enclosed and post it back to us in the smaller pre-paid envelope provided. You will be sent a copy of your signed consent form to keep.

WHAT ARE THE POSSIBLE DISADVANTAGES AND RISKS OF TAKING PART?

Your participation in this study involves no physical risk. Some of the questions are sensitive and ask about personal issues and feelings. You have the right not to answer any questions you feel are uncomfortable. If during the course of completing the questionnaires you feel the need to talk to someone further about these issues the contact details of a clinical psychologist are provided at the end of this document.

Some of the questions ask about personal issues around your relationship with your partner. It is possible that during the course of completing the questionnaires you and/or your partner might feel the need to talk to someone about your relationship. The contact details of local services you can contact for advice and help around relationships are provided at the end of this document.

WHAT ARE THE POSSIBLE BENEFITS OF TAKING PART?

We cannot promise the study will help you but your participation in this study may help psychologists and other mental health professionals in providing better care to parents and families of children with ASD.

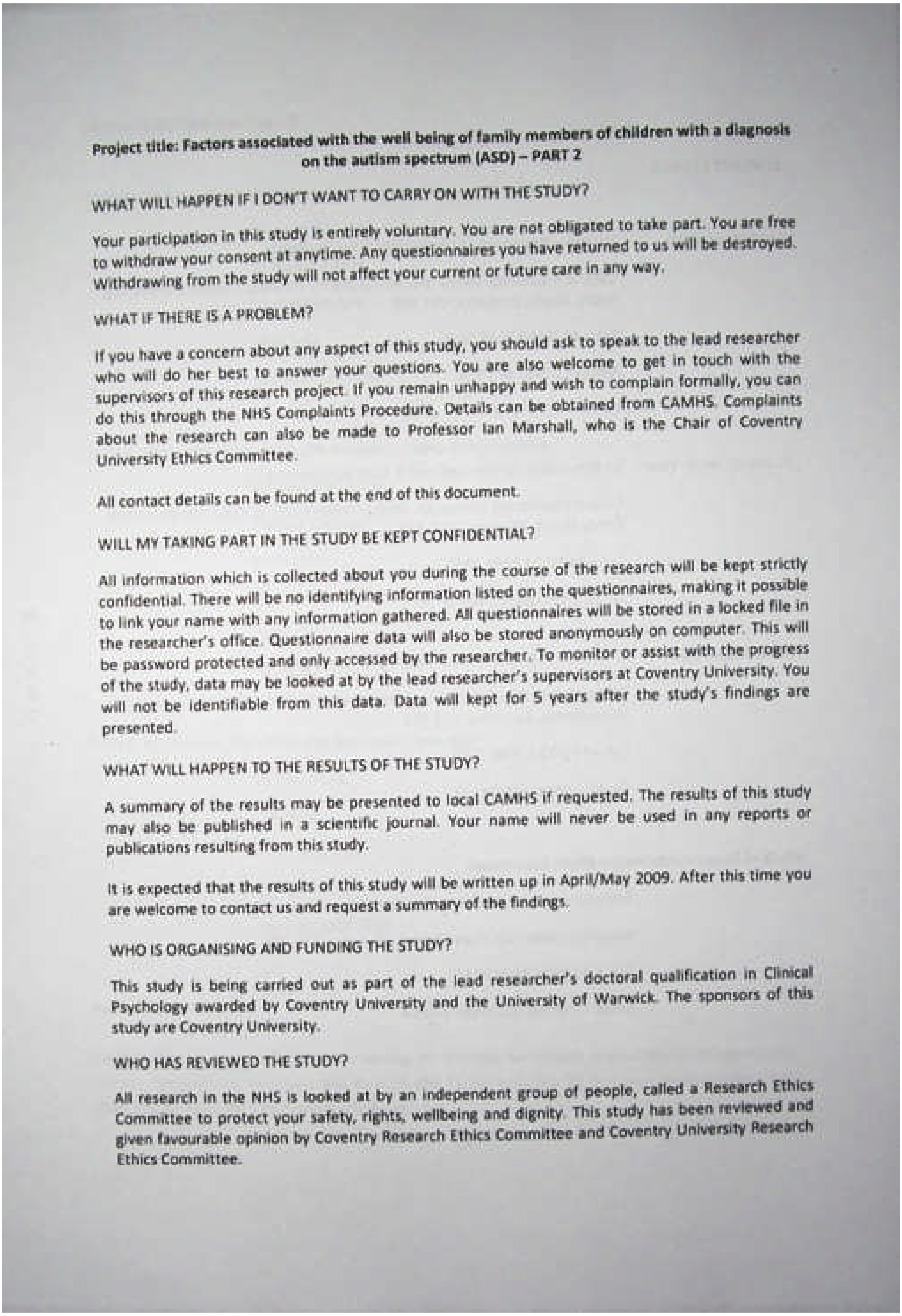
WHAT IF THERE'S A PROBLEM?

Any complaint about the way you have been dealt with during the study or any possible harm you might suffer will be addressed. The detailed information on this is given in Part 2.

WILL MY TAKING PART IN THE STUDY BE KEPT CONFIDENTIAL?

Yes. We will follow ethical and legal practice and all information about you will be handled in confidence. The details are included in Part 2.

If the information in Part 1 has interested you and you are considering participation, please read the additional information in Part 2.



Project title: Factors associated with the well being of family members of children with a diagnosis on the autism spectrum (ASD) – PART 2

WHAT WILL HAPPEN IF I DON'T WANT TO CARRY ON WITH THE STUDY?

Your participation in this study is entirely voluntary. You are not obligated to take part. You are free to withdraw your consent at anytime. Any questionnaires you have returned to us will be destroyed. Withdrawing from the study will not affect your current or future care in any way.

WHAT IF THERE IS A PROBLEM?

If you have a concern about any aspect of this study, you should ask to speak to the lead researcher who will do her best to answer your questions. You are also welcome to get in touch with the supervisors of this research project. If you remain unhappy and wish to complain formally, you can do this through the NHS Complaints Procedure. Details can be obtained from CAMHS. Complaints about the research can also be made to Professor Ian Marshall, who is the Chair of Coventry University Ethics Committee.

All contact details can be found at the end of this document.

WILL MY TAKING PART IN THE STUDY BE KEPT CONFIDENTIAL?

All information which is collected about you during the course of the research will be kept strictly confidential. There will be no identifying information listed on the questionnaires, making it possible to link your name with any information gathered. All questionnaires will be stored in a locked file in the researcher's office. Questionnaire data will also be stored anonymously on computer. This will be password protected and only accessed by the researcher. To monitor or assist with the progress of the study, data may be looked at by the lead researcher's supervisors at Coventry University. You will not be identifiable from this data. Data will kept for 5 years after the study's findings are presented.

WHAT WILL HAPPEN TO THE RESULTS OF THE STUDY?

A summary of the results may be presented to local CAMHS if requested. The results of this study may also be published in a scientific journal. Your name will never be used in any reports or publications resulting from this study.

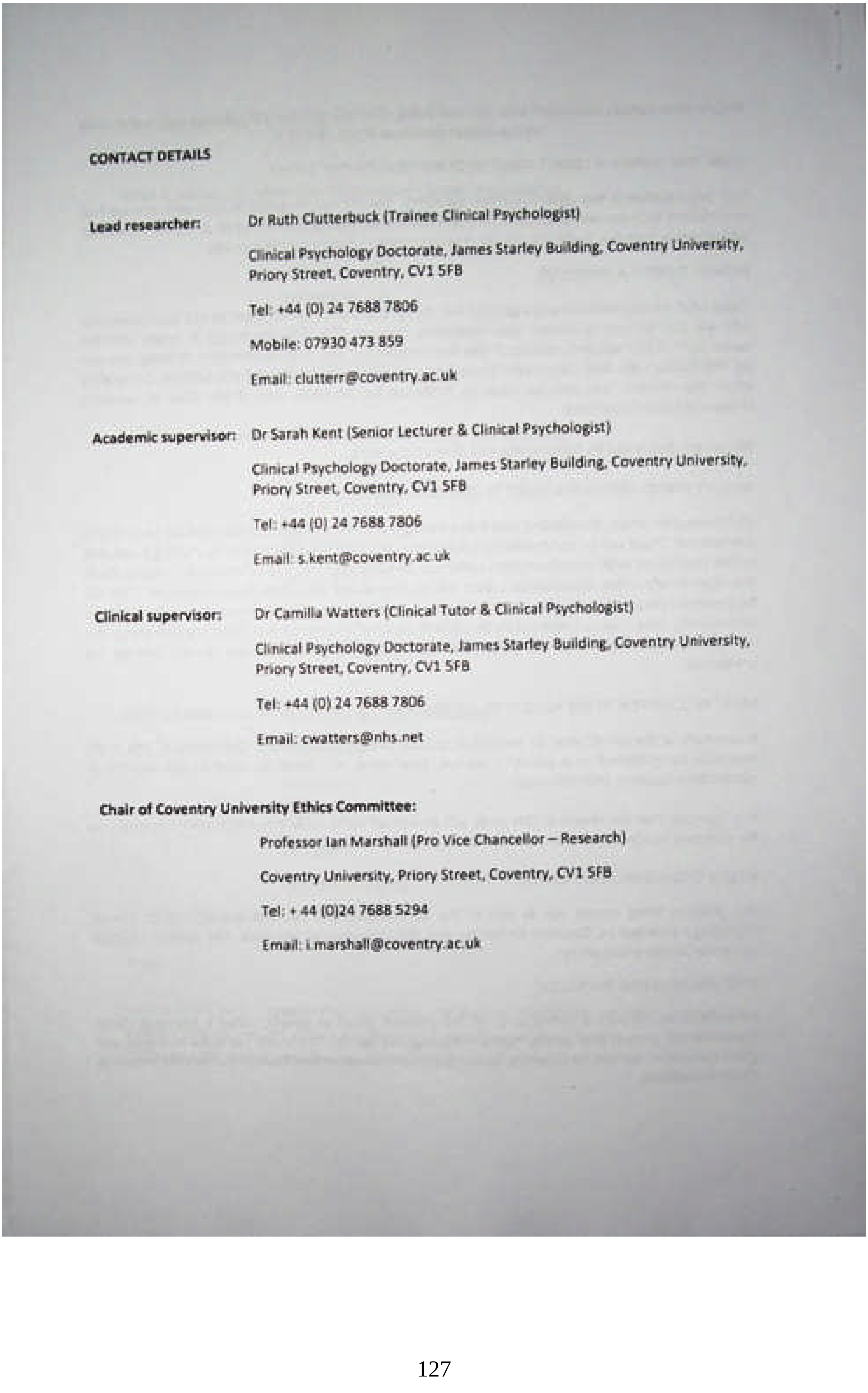
It is expected that the results of this study will be written up in April/May 2009. After this time you are welcome to contact us and request a summary of the findings.

WHO IS ORGANISING AND FUNDING THE STUDY?

This study is being carried out as part of the lead researcher's doctoral qualification in Clinical Psychology awarded by Coventry University and the University of Warwick. The sponsors of this study are Coventry University.

WHO HAS REVIEWED THE STUDY?

All research in the NHS is looked at by an independent group of people, called a Research Ethics Committee to protect your safety, rights, wellbeing and dignity. This study has been reviewed and given favourable opinion by Coventry Research Ethics Committee and Coventry University Research Ethics Committee.



CONTACT DETAILS

Lead researcher: Dr Ruth Clutterbuck (Trainee Clinical Psychologist)

Clinical Psychology Doctorate, James Starley Building, Coventry University,
Priory Street, Coventry, CV1 5FB

Tel: +44 (0) 24 7688 7806

Mobile: 07930 473 859

Email: clutterr@coventry.ac.uk

Academic supervisor: Dr Sarah Kent (Senior Lecturer & Clinical Psychologist)

Clinical Psychology Doctorate, James Starley Building, Coventry University,
Priory Street, Coventry, CV1 5FB

Tel: +44 (0) 24 7688 7806

Email: s.kent@coventry.ac.uk

Clinical supervisor: Dr Camilla Watters (Clinical Tutor & Clinical Psychologist)

Clinical Psychology Doctorate, James Starley Building, Coventry University,
Priory Street, Coventry, CV1 5FB

Tel: +44 (0) 24 7688 7806

Email: cwatters@nhs.net

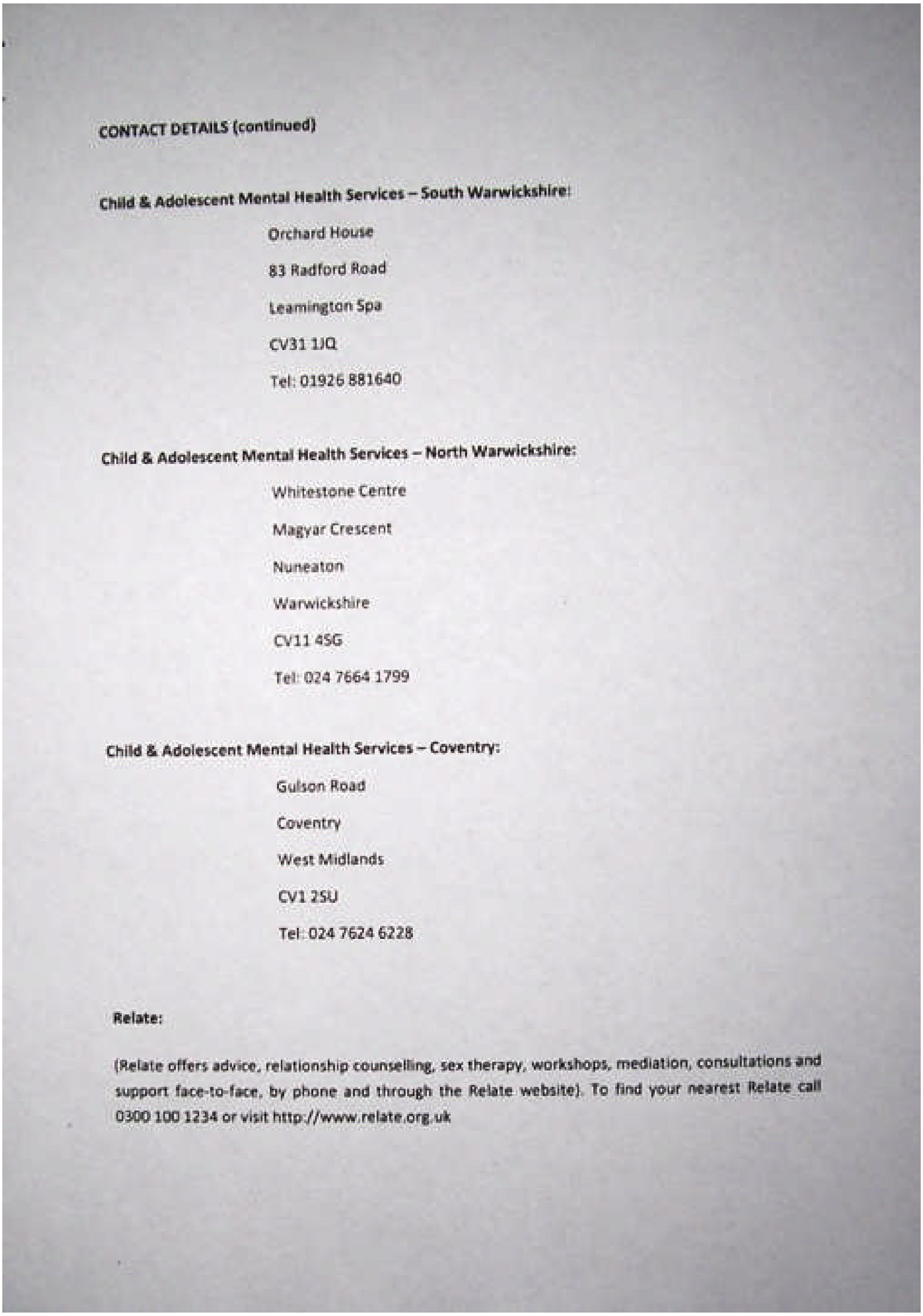
Chair of Coventry University Ethics Committee:

Professor Ian Marshall (Pro Vice Chancellor – Research)

Coventry University, Priory Street, Coventry, CV1 5FB

Tel: + 44 (0)24 7688 5294

Email: i.marshall@coventry.ac.uk



CONTACT DETAILS (continued)

Child & Adolescent Mental Health Services – South Warwickshire:

Orchard House
83 Radford Road
Leamington Spa
CV31 1JQ
Tel: 01926 881640

Child & Adolescent Mental Health Services – North Warwickshire:

Whitestone Centre
Magyar Crescent
Nuneaton
Warwickshire
CV11 4SG
Tel: 024 7664 1799

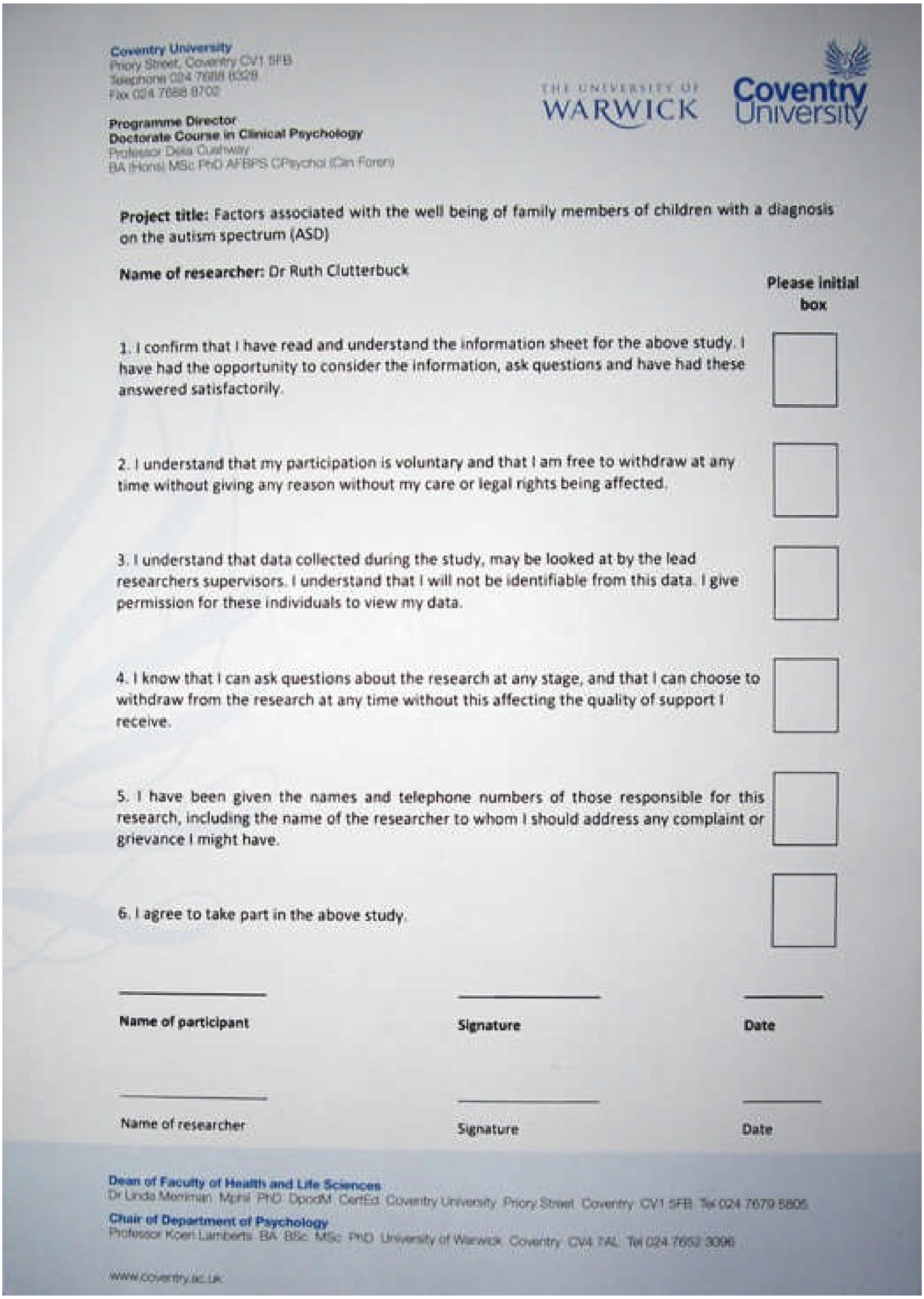
Child & Adolescent Mental Health Services – Coventry:

Gulson Road
Coventry
West Midlands
CV1 2SU
Tel: 024 7624 6228

Relate:

(Relate offers advice, relationship counselling, sex therapy, workshops, mediation, consultations and support face-to-face, by phone and through the Relate website). To find your nearest Relate call 0300 100 1234 or visit http://www.relate.org.uk

Appendix 4: Consent Form



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Programme Director
Doctorate Course in Clinical Psychology
Professor Delia Cushway
BA (Hons) MSc PhD AFBPS CPsychol (Clin Foren)

THE UNIVERSITY OF WARWICK

Coventry University

Project title: Factors associated with the well being of family members of children with a diagnosis on the autism spectrum (ASD)

Name of researcher: Dr Ruth Clutterbuck

Please initial box

1. I confirm that I have read and understand the information sheet for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily. ☐

2. I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason without my care or legal rights being affected. ☐

3. I understand that data collected during the study, may be looked at by the lead researchers supervisors. I understand that I will not be identifiable from this data. I give permission for these individuals to view my data. ☐

4. I know that I can ask questions about the research at any stage, and that I can choose to withdraw from the research at any time without this affecting the quality of support I receive. ☐

5. I have been given the names and telephone numbers of those responsible for this research, including the name of the researcher to whom I should address any complaint or grievance I might have. ☐

6. I agree to take part in the above study. ☐

______________	______________	________
Name of participant	**Signature**	**Date**
______________	______________	________
Name of researcher	Signature	Date

Dean of Faculty of Health and Life Sciences
Dr Linda Merriman MPhil PhD DpodM CertEd Coventry University Priory Street Coventry CV1 5FB Tel 024 7679 5805
Chair of Department of Psychology
Professor Koen Lamberts BA BSc MSc PhD University of Warwick Coventry CV4 7AL Tel 024 7652 3096

www.coventry.ac.uk

Appendix 5: Questionnaire pack guidance for parents

QUESTIONNAIRE PACK

Information & Instructions

1. This questionnaire pack has been coded in the top right hand corner. This code corresponds to your partner’s questionnaire pack code so we can match up parents when analysing the data. Please note that we do not have a record of which parent has been sent which code so your anonymity is protected.

2. Please complete the background information section and all 7 questionnaires. The instructions for each questionnaire are at the top of each page. Please make sure you answer all the questions and please complete the questionnaires without consulting your partner about the answers.

3. Please send back the questionnaire pack in the A4 size, pre paid envelope provided.

Thank you for taking part in the study.

PLEASE TURN OVER

Appendix 6: Parent background information sheet

These questionnaires have been sent to many parents over a wide geographical area. Please note that no one will be able to trace your answers to you. In addition, you, your child or your family cannot be identified by the information you provide.

1. BACKGROUND INFORMATION

Your age	Years_______ Months_______

Your ethnic background		**PLEASE TICK**
	White	____
	Mixed	____
	Indian	____
	Pakistani	____
	Bangladeshi	____
	Other Asian	____
	Black Caribbean	____
	Black African	____
	Other Black	____
	Chinese	____
	Other Ethnic Group (please state)______________________	

Your Education		
	Some secondary school	____
	Completed secondary school	____
	Some college	____
	Completed college	____
	Advanced degree	____

Household income (per year)		
	Less than £5 000	____
	£5 000 - £10 000	____
	£10 000 - £20 000	____
	£20 000 - £30 000	____
	£30 000 - £40 000	____
	£40 000 - £50 000	____
	£50 000 - £60 000	____
	£60 000 - £70 000	____
	£70 000 or more	____

Current relationship status		
	Married	____
	Living together	____

PLEASE TURN OVER

2. INFORMATION ABOUT YOUR CHILD ON THE AUTISM SPECTRUM

Age of your child	Years_______ Months______

Sex of your child (please tick)	Male______ Female_____

What is your child's specific diagnosis? (please state)	______________________ ______________________

How old was he/she when he/she received this diagnosis?	Years_______ Months_______

Does your child live with you? (please tick)	Yes______ No_____

Your child's education		**Please Tick**
	My child attends mainstream school	_____
	My child attends school for children with special educational needs	_____
	Other (please state) _______________________ _______________________	

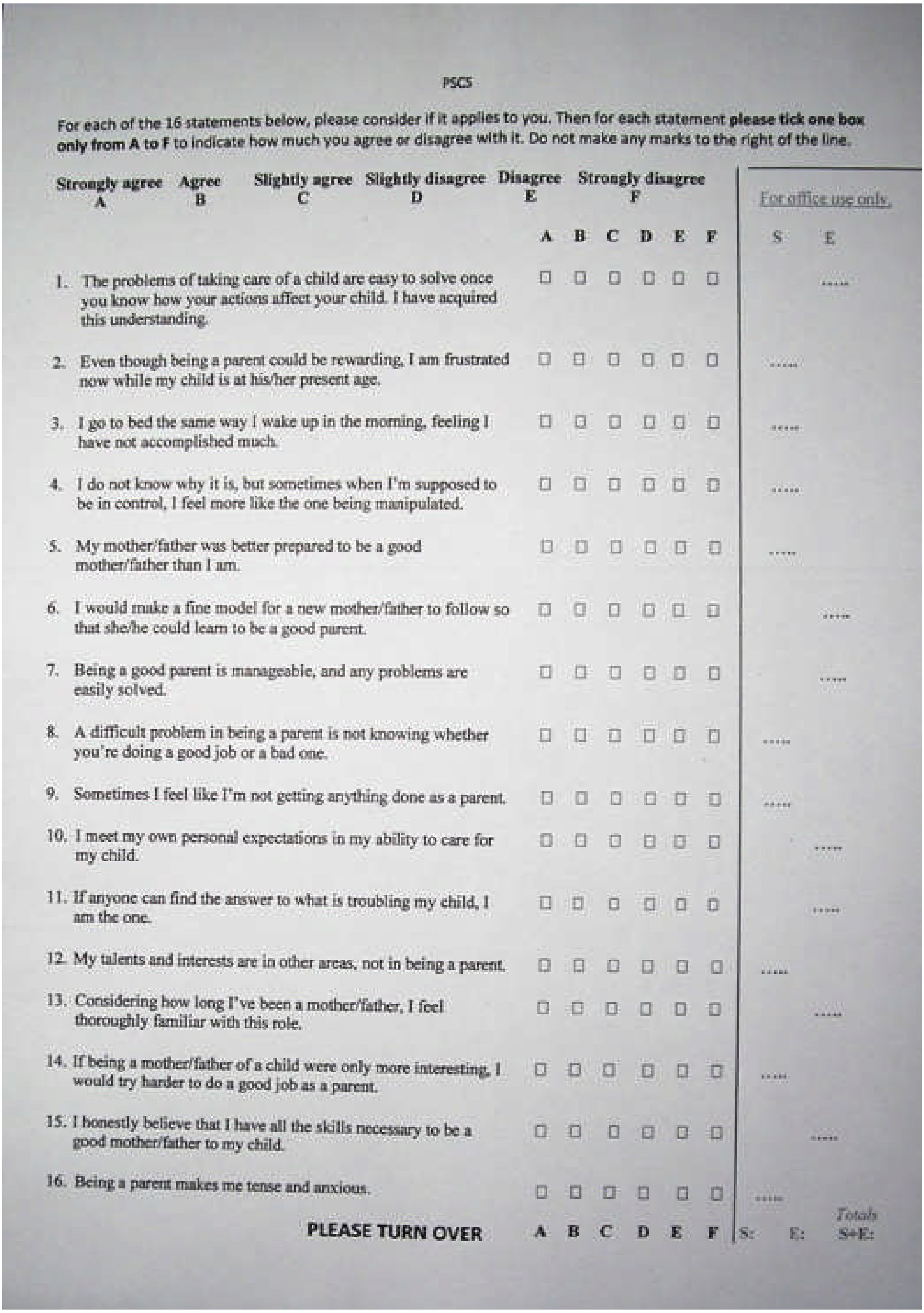
3. INFORMATION ABOUT YOUR CHILD'S SIBLINGS

Please include the age and gender of any brothers and sisters the above child has. Please also indicate whether or not each of these children currently lives with you.

	Age of each sibling	Sex of each sibling (please tick)	Living with you? (please tick)
	Years______ Months_____	Male____ Female____	Yes____ No____
Sibling 1	Years______ Months_____	Male____ Female____	Yes____ No____
Sibling 2	Years______ Months_____	Male____ Female____	Yes____ No____
Sibling 3	Years______ Months_____	Male____ Female____	Yes____ No____
Sibling 4	Years______ Months_____	Male____ Female____	Yes____ No____
Sibling 5	Years______ Months_____	Male____ Female____	Yes____ No____
Sibling 6	Years______ Months_____	Male____ Female____	Yes____ No____
Sibling 7	Years______ Months_____	Male____ Female____	Yes____ No____
Sibling 8	Years______ Months_____	Male____ Female____	Yes____ No____

PLEASE TURN OVER

Appendix 7: Parent Sense of Competence Scale (PSCS)



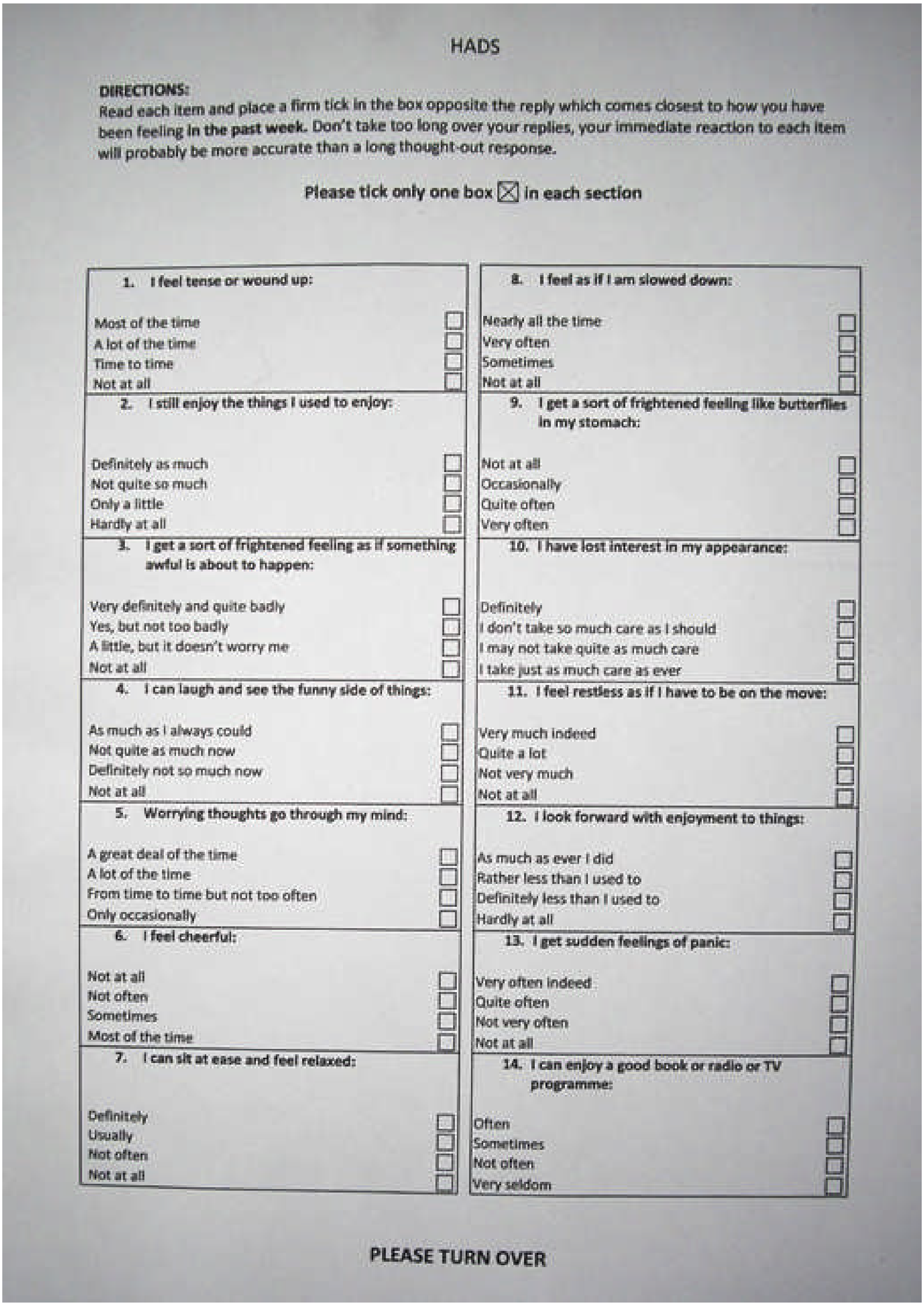
PSCS

For each of the 16 statements below, please consider if it applies to you. Then for each statement **please tick one box only from A to F** to indicate how much you agree or disagree with it. Do not make any marks to the right of the line.

Strongly agree A **Agree** B **Slightly agree** C **Slightly disagree** D **Disagree** E **Strongly disagree** F

	A	B	C	D	E	F	For office use only. S	E
1. The problems of taking care of a child are easy to solve once you know how your actions affect your child. I have acquired this understanding.	☐	☐	☐	☐	☐	☐		......
2. Even though being a parent could be rewarding, I am frustrated now while my child is at his/her present age.	☐	☐	☐	☐	☐	☐	......	
3. I go to bed the same way I wake up in the morning, feeling I have not accomplished much.	☐	☐	☐	☐	☐	☐	......	
4. I do not know why it is, but sometimes when I'm supposed to be in control, I feel more like the one being manipulated.	☐	☐	☐	☐	☐	☐	......	
5. My mother/father was better prepared to be a good mother/father than I am.	☐	☐	☐	☐	☐	☐	......	
6. I would make a fine model for a new mother/father to follow so that she/he could learn to be a good parent.	☐	☐	☐	☐	☐	☐		......
7. Being a good parent is manageable, and any problems are easily solved.	☐	☐	☐	☐	☐	☐		......
8. A difficult problem in being a parent is not knowing whether you're doing a good job or a bad one.	☐	☐	☐	☐	☐	☐	......	
9. Sometimes I feel like I'm not getting anything done as a parent.	☐	☐	☐	☐	☐	☐	......	
10. I meet my own personal expectations in my ability to care for my child.	☐	☐	☐	☐	☐	☐		......
11. If anyone can find the answer to what is troubling my child, I am the one.	☐	☐	☐	☐	☐	☐		......
12. My talents and interests are in other areas, not in being a parent.	☐	☐	☐	☐	☐	☐	......	
13. Considering how long I've been a mother/father, I feel thoroughly familiar with this role.	☐	☐	☐	☐	☐	☐		......
14. If being a mother/father of a child were only more interesting, I would try harder to do a good job as a parent.	☐	☐	☐	☐	☐	☐	......	
15. I honestly believe that I have all the skills necessary to be a good mother/father to my child.	☐	☐	☐	☐	☐	☐		......
16. Being a parent makes me tense and anxious.	☐	☐	☐	☐	☐	☐	......	
PLEASE TURN OVER	A	B	C	D	E	F	S:	E: *Totals* S+E:

Appendix 8: Hospital Anxiety & Depression Scale (HADS)



HADS

DIRECTIONS:
Read each item and place a firm tick in the box opposite the reply which comes closest to how you have been feeling **in the past week.** Don't take too long over your replies, your immediate reaction to each item will probably be more accurate than a long thought-out response.

Please tick only one box ☒ in each section

1. I feel tense or wound up:
- Most of the time ☐
- A lot of the time ☐
- Time to time ☐
- Not at all ☐

2. I still enjoy the things I used to enjoy:
- Definitely as much ☐
- Not quite so much ☐
- Only a little ☐
- Hardly at all ☐

3. I get a sort of frightened feeling as if something awful is about to happen:
- Very definitely and quite badly ☐
- Yes, but not too badly ☐
- A little, but it doesn't worry me ☐
- Not at all ☐

4. I can laugh and see the funny side of things:
- As much as I always could ☐
- Not quite as much now ☐
- Definitely not so much now ☐
- Not at all ☐

5. Worrying thoughts go through my mind:
- A great deal of the time ☐
- A lot of the time ☐
- From time to time but not too often ☐
- Only occasionally ☐

6. I feel cheerful:
- Not at all ☐
- Not often ☐
- Sometimes ☐
- Most of the time ☐

7. I can sit at ease and feel relaxed:
- Definitely ☐
- Usually ☐
- Not often ☐
- Not at all ☐

8. I feel as if I am slowed down:
- Nearly all the time ☐
- Very often ☐
- Sometimes ☐
- Not at all ☐

9. I get a sort of frightened feeling like butterflies in my stomach:
- Not at all ☐
- Occasionally ☐
- Quite often ☐
- Very often ☐

10. I have lost interest in my appearance:
- Definitely ☐
- I don't take so much care as I should ☐
- I may not take quite as much care ☐
- I take just as much care as ever ☐

11. I feel restless as if I have to be on the move:
- Very much indeed ☐
- Quite a lot ☐
- Not very much ☐
- Not at all ☐

12. I look forward with enjoyment to things:
- As much as ever I did ☐
- Rather less than I used to ☐
- Definitely less than I used to ☐
- Hardly at all ☐

13. I get sudden feelings of panic:
- Very often indeed ☐
- Quite often ☐
- Not very often ☐
- Not at all ☐

14. I can enjoy a good book or radio or TV programme:
- Often ☐
- Sometimes ☐
- Not often ☐
- Very seldom ☐

PLEASE TURN OVER

Appendix 9: Parenting Stress Index – short form (PSI-SF)

PARENTING STRESS INDEX - SF

DIRECTIONS:
In answering the following questions, please think about your child who has received a diagnosis on the autism spectrum.

The questions on the following pages ask you to mark and answer which best describes your feelings. While you may not find an answer which exactly states your feelings, please mark the answer which comes closest to describing how you feel.

YOUR FIRST REACTION TO EACH QUESTION SHOULD BE YOUR ANSWER.

Please mark the degree to which you agree or disagree with the following statements by ticking the column which best matches how you feel. If you are not sure, please tick **Not Sure**.

Strongly Agree **Agree** **Not Sure** **Disagree** **Strongly Disagree**

Example: I enjoy going to the cinema. (If you sometimes enjoy going to the cinema, you would tick the **Agree** column).

Please tick one statement below that best describes your feelings as a parent.

	Strongly Agree	Agree	Not Sure	Disagree	Strongly Disagree
1. I often have the feeling that I cannot handle things very well.					
2. I find myself giving up more of my life to meet my children's needs than I ever expected.					
3. I feel trapped by my responsibilities as a parent.					
4. Since having a child I have been unable to do new and different things.					
5. Since having a child I feel that I am almost never able to do things that I like to do.					
6. I am unhappy with the last purchase of clothing I made for myself.					
7. There are quite a few things that bother me about my life.					
8. Having a child has caused more problems than I expected in my relationship with my partner.					
9. I feel alone and without friends.					
10. When I go to a party I usually expect not to enjoy myself.					
11. I am not as interested in people as I used to be.					
12. I don't enjoy things as I used to.					
13. My child rarely does things for me that make me feel good.					
14. Most times I feel that my child does not like me and does not want to be close to me.					
15. My child smiles at me much less than I expected.					
16. When I do things for my child I get the feeling that my efforts are not appreciated very much.					
17. When playing, my child doesn't often giggle or laugh.					
18. My child doesn't seem to learn as quickly as most children.					
19. My child doesn't seem to smile as much as most children.					
20. My child is not able to do as much as I expected.					
21. It takes a long time and it is very hard for my child to get used to new things.					

PLEASE TURN OVER

Please tick one statement below that best describes your feelings as a parent.

22. I feel that I am:

not very good at being a parent, ____
a person who has some trouble being a parent , ____
an average parent, ____
a better than average parent, ____
a very good parent. ____

	Strongly Agree	**Agree**	**Not Sure**	**Disagree**	**Strongly Disagree**
23. I expected to have a closer and warmer feelings for my child than I do and this bothers me.					
24. Sometimes my child does things that bother me just to be mean.					
25. My child seems to cry or fuss more often than most children.					
26. My child generally wakes up in a bad mood.					
27. I feel that my child is very moody and easily upset.					
28. My child does a few things which bother me a great deal.					
29. My child reacts very strongly when something happens that my child doesn't like.					
30. My child gets upset over the smallest thing.					
31. My child's sleeping or eating schedule was much harder to establish than I expected.					

Please tick one statement below that best describes your feelings toward the following statement:

32. I have found that getting my child to do something or stop doing something is:

much harder than I expected, ____
somewhat harder than I expected, ____
about as hard as I expected, ____
somewhat easier than I expected, ____
much easier than I expected. ____

33. Think carefully and count the number of things which your child does that bother you. For example: dawdles, refuses to listen, overactive, cries, interrupts, fights, whines, etc. Please circle the number which includes the number of things you counted.

10+ **8-9** **6-7** **4-5** **1-3**

	Strongly Agree	**Agree**	**Not Sure**	**Disagree**	**Strongly Disagree**
34. There are some things my child does that really bother me a lot.					
35. My child turned out to be more of a problem than I expected.					
36. My child makes more demands on me than most children.					

Appendix 10: Family Impact Questionnaire (FIQ)

- Impact on relationship subscale
- Impact on siblings subscale

Family Impact Questionnaire-R

Being a parent can be difficult, and children have different effects on the family. We would like to know what impact your child has had on the family compared to the impact other children his/her age have on their families. The following questions attempt to understand children's impact on different areas of family functioning.

Please tick the category that best describes your situation in terms of how things have been in general for you with reference to the child who has received a diagnosis on the autism spectrum.

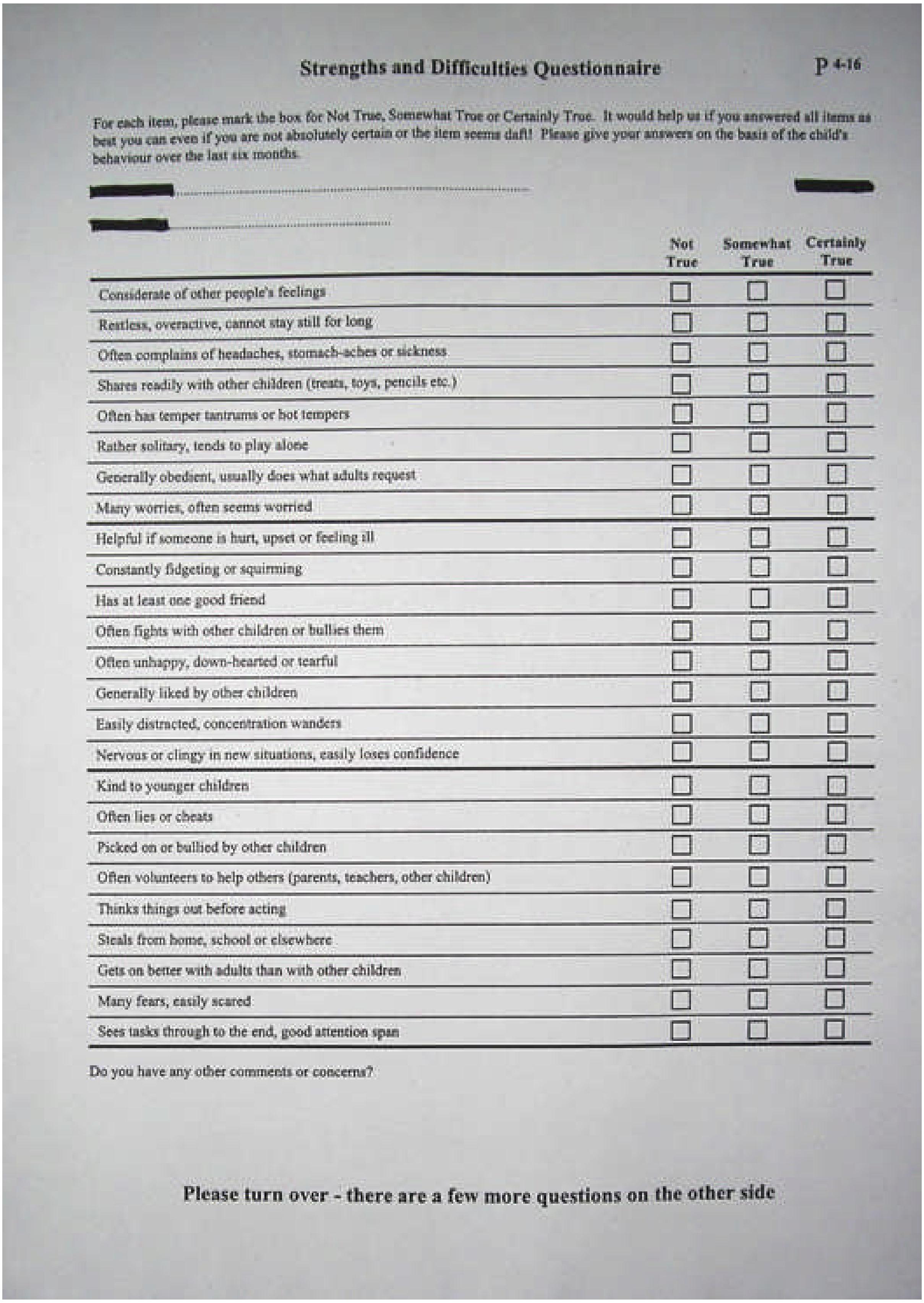
COMPARED TO PARENTS WITH CHILDREN THE SAME AGE AS MY CHILD …	**Not at all**	**Some-what**	**Much**	**Very much**
1. my partner and I disagree more about how to raise this child.				
2. my partner is more supportive of the way I deal with my child's behaviour.				
3. this child pits my partner and me against each other more.				
4. raising this child has brought my partner and me closer together.				
5. my child causes more disagreements between my partner and me.				
6. my partner is less supportive of the way I deal with my child's behaviour.				
7. raising this child has pushed my partner and me farther apart.				

IF YOU HAVE OTHER CHILDREN, PLEASE ALSO COMPLETE THE FOLLOWING SECTION, IF NOT, **PLEASE TURN OVER.**

COMPARED WITH OTHER CHILDREN MY CHILD'S AGE ...	**Not at all**	**Some what**	**Much**	**Very much**
8. the other children in the family help take care of him/her more.				
9. my child prevents his/her siblings from participating in activities more.				
10. the other children in the family complain about his/her behaviour more.				
11. the other children in the family feel more embarrassed by his/her behaviour.				
12. my child is more rejected by his/her siblings.				
13. the other children in the family invite friends over to the house less often because of his/her behaviour.				
14. the other children in the family enjoy spending time with him/her more.				
15. my child uses his/her siblings' toys without asking permission more.				
16. my child breaks or loses his/her siblings toys more.				

PLEASE TURN OVER

Appendix 11: Strengths & Difficulties Questionnaire (SDQ)



Strengths and Difficulties Questionnaire

P 4-16

For each item, please mark the box for Not True, Somewhat True or Certainly True. It would help us if you answered all items as best you can even if you are not absolutely certain or the item seems daft! Please give your answers on the basis of the child's behaviour over the last six months.

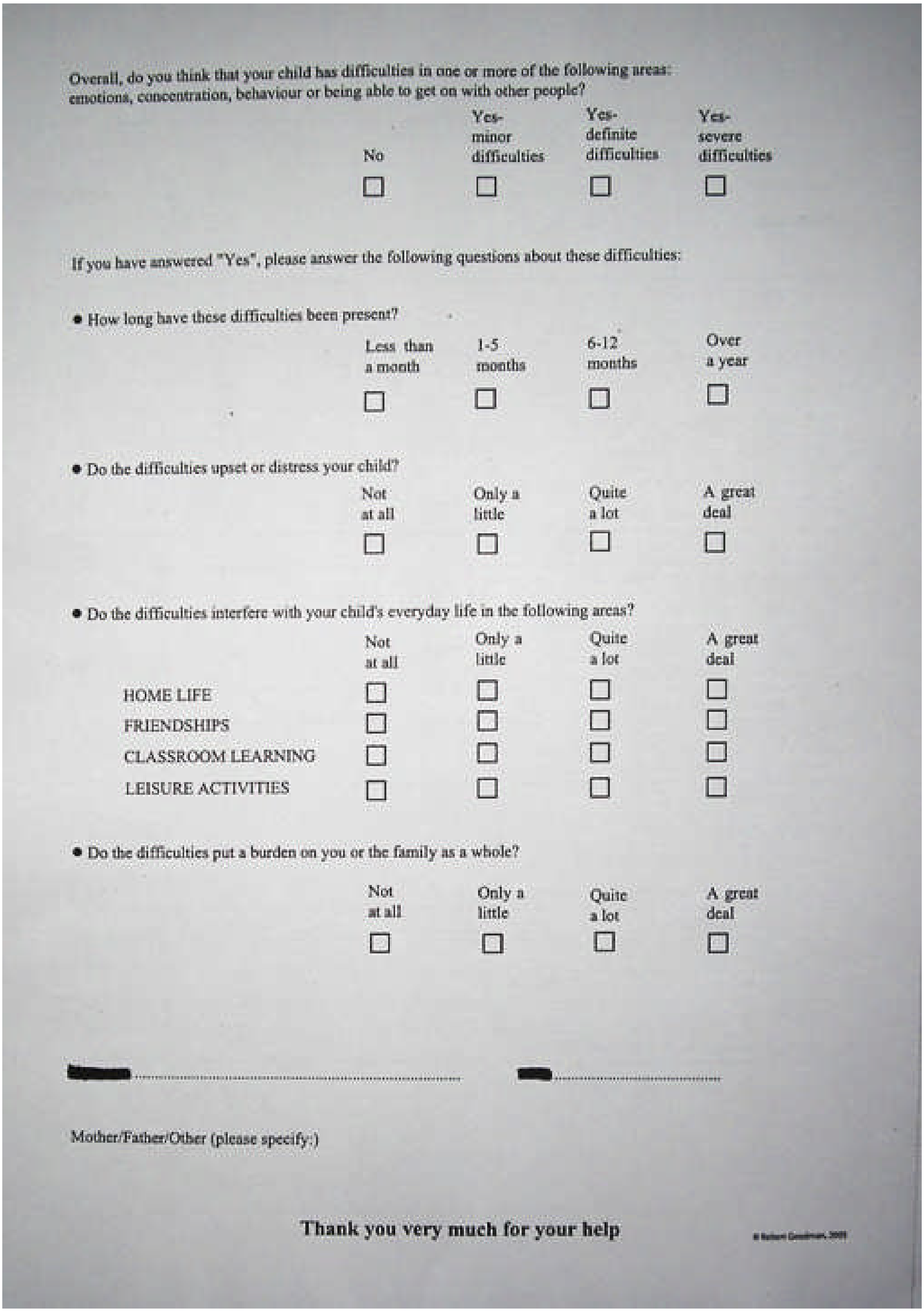
[redacted] .... [redacted]

[redacted] ....

	Not True	Somewhat True	Certainly True
Considerate of other people's feelings	☐	☐	☐
Restless, overactive, cannot stay still for long	☐	☐	☐
Often complains of headaches, stomach-aches or sickness	☐	☐	☐
Shares readily with other children (treats, toys, pencils etc.)	☐	☐	☐
Often has temper tantrums or hot tempers	☐	☐	☐
Rather solitary, tends to play alone	☐	☐	☐
Generally obedient, usually does what adults request	☐	☐	☐
Many worries, often seems worried	☐	☐	☐
Helpful if someone is hurt, upset or feeling ill	☐	☐	☐
Constantly fidgeting or squirming	☐	☐	☐
Has at least one good friend	☐	☐	☐
Often fights with other children or bullies them	☐	☐	☐
Often unhappy, down-hearted or tearful	☐	☐	☐
Generally liked by other children	☐	☐	☐
Easily distracted, concentration wanders	☐	☐	☐
Nervous or clingy in new situations, easily loses confidence	☐	☐	☐
Kind to younger children	☐	☐	☐
Often lies or cheats	☐	☐	☐
Picked on or bullied by other children	☐	☐	☐
Often volunteers to help others (parents, teachers, other children)	☐	☐	☐
Thinks things out before acting	☐	☐	☐
Steals from home, school or elsewhere	☐	☐	☐
Gets on better with adults than with other children	☐	☐	☐
Many fears, easily scared	☐	☐	☐
Sees tasks through to the end, good attention span	☐	☐	☐

Do you have any other comments or concerns?

Please turn over - there are a few more questions on the other side



Overall, do you think that your child has difficulties in one or more of the following areas: emotions, concentration, behaviour or being able to get on with other people?

No	Yes- minor difficulties	Yes- definite difficulties	Yes- severe difficulties
☐	☐	☐	☐

If you have answered "Yes", please answer the following questions about these difficulties:

- How long have these difficulties been present?

Less than a month	1-5 months	6-12 months	Over a year
☐	☐	☐	☐

- Do the difficulties upset or distress your child?

Not at all	Only a little	Quite a lot	A great deal
☐	☐	☐	☐

- Do the difficulties interfere with your child's everyday life in the following areas?

	Not at all	Only a little	Quite a lot	A great deal
HOME LIFE	☐	☐	☐	☐
FRIENDSHIPS	☐	☐	☐	☐
CLASSROOM LEARNING	☐	☐	☐	☐
LEISURE ACTIVITIES	☐	☐	☐	☐

- Do the difficulties put a burden on you or the family as a whole?

Not at all	Only a little	Quite a lot	A great deal
☐	☐	☐	☐

[redacted].. [redacted]..................................

Mother/Father/Other (please specify:)

Thank you very much for your help

Appendix 12: Dyadic Satisfaction Scale

DSS

The following questionnaire is about your relationship with your partner. Unless you chose to show them, your partner will not get to know your answers.

1: The dots on the following line represent different degrees of happiness in your relationship. The middle point, “Happy”, represents the degree of happiness of most relationships. Please circle the dot which best describes the degree of happiness, all things considered, in your relationship.

0	**1**	**2**	**3**	**4**	**5**	**6**
.	.	.	.	.	.	.
Extremely Unhappy	Fairly Unhappy	A Little Unhappy	Happy	Very Happy	Extremely Happy	Perfect

	All of the time	Most of the time	More often than not	Occa-sionally	Rarely	Never
2. How often do you discuss or have you considered divorce, separation, or terminating your relationship?						
3. How often do you or your partner leave the house after a fight?						
4. In general, how often do you think that things between you and your partner are going well?						
5. Do you confide in your partner?						
6. Do you ever regret you married (or lived together)?						
7. How often do you and your partner quarrel?						
8. How often do you and your partner ‘get on each other’s nerves’?						

	Never	Rarely	Occa-sionally	Almost Every Day	Every Day
9. Do you kiss your partner?					

10: Which of the following statements best describes how you feel about the future of your relationship?

Please tick	
	I want desperately for my relationship to succeed, and *would go to almost any length* to see that it does.
	I want very much for my relationship to succeed, and *will do all I can* to see that it does.
	I want very much for my relationship to succeed, *and will do my fair share* to see that it does.
	It would be nice if my relationship succeeded, *but I can’t do more than I am doing now* to help it succeed.
	It would be nice if my relationship succeeded, but *I refuse to do any more than I am doing* now to keep the relationship going.
	My relationship can never succeed, and *there is no more that I can do* to keep the relationship going.

PLEASE TURN OVER

Appendix 13: Family Adaptability & Cohesion Evaluation Scale (FACES)

- **Cohesion subscale**

FACES-IV

Please think about your immediate family when answering the questions below. Please indicate below the extent you agree or disagree with each statement on the following list:

	Strongly **Disagree**	Generally **Disagree**	Undecided	Generally **Agree**	Strongly **Agree**
1. Family members are involved in each others lives					
2. Family members feel close to one another.					
3. Family members are supportive of each other during difficult times.					
4. Family members consult other family members on difficult decisions.					
5. Family members like to spend some of their free time with each other.					
6. Although family members have individual interests, they still participate in family activities.					
7. Our family has a good balance of separateness and closeness.					

PLEASE TURN OVER

Appendix 14: Request for parent reflections

If you have any comments you would like to make about the subject matter of this study, your participation, or anything else you feel would be important for us to know, please record these below.

____

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Please return this document by post in the stamped addressed A4 envelope provided.

THANK YOU VERY MUCH FOR YOUR PARTICIPATION IN THIS STUDY.

Appendix 15: Table 4: All correlations between child, maternal and paternal variables

Table 5: All correlations between maternal, paternal and child variables

Variable	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16	17	18	19	20	21
1. Mother's age	.94**	.73**	-.29	-.36	-.41	-.17	-.02	.40	.54**	.37	.46*	.39	.09	-.14	-.18	.11	.01	.17	.06	.55*
2. Father's age		.69**	-.45*	-.44	-.43	-.26	.11	.38	.62**	.49*	.49*	.45*	-.32	.05	-.32	-.11	-.02	.18	.07	.55*
3. Child's age			-.29	-.10	-.29	-.09	.05	.45*	.51*	.32	.37	.14	.09	-.19	-.03	.13	.24	.39	.01	.31
4.Parenting satisfaction (M)				.51*	.74**	.08	-.59**	-.25	-.81**	-.54*	-.76**	-.50*	-.46*	-.40	.47*	.41	-.17	-.37	-.71**	-.61**
5.Parenting satisfaction (F)					.44	.45*	-.35	-.61**	-.55*	-.66**	-.54*	-.78**	-.33	-.33	.45*	.37	-.17	-.39	-.40	-.58*
6.Parenting efficiency (M)						.08	-.28	-.15	-.71**	-.53*	-.67**	-.59**	-.42	-.12	.45*	.41	-.32	-.38	-.58*	-.32
7.Parenting efficiency (F)							-.20	-.34	-.29	-.46*	-.14	-.39	-.17	-.39	.18	.18	.02	-.22	.16	.02
8. Anxiety (M)								.23	.45*	.35	.32	.15	.17	.47*	-.17	-.10	.38	.25	.45	.49*
9. Anxiety (F)									.53*	.63**	.36	.47*	.10	.10	-.26	-.03	.33	.33	.21	.65**
10. Depression (M)										.62**	.77**	.56*	.37	.25	-.58**	-.36	.48*	.52*	.50*	.67**
11. Depression (F)											.47*	.69**	.31	.32	-.32	-.25	.08	.08	.29	.48
12. Parenting stress (M)												.70**	.76**	.48*	-.75**	-.45*	.28	.54*	.75**	.60*
13. Parenting stress (F)													.65**	.47*	-.67**	-.59**	.09	.28	.63**	.61
14. Child difficulties (M)														.70**	-.51*	-.48*	.26	.31	.67*	.25
15. Child difficulties (F)															-.44	-.17	.06	.02	.40	.26
16. Child pro-social behaviours (M)																.57**	-.13	-.43	-.64**	-.54*
17. Child pro-social behaviours (F)																	-.04	-.08	-.62**	-.41
18. Impact on relationship (M)																		.62**	.29	.29
19. Impact on relationship (F)																			.30	.20
20.Impact on siblings (M)																				.59*
21.Impact on siblings (F)																				
22.Marital satisfaction (M)																				
23.Marital satisfaction (F)																				
24. Family cohesion (M)																				
25. Family cohesion (F)																				

***p<0.05, **p<0.01;** M = mother rating, F = father rating; 4, 5, 6 & 7 = measured by the Parenting Sense of Competence Scale; 8, 9, 10 & 11 = measured by the Hospital Anxiety & Depression Scale; 12 & 13 = measured by the Parenting Stress Index-Short Form; 14, 15, 16 & 17 = measured by the Strengths & Difficulties Questionnaire; 18 & 19 = measured by the Family Impact Questionnaire Impact on Relationship Subscale; 20 & 21 = as measured by the Dyadic Adjustment Scale Satisfaction Subscale; 22 & 23 = measured by the Family Adaptation & Cohesion Evaluation Scale Cohesion Subscale.

Table 5: All correlations between maternal, paternal and child variables - continued

Variable	22	23	24	25
1. Mother's age	-.13	.02	-.03	.20
2. Father's age	-.36	-.09	-.23	.21
3. Child's age	-.01	-.16	.07	-.08
4.Parenting satisfaction (M)	.48*	.55*	.26	.09
5.Parenting satisfaction (F)	.49*	.36	.58**	.32
6.Parenting efficiency (M)	.44*	.42	.25	.06
7.Parenting efficiency (F)	.17	.33	.31	.45*
8. Anxiety (M)	-.38	-.47*	-.19	-.35
9. Anxiety (F)	-.51*	-.44	-.52*	-.40
10. Depression (M)	-.61**	-.63**	-.53*	-.32
11. Depression (F)	-.63**	-.45*	-.54*	-.30
12. Parenting stress (M)	-.39	-.55*	-.42*	-.21
13. Parenting stress (F)	-.55*	-.46*	-.66**	-.33
14. Child difficulties (M)	-.33	-.58**	-.33	-.34
15. Child difficulties (F)	-.36	-.60**	-.34	-.29
16. Child pro-social behaviours (M)	.46*	.50*	.64**	.26
17. Child pro-social behaviours (F)	.35	.15	.50*	.13
18. Impact on relationship (M)	-51*	-68**	-.34	-.34
19. Impact on relationship (F)	-.13	-.52*	-.35	-.46*
20.Impact on siblings (M)	-.34	-.45	-.32	-.27
21.Impact on siblings (F)	-.69**	-.44	-.59*	-.15
22.Marital satisfaction (M)		.70**	.78**	.18
23.Marital satisfaction (F)			.62**	.52*
24. Family cohesion (M)				.63**
25. Family cohesion (F)				

***p<0.05, **p<0.01;** M = mother rating, F = father rating; 4, 5, 6 & 7 = measured by the Parenting Sense of Competence Scale; 8, 9, 10 & 11 = measured by the Hospital Anxiety & Depression Scale; 12 & 13 = measured by the Parenting Stress Index-Short Form; 14, 15, 16 & 17 = measured by the Strengths & Difficulties Questionnaire; 18 & 19 = measured by the Family Impact Questionnaire Impact on Relationship Subscale; 20 & 21 = as measured by the Dyadic Adjustment Scale Satisfaction Subscale; 22 & 23 = measured by the Family Adaptation & Cohesion Evaluation Scale Cohesion Subscale.

Appendix 16: Parent reflections

Parent reflections

- My oldest son has ASD. He makes me very happy every single day. He just needs patience and a bit of love.

- I believe having a positive attitude and outlook on life has helped our family through our sons diagnosis. We have chosen to focus on the progress, however small, achieved from one day to the next rather than to worry about a future, which we do not know what holds. One book to recommend to every parent of a child with autism: ‘10 things every child with autism wishes you knew’. Enjoy.

- Feel its important people know our son has ASD as they then find it easier to accept any upsets or ‘odd’ behaviour. Our son takes things very literally i.e., ‘wait a minute’ he will stand outside and wait for someone. Also his love for adult company he can be ‘in your face’ so its best to ask them to be honest and say ‘not now’ otherwise he isn’t sure what’s happening. We feel humour is very important its helped in changes, i.e. ‘silly mommy forgot to tell you’ gets us through a lot of tricky situations. He is very trusting and loyal, which is a little worrying as other children can take advantage.

- Hope and pray that my son gets all the help and needs when I am dead hope he don’t get push in a corner and left to rot and taken for a ride on what he is needs like money what he gets after we have passed away

- I never feel I am able to relax or get on with other tasks while my 2 children play together. I am constantly monitoring what they are doing – watching – listening out – for problems. My child with ASD gets very rough, and his sister, although they are friends, often comes off worse. I also cannot trust him not to do dangerous things – i.e. – climbing – and so I listen out for this reason too.

  My relationship with partner changed dramatically when my son was diagnosed because we also realised that my husband has Asperger’s. Although he was ‘moody’ and clearly had ups and owns, he got on with life. After discovering he himself has Asperger’s this too over – it became his ‘special interest’ – and was not much support to me. He related all of our sons issues/difficulties back to himself, and at times painted a dark picture for our sons outcomes in life (applying what he felt about himself to our sons). I feel life is very stressful, and that I carry it all. I work full time because husband can’t cope with full time work. I feel I have missed out on ‘being at the school gates’ for kids. I have to organise everything and sometimes feel desperate, especially if I am not coping well with sons behaviour. It is difficult to separate out impact of child with ASD from husband with ASD. If I had a more supportive husband, if I had more time etc, would I/we as a family cope better with son? I also often feel guilt that daughter has to compromise/gets a rough deal due to sons ASD.

- Responses would have probably been quite different had my son been younger. At 16, some earlier concerns have become less worrying due to growing maturity and independence.

- As ******’s older brother is a teenager and displaying teenager’s behaviour, ****** often tries to copy him and this makes his behaviour also more difficult.

- My older boy is very dyslexic and I often feel that because both of my sons have very different problems it brings more balance to my family than if one child had no problems at all.

- Our son (ASD) has placed a huge amount of stress upon our family, through no fault of his own this has impacted detrimentally on our relationships with friends and family and each other. I personally feel that had we received a diagnosis much earlier the impact would have been less stressful. Our son suffered terribly with high anxiety levels, depression, suicidal thoughts and low self esteem. Had the diagnosis been made when our son was much younger, we as parents and close family and friends would have better understood his needs therefore we as parents wouldn’t have been judged so terribly by other parents and close family. Also, ***** may not have been labelled as naughty. He would have been able to cope much better at school, and more able to learn, rather than falling further behind peers, exacerbating his self loathing and low self esteem.

  Sleep was, and remains to be a major issue for our son. Rather than constantly struggling to force him to sleep alone, we would have been able to understand that he had real fears, rather than us parents feeling like failing parents with a stubborn child.

  Since our son received his diagnosis, my partner and I agree much more on how we parent our son. Our home is much more calm, and far less stressful for our daughter. We have had fabulous training. I could go on for much longer but I won’t.

- Although I have answered all the questions truthfully a lot of the answers depend on how things are going with your child at this moment in time. If the child is having a particularly bad time then obviously this will impact on family life and the answers to the questions and vica versa.

  Having a child with special needs is very stressful but it’s also very rewarding and has changed my whole outlook on life. I think if families pull together it can make a massive difference and parents try and stay positive. It’s not our fault and we can only do what we can do.

- Over the years I have answered many questionnaires similar to this one with regard to one study or another on ASD. I have always tried to ask the head Researcher for a copy, or at least access to it, or the results of the study and I, and many others, who have taken the time to answer the questionnaires would find the results very interesting. Unfortunately, despite reassurances that it would not be a problem to show the results of the study or allow the study to be accessed – it has never been forthcoming. So I will ask again. Would it be possible for the helpful participants of this study to access the study results in the future? Perhaps a one line email or note so we can access the study via the web or something.

- I was quite disappointed with the use of inflexible ‘standard’ questions. It would have been interesting to complete some which gathered more information. I felt the ‘PSCS’ and ‘Parenting Stress Index’ were very negative and ‘leading’ – not making allowance for those parents who ‘accepted’ their children. The ‘HADS’ form did not ask about ‘other’ factors influencing your state of mind e.g., working, parenting and studying.

The study: - the wellbeing of the family is affected by early acceptance of the type of needs a child has. Embracing strengths and ‘appropriate’ obsessions/interest allows for all family members to be valued. Making sure everyone is treated fairly and is valued is extremely important. This does generally rest on the shoulders of one parent acting as the:-teacher/mediator/councillor/facilitator/provider (of food and love) etc/ and the other parent as supporter/mentor/provider (money and love)!

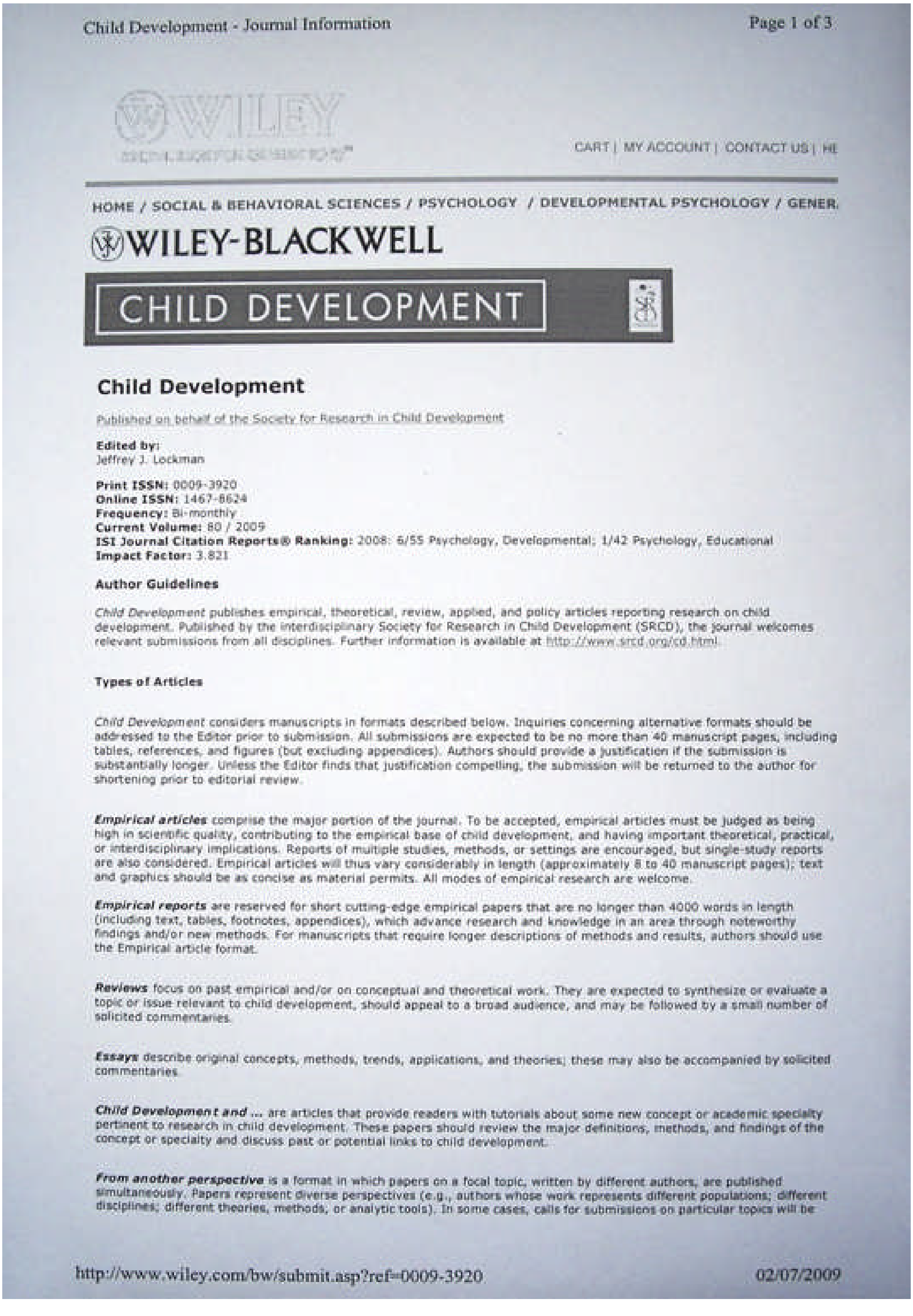
- The regularity I discuss issues with my wife varies greatly, as I am a ************ and spend up to 6 months away from home in a single spell. This also means that most of the day to day issues on raising our child are down to her.

- Initial reaction: I must get my Asperger’s book out and read it again. I’m thinking that some of your pointed questions are relative to symptoms which I need to understand better. My partner does not acknowledge that our child has a problem, although he was present at the time of diagnosis by *******.

  My Asperger’s child is incredibly demanding of my time, wanting to get things organised and expecting me to be her personal assistant / getting blamed if things go wrong. This is a real strain. She also comes across as ungrateful of the effort involved especially when I ask for help in return, or by being rude, she is in teens in age.

- It has been very interesting participating in this study and I cannot wait for your survey results.

Appendix 17: Instructions for authors – *Child Development*



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CHILD DEVELOPMENT

Child Development

Published on behalf of the Society for Research in Child Development

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Author Guidelines

Child Development publishes empirical, theoretical, review, applied, and policy articles reporting research on child development. Published by the interdisciplinary Society for Research in Child Development (SRCD), the journal welcomes relevant submissions from all disciplines. Further information is available at http://www.srcd.org/cd.html.

Types of Articles

Child Development considers manuscripts in formats described below. Inquiries concerning alternative formats should be addressed to the Editor prior to submission. All submissions are expected to be no more than 40 manuscript pages, including tables, references, and figures (but excluding appendices). Authors should provide a justification if the submission is substantially longer. Unless the Editor finds that justification compelling, the submission will be returned to the author for shortening prior to editorial review.

Empirical articles comprise the major portion of the journal. To be accepted, empirical articles must be judged as being high in scientific quality, contributing to the empirical base of child development, and having important theoretical, practical, or interdisciplinary implications. Reports of multiple studies, methods, or settings are encouraged, but single-study reports are also considered. Empirical articles will thus vary considerably in length (approximately 8 to 40 manuscript pages); text and graphics should be as concise as material permits. All modes of empirical research are welcome.

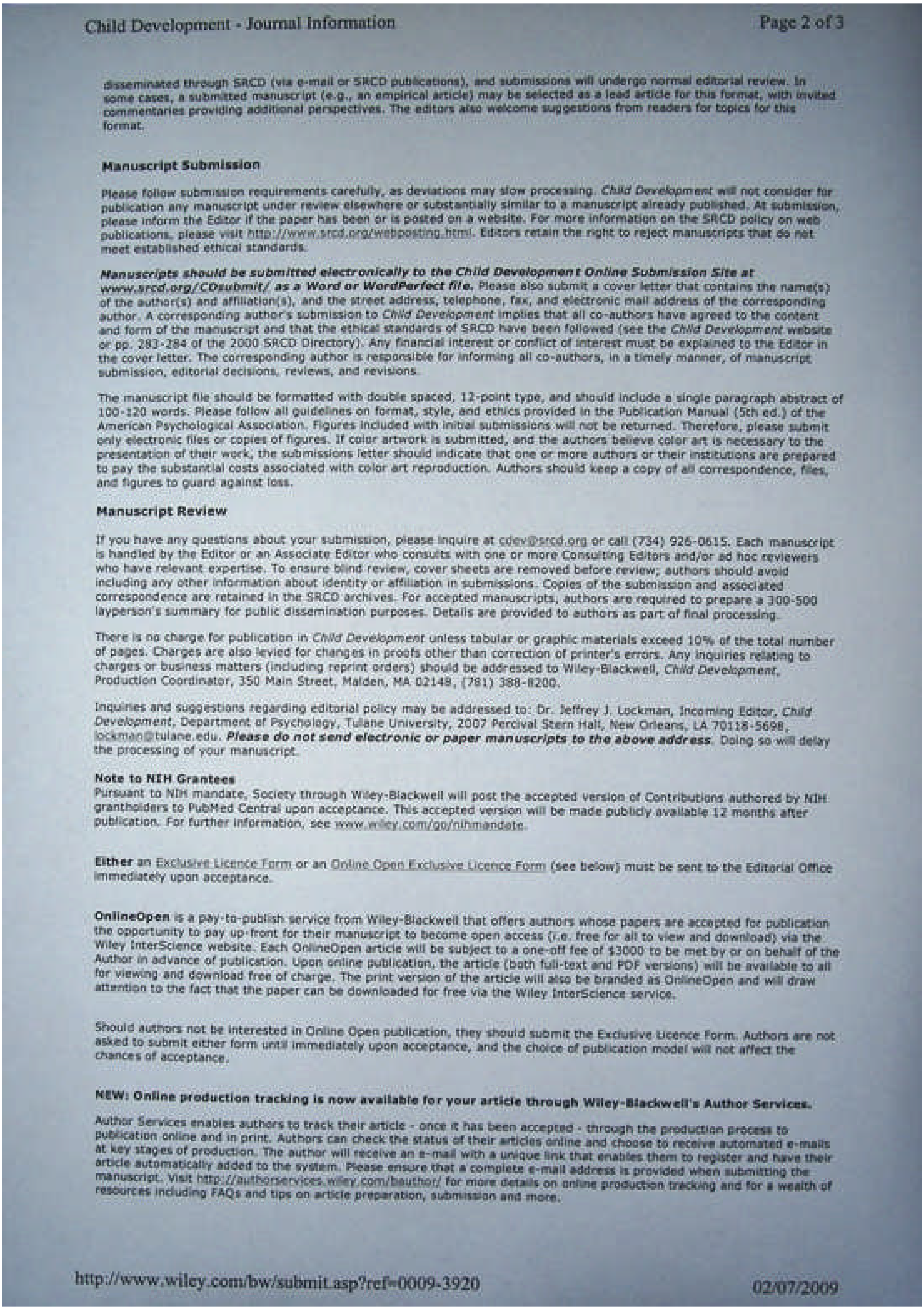
Empirical reports are reserved for short cutting-edge empirical papers that are no longer than 4000 words in length (including text, tables, footnotes, appendices), which advance research and knowledge in an area through noteworthy findings and/or new methods. For manuscripts that require longer descriptions of methods and results, authors should use the Empirical article format.

Reviews focus on past empirical and/or on conceptual and theoretical work. They are expected to synthesize or evaluate a topic or issue relevant to child development, should appeal to a broad audience, and may be followed by a small number of solicited commentaries.

Essays describe original concepts, methods, trends, applications, and theories; these may also be accompanied by solicited commentaries.

Child Development and ... are articles that provide readers with tutorials about some new concept or academic specialty pertinent to research in child development. These papers should review the major definitions, methods, and findings of the concept or specialty and discuss past or potential links to child development.

From another perspective is a format in which papers on a focal topic, written by different authors, are published simultaneously. Papers represent diverse perspectives (e.g., authors whose work represents different populations; different disciplines; different theories, methods, or analytic tools). In some cases, calls for submissions on particular topics will be



Child Development - Journal Information Page 2 of 3

disseminated through SRCD (via e-mail or SRCD publications), and submissions will undergo normal editorial review. In some cases, a submitted manuscript (e.g., an empirical article) may be selected as a lead article for this format, with invited commentaries providing additional perspectives. The editors also welcome suggestions from readers for topics for this format.

Manuscript Submission

Please follow submission requirements carefully, as deviations may slow processing. *Child Development* will not consider for publication any manuscript under review elsewhere or substantially similar to a manuscript already published. At submission, please inform the Editor if the paper has been or is posted on a website. For more information on the SRCD policy on web publications, please visit http://www.srcd.org/webposting.html. Editors retain the right to reject manuscripts that do not meet established ethical standards.

Manuscripts should be submitted electronically to the Child Development Online Submission Site at www.srcd.org/CDsubmit/ as a Word or WordPerfect file. Please also submit a cover letter that contains the name(s) of the author(s) and affiliation(s), and the street address, telephone, fax, and electronic mail address of the corresponding author. A corresponding author's submission to *Child Development* implies that all co-authors have agreed to the content and form of the manuscript and that the ethical standards of SRCD have been followed (see the *Child Development* website or pp. 283-284 of the 2000 SRCD Directory). Any financial interest or conflict of interest must be explained to the Editor in the cover letter. The corresponding author is responsible for informing all co-authors, in a timely manner, of manuscript submission, editorial decisions, reviews, and revisions.

The manuscript file should be formatted with double spaced, 12-point type, and should include a single paragraph abstract of 100-120 words. Please follow all guidelines on format, style, and ethics provided in the Publication Manual (5th ed.) of the American Psychological Association. Figures included with initial submissions will not be returned. Therefore, please submit only electronic files or copies of figures. If color artwork is submitted, and the authors believe color art is necessary to the presentation of their work, the submissions letter should indicate that one or more authors or their institutions are prepared to pay the substantial costs associated with color art reproduction. Authors should keep a copy of all correspondence, files, and figures to guard against loss.

Manuscript Review

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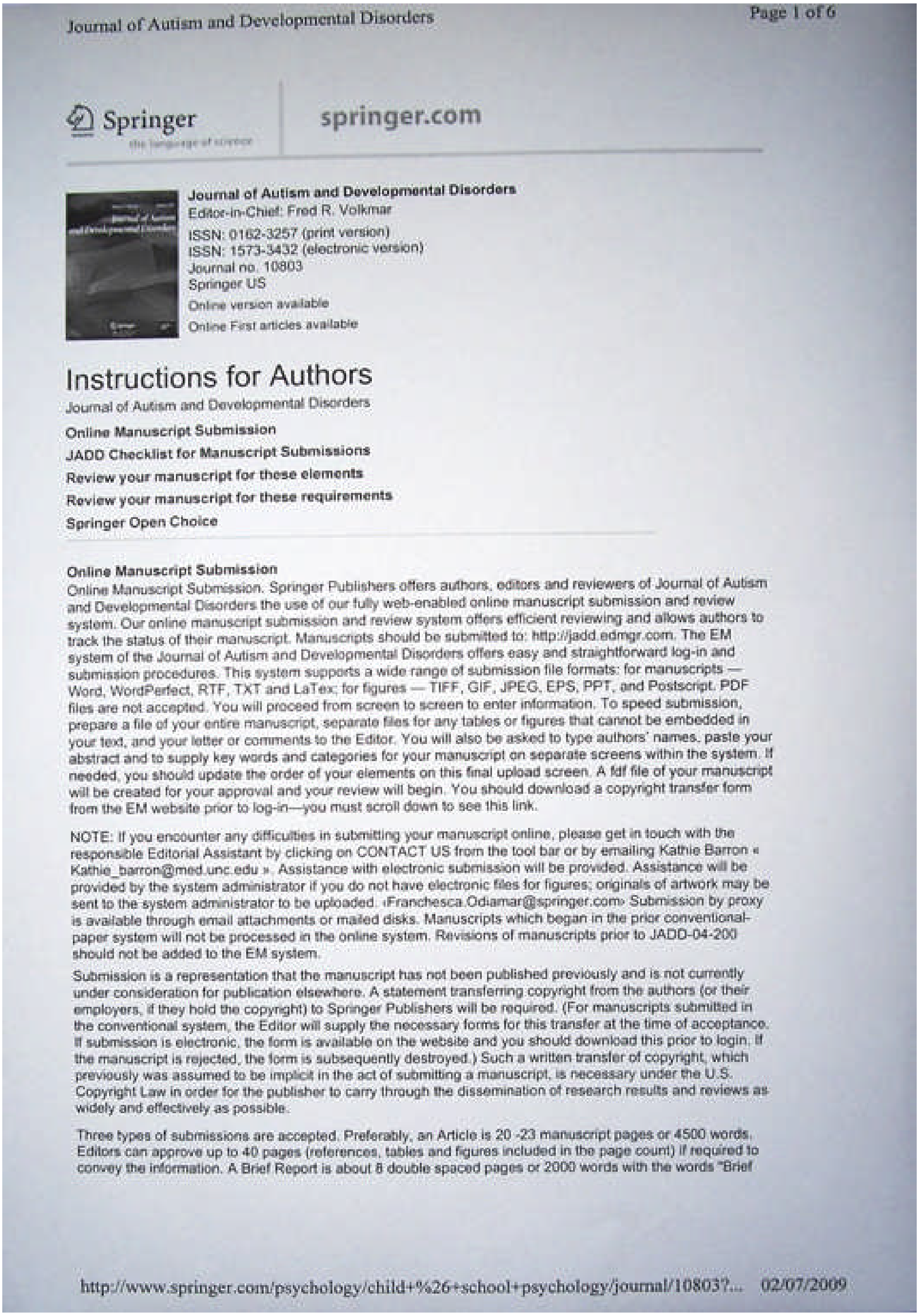
Appendix 18: Instructions for authors – *Journal of Autism & Developmental Disorders*



Journal of Autism and Developmental Disorders Page 1 of 6

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Instructions for Authors

Journal of Autism and Developmental Disorders

Online Manuscript Submission
JADD Checklist for Manuscript Submissions
Review your manuscript for these elements
Review your manuscript for these requirements
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Online Manuscript Submission. Springer Publishers offers authors, editors and reviewers of Journal of Autism and Developmental Disorders the use of our fully web-enabled online manuscript submission and review system. Our online manuscript submission and review system offers efficient reviewing and allows authors to track the status of their manuscript. Manuscripts should be submitted to: http://jadd.edmgr.com. The EM system of the Journal of Autism and Developmental Disorders offers easy and straightforward log-in and submission procedures. This system supports a wide range of submission file formats: for manuscripts — Word, WordPerfect, RTF, TXT and LaTex; for figures — TIFF, GIF, JPEG, EPS, PPT, and Postscript. PDF files are not accepted. You will proceed from screen to screen to enter information. To speed submission, prepare a file of your entire manuscript, separate files for any tables or figures that cannot be embedded in your text, and your letter or comments to the Editor. You will also be asked to type authors' names, paste your abstract and to supply key words and categories for your manuscript on separate screens within the system. If needed, you should update the order of your elements on this final upload screen. A fdf file of your manuscript will be created for your approval and your review will begin. You should download a copyright transfer form from the EM website prior to log-in—you must scroll down to see this link.

NOTE: If you encounter any difficulties in submitting your manuscript online, please get in touch with the responsible Editorial Assistant by clicking on CONTACT US from the tool bar or by emailing Kathie Barron « Kathie_barron@med.unc.edu ». Assistance with electronic submission will be provided. Assistance will be provided by the system administrator if you do not have electronic files for figures; originals of artwork may be sent to the system administrator to be uploaded. ‹Franchesca.Odiamar@springer.com› Submission by proxy is available through email attachments or mailed disks. Manuscripts which began in the prior conventional-paper system will not be processed in the online system. Revisions of manuscripts prior to JADD-04-200 should not be added to the EM system.

Submission is a representation that the manuscript has not been published previously and is not currently under consideration for publication elsewhere. A statement transferring copyright from the authors (or their employers, if they hold the copyright) to Springer Publishers will be required. (For manuscripts submitted in the conventional system, the Editor will supply the necessary forms for this transfer at the time of acceptance. If submission is electronic, the form is available on the website and you should download this prior to login. If the manuscript is rejected, the form is subsequently destroyed.) Such a written transfer of copyright, which previously was assumed to be implicit in the act of submitting a manuscript, is necessary under the U.S. Copyright Law in order for the publisher to carry through the dissemination of research results and reviews as widely and effectively as possible.

Three types of submissions are accepted. Preferably, an Article is 20 -23 manuscript pages or 4500 words. Editors can approve up to 40 pages (references, tables and figures included in the page count) if required to convey the information. A Brief Report is about 8 double spaced pages or 2000 words with the words "Brief

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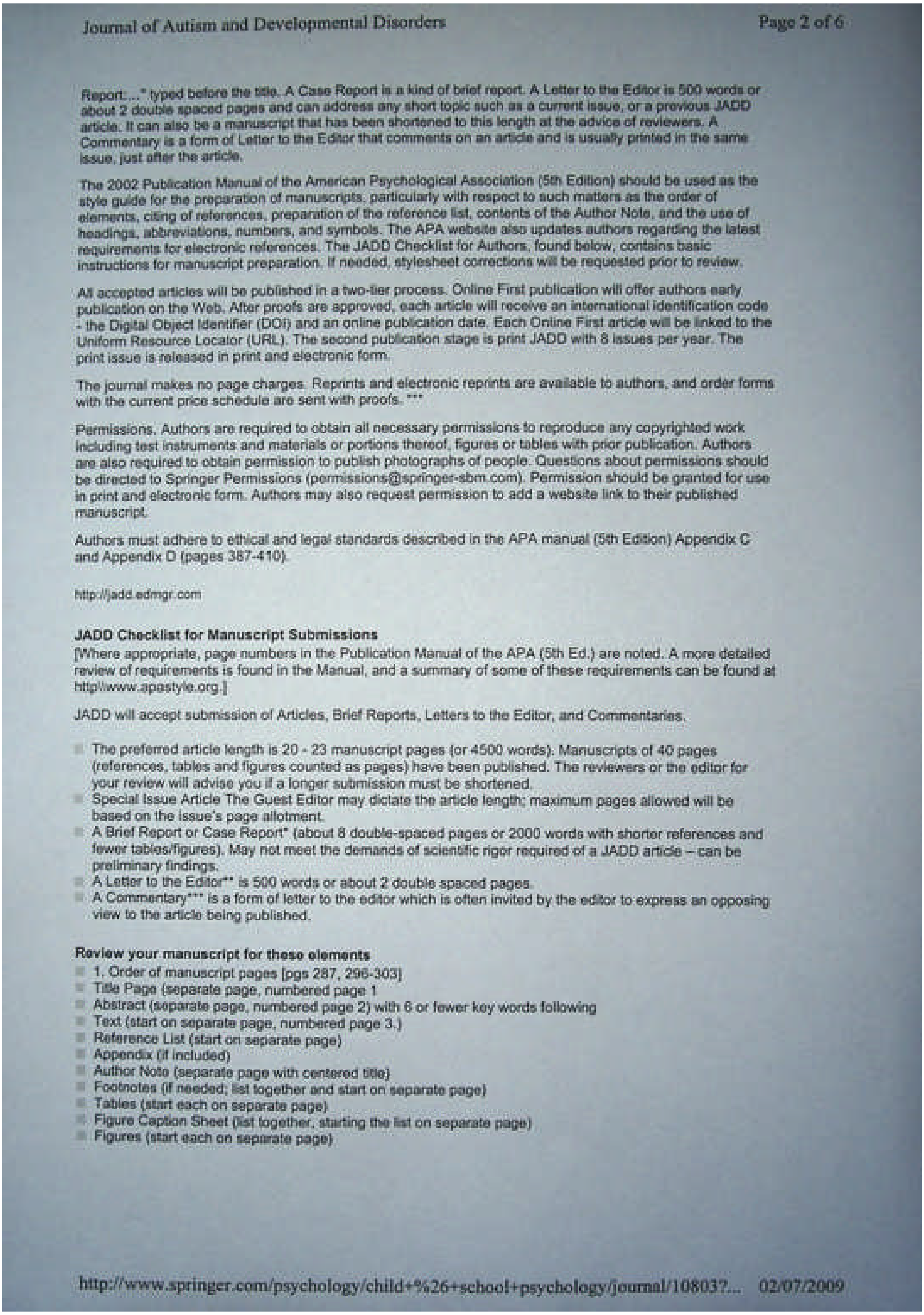

Journal of Autism and Developmental Disorders Page 2 of 6

Report:..." typed before the title. A Case Report is a kind of brief report. A Letter to the Editor is 500 words or about 2 double spaced pages and can address any short topic such as a current issue, or a previous JADD article. It can also be a manuscript that has been shortened to this length at the advice of reviewers. A Commentary is a form of Letter to the Editor that comments on an article and is usually printed in the same issue, just after the article.

The 2002 Publication Manual of the American Psychological Association (5th Edition) should be used as the style guide for the preparation of manuscripts, particularly with respect to such matters as the order of elements, citing of references, preparation of the reference list, contents of the Author Note, and the use of headings, abbreviations, numbers, and symbols. The APA website also updates authors regarding the latest requirements for electronic references. The JADD Checklist for Authors, found below, contains basic instructions for manuscript preparation. If needed, stylesheet corrections will be requested prior to review.

All accepted articles will be published in a two-tier process. Online First publication will offer authors early publication on the Web. After proofs are approved, each article will receive an international identification code - the Digital Object Identifier (DOI) and an online publication date. Each Online First article will be linked to the Uniform Resource Locator (URL). The second publication stage is print JADD with 8 issues per year. The print issue is released in print and electronic form.

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Authors must adhere to ethical and legal standards described in the APA manual (5th Edition) Appendix C and Appendix D (pages 387-410).

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JADD Checklist for Manuscript Submissions

[Where appropriate, page numbers in the Publication Manual of the APA (5th Ed.) are noted. A more detailed review of requirements is found in the Manual, and a summary of some of these requirements can be found at http//www.apastyle.org.]

JADD will accept submission of Articles, Brief Reports, Letters to the Editor, and Commentaries.

- The preferred article length is 20 - 23 manuscript pages (or 4500 words). Manuscripts of 40 pages (references, tables and figures counted as pages) have been published. The reviewers or the editor for your review will advise you if a longer submission must be shortened.
- Special Issue Article The Guest Editor may dictate the article length; maximum pages allowed will be based on the issue's page allotment.
- A Brief Report or Case Report* (about 8 double-spaced pages or 2000 words with shorter references and fewer tables/figures). May not meet the demands of scientific rigor required of a JADD article – can be preliminary findings.
- A Letter to the Editor** is 500 words or about 2 double spaced pages.
- A Commentary*** is a form of letter to the editor which is often invited by the editor to express an opposing view to the article being published.

Review your manuscript for these elements

- 1. Order of manuscript pages [pgs 287, 296-303]
- Title Page (separate page, numbered page 1
- Abstract (separate page, numbered page 2) with 6 or fewer key words following
- Text (start on separate page, numbered page 3.)
- Reference List (start on separate page)
- Appendix (if included)
- Author Note (separate page with centered title)
- Footnotes (if needed; list together and start on separate page)
- Tables (start each on separate page)
- Figure Caption Sheet (list together, starting the list on separate page)
- Figures (start each on separate page)

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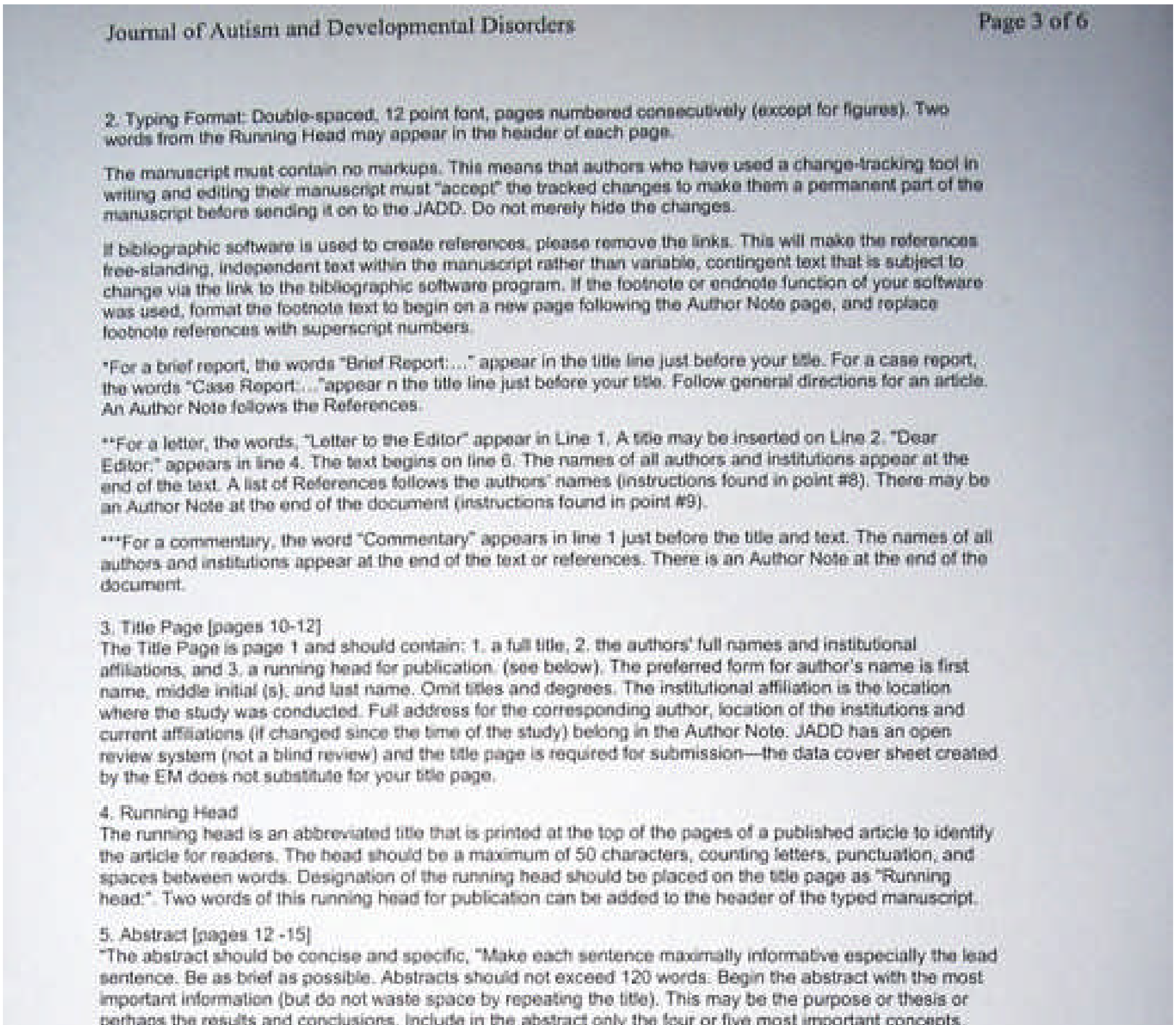

Journal of Autism and Developmental Disorders Page 3 of 6

2. Typing Format: Double-spaced, 12 point font, pages numbered consecutively (except for figures). Two words from the Running Head may appear in the header of each page.

The manuscript must contain no markups. This means that authors who have used a change-tracking tool in writing and editing their manuscript must "accept" the tracked changes to make them a permanent part of the manuscript before sending it on to the JADD. Do not merely hide the changes.

If bibliographic software is used to create references, please remove the links. This will make the references free-standing, independent text within the manuscript rather than variable, contingent text that is subject to change via the link to the bibliographic software program. If the footnote or endnote function of your software was used, format the footnote text to begin on a new page following the Author Note page, and replace footnote references with superscript numbers.

*For a brief report, the words "Brief Report:..." appear in the title line just before your title. For a case report, the words "Case Report:..."appear n the title line just before your title. Follow general directions for an article. An Author Note follows the References.

**For a letter, the words, "Letter to the Editor" appear in Line 1. A title may be inserted on Line 2. "Dear Editor:" appears in line 4. The text begins on line 6. The names of all authors and institutions appear at the end of the text. A list of References follows the authors' names (instructions found in point #8). There may be an Author Note at the end of the document (instructions found in point #9).

***For a commentary, the word "Commentary" appears in line 1 just before the title and text. The names of all authors and institutions appear at the end of the text or references. There is an Author Note at the end of the document.

3. Title Page [pages 10-12]
The Title Page is page 1 and should contain: 1. a full title, 2. the authors' full names and institutional affiliations, and 3. a running head for publication. (see below). The preferred form for author's name is first name, middle initial (s), and last name. Omit titles and degrees. The institutional affiliation is the location where the study was conducted. Full address for the corresponding author, location of the institutions and current affiliations (if changed since the time of the study) belong in the Author Note. JADD has an open review system (not a blind review) and the title page is required for submission—the data cover sheet created by the EM does not substitute for your title page.

4. Running Head
The running head is an abbreviated title that is printed at the top of the pages of a published article to identify the article for readers. The head should be a maximum of 50 characters, counting letters, punctuation, and spaces between words. Designation of the running head should be placed on the title page as "Running head:". Two words of this running head for publication can be added to the header of the typed manuscript.

5. Abstract [pages 12 -15]
"The abstract should be concise and specific, "Make each sentence maximally informative especially the lead sentence. Be as brief as possible. Abstracts should not exceed 120 words. Begin the abstract with the most important information (but do not waste space by repeating the title). This may be the purpose or thesis or perhaps the results and conclusions. Include in the abstract only the four or five most important concepts, findings, or implications." The abstract is found on page 2. Six or fewer key words should appear one line below the abstract ("Key Words:...:"). In addition, include the corresponding authors email address below key words and the reason for this is if someone searches on Medline, they can get the abstracts and it would be nice for them to be able to reach the authors. Please note: An abstract is needed for all submissions. Failure to provide an abstract, or providing one that is too long, will delay the publication of your manuscript.

6. Body
The body of the manuscript should begin on a separate page. The manuscript page header (if used) and page number 3 should appear in the upper right corner. Type the title of the paper centered at the top of the page, add a hard return, and then type the text using the format noted above. The body should contain:

- Introduction (APA pgs 15-17) (The introduction has no label.)
- Methods (APA pgs 17-20) (Center the heading. Use uncentered subheadings such as: Participants, Materials, Procedure.)
- Results (APA pgs 20-26) (Center the heading.)
- Discussion (APA pgs 26-27) (Center the heading.

7. Reference citations [pgs 207-214]
Citations within the text guide the reader to the correct location on the reference list. Correct citation form is the surname of the authors and the year of publication, which are inserted in the text. For publications with one or two authors, cite one or two names. If there are multiple authors, cite all at first mention and only the first author at subsequent mentions. Separate multiple citations within parentheses with a semicolon.

Basic style:

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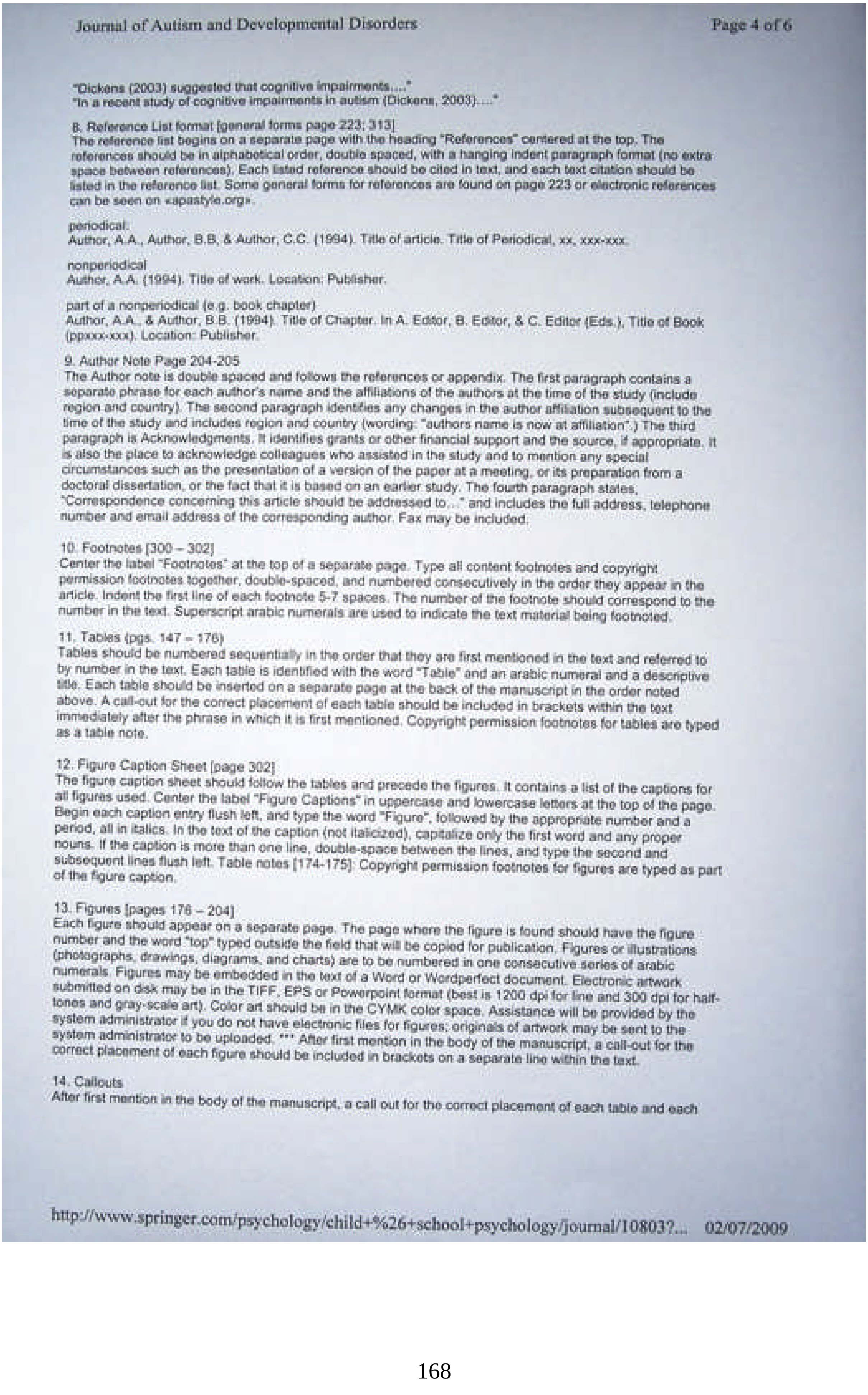

Journal of Autism and Developmental Disorders Page 4 of 6

"Dickens (2003) suggested that cognitive impairments...."
"In a recent study of cognitive impairments in autism (Dickens, 2003)...."

8. Reference List format [general forms page 223; 313]
The reference list begins on a separate page with the heading "References" centered at the top. The references should be in alphabetical order, double spaced, with a hanging indent paragraph format (no extra space between references). Each listed reference should be cited in text, and each text citation should be listed in the reference list. Some general forms for references are found on page 223 or electronic references can be seen on «apastyle.org».

periodical:
Author, A.A., Author, B.B, & Author, C.C. (1994). Title of article. Title of Periodical, xx, xxx-xxx.

nonperiodical
Author, A.A. (1994). Title of work. Location: Publisher.

part of a nonperiodical (e.g. book chapter)
Author, A.A., & Author, B.B. (1994). Title of Chapter. In A. Editor, B. Editor, & C. Editor (Eds.), Title of Book (ppxxx-xxx). Location: Publisher.

9. Author Note Page 204-205
The Author note is double spaced and follows the references or appendix. The first paragraph contains a separate phrase for each author's name and the affiliations of the authors at the time of the study (include region and country). The second paragraph identifies any changes in the author affiliation subsequent to the time of the study and includes region and country (wording: "authors name is now at affiliation".) The third paragraph is Acknowledgments. It identifies grants or other financial support and the source, if appropriate. It is also the place to acknowledge colleagues who assisted in the study and to mention any special circumstances such as the presentation of a version of the paper at a meeting, or its preparation from a doctoral dissertation, or the fact that it is based on an earlier study. The fourth paragraph states, "Correspondence concerning this article should be addressed to..." and includes the full address, telephone number and email address of the corresponding author. Fax may be included.

10. Footnotes [300 – 302]
Center the label "Footnotes" at the top of a separate page. Type all content footnotes and copyright permission footnotes together, double-spaced, and numbered consecutively in the order they appear in the article. Indent the first line of each footnote 5-7 spaces. The number of the footnote should correspond to the number in the text. Superscript arabic numerals are used to indicate the text material being footnoted.

11. Tables (pgs. 147 – 176)
Tables should be numbered sequentially in the order that they are first mentioned in the text and referred to by number in the text. Each table is identified with the word "Table" and an arabic numeral and a descriptive title. Each table should be inserted on a separate page at the back of the manuscript in the order noted above. A call-out for the correct placement of each table should be included in brackets within the text immediately after the phrase in which it is first mentioned. Copyright permission footnotes for tables are typed as a table note.

12. Figure Caption Sheet [page 302]
The figure caption sheet should follow the tables and precede the figures. It contains a list of the captions for all figures used. Center the label "Figure Captions" in uppercase and lowercase letters at the top of the page. Begin each caption entry flush left, and type the word "Figure", followed by the appropriate number and a period, all in italics. In the text of the caption (not italicized), capitalize only the first word and any proper nouns. If the caption is more than one line, double-space between the lines, and type the second and subsequent lines flush left. Table notes [174-175]: Copyright permission footnotes for figures are typed as part of the figure caption.

13. Figures [pages 176 – 204]
Each figure should appear on a separate page. The page where the figure is found should have the figure number and the word "top" typed outside the field that will be copied for publication. Figures or illustrations (photographs, drawings, diagrams, and charts) are to be numbered in one consecutive series of arabic numerals. Figures may be embedded in the text of a Word or Wordperfect document. Electronic artwork submitted on disk may be in the TIFF, EPS or Powerpoint format (best is 1200 dpi for line and 300 dpi for half-tones and gray-scale art). Color art should be in the CYMK color space. Assistance will be provided by the system administrator if you do not have electronic files for figures; originals of artwork may be sent to the system administrator to be uploaded. *** After first mention in the body of the manuscript, a call-out for the correct placement of each figure should be included in brackets on a separate line within the text.

14. Callouts
After first mention in the body of the manuscript, a call out for the correct placement of each table and each

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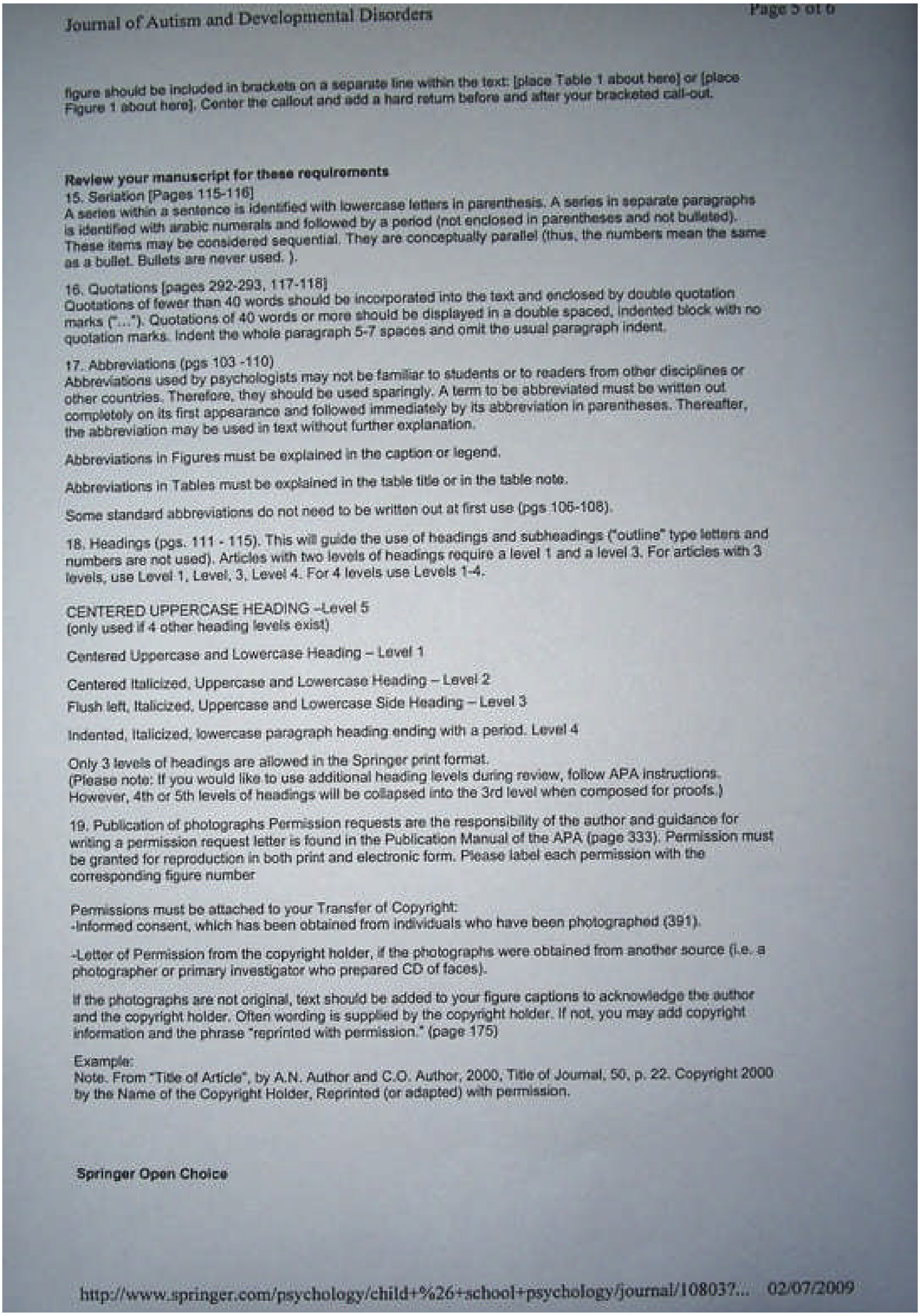

figure should be included in brackets on a separate line within the text: [place Table 1 about here] or [place Figure 1 about here]. Center the callout and add a hard return before and after your bracketed call-out.

Review your manuscript for these requirements
15. Seriation [Pages 115-116]
A series within a sentence is identified with lowercase letters in parenthesis. A series in separate paragraphs is identified with arabic numerals and followed by a period (not enclosed in parentheses and not bulleted). These items may be considered sequential. They are conceptually parallel (thus, the numbers mean the same as a bullet. Bullets are never used.).

16. Quotations [pages 292-293, 117-118]
Quotations of fewer than 40 words should be incorporated into the text and enclosed by double quotation marks ("..."). Quotations of 40 words or more should be displayed in a double spaced, indented block with no quotation marks. Indent the whole paragraph 5-7 spaces and omit the usual paragraph indent.

17. Abbreviations (pgs 103 -110)
Abbreviations used by psychologists may not be familiar to students or to readers from other disciplines or other countries. Therefore, they should be used sparingly. A term to be abbreviated must be written out completely on its first appearance and followed immediately by its abbreviation in parentheses. Thereafter, the abbreviation may be used in text without further explanation.

Abbreviations in Figures must be explained in the caption or legend.

Abbreviations in Tables must be explained in the table title or in the table note.

Some standard abbreviations do not need to be written out at first use (pgs 106-108).

18. Headings (pgs. 111 - 115). This will guide the use of headings and subheadings ("outline" type letters and numbers are not used). Articles with two levels of headings require a level 1 and a level 3. For articles with 3 levels, use Level 1, Level, 3, Level 4. For 4 levels use Levels 1-4.

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Centered Italicized, Uppercase and Lowercase Heading – Level 2
Flush left, Italicized, Uppercase and Lowercase Side Heading – Level 3

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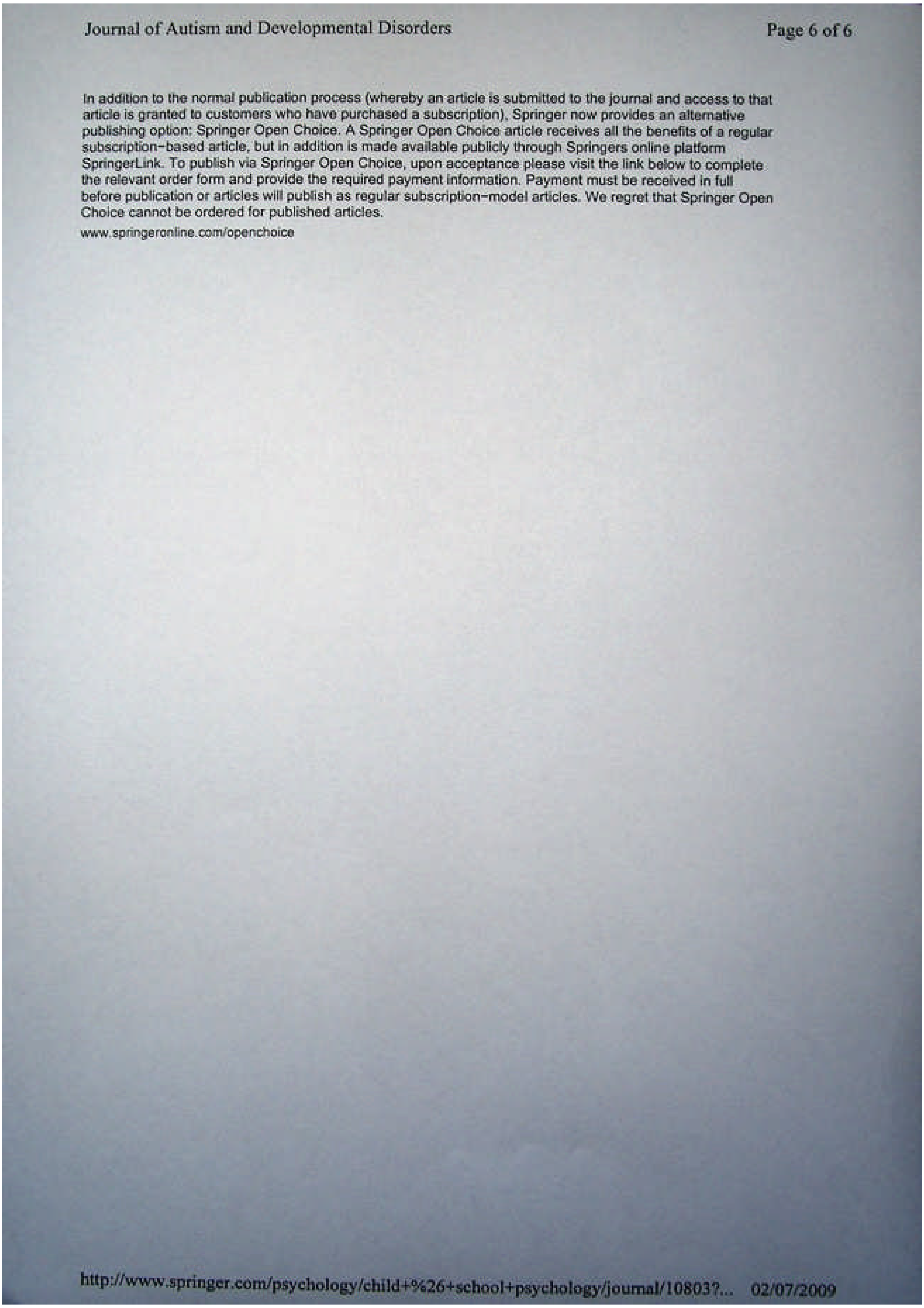

Journal of Autism and Developmental Disorders Page 6 of 6

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