Oxford Doctoral Course in Clinical Psychology

PARENTS WITH NEURODEVELOPMENTAL DISORDERS AND THEIR CHILDREN

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Abstract

Adults with neurodevelopmental disorders, such as Attention-Deficit Hyperactivity Disorder (ADHD) or Autism Spectrum Disorder (ASD) face a varying degree of associated challenges and impairment. However, there is a scarcity of literature regarding those adults who go on to become parents. Understanding the experiences of parents with neurodevelopmental disorders and their children is vital in providing the appropriate, specialist support.

The first paper systematically reviewed the literature relating to parental ADHD and child externalising, internalising, social and cognitive outcomes. Despite the well-established link between parental ADHD and child ADHD, little is known about other important child outcomes. Twenty-one eligible studies were identified, synthesised and critiqued. The review found that parental ADHD was associated with child externalising problems. However, this was not found for child oppositional defiance disorder. Parenting and parental gender were highlighted as important moderating and mediating factors. Due to low study numbers and quality issues, results were inconclusive regarding child internalising, social and cognitive outcomes. The review highlighted the importance of future research, theory and services addressing the needs of both parents with ADHD and their children.

The second paper sought to explore the parenting experiences of adults with ASD who have children with ASD. Little is known about these parents, despite the challenges known to be associated with adult ASD and with parenting a child with ASD. Eight parents were interviewed, and data was analysed using Interpretative Phenomenological Analysis, revealing four superordinate themes. These captured parents' experiences of the parent-child relationship, the personal impact of parenting, the acceptance and

challenge of living with a child with ASD and managing the complexities of professional services. These findings highlighted the need to provide integrated services which address the multiple needs of families with ASD. Future research and theoretical implications were also considered.

Acknowledgments

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PAPER A:

Parents with Attention Deficit Hyperactivity Disorder (ADHD) and Their Children: A Systematic Review of Child Psychological Outcomes beyond Child ADHD

Elise Marriott

A thesis submitted in partial fulfilment of the requirements of the degree of Doctor of Clinical Psychology, validated by the University of Oxford

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Abstract

Objective: To systematically review, synthesise and appraise evidence regarding parental Attention Deficit/Hyperactivity Disorder (ADHD) and child externalising, internalising, social and cognitive outcomes, beyond child ADHD.

Method: PsychINFO, Medline, Embase, CINAHL, AMED and Scopus databases were searched for studies directly addressing parental ADHD and child outcomes. Study quality was evaluated against a quality checklist.

Results: Twenty-one studies were reviewed. Associations were found between parental ADHD and child externalising difficulties, although this was not found for Oppositional Defiance Disorder outcomes. Results were inconclusive regarding child internalising, social and cognitive outcomes due to low study numbers and study quality issues. Important moderating and mediating factors included parenting and parental gender were implicated.

Conclusion: To date there are no systematic studies evaluating parental ADHD and child outcomes beyond child ADHD. Associations were found with parental ADHD and child externalising outcomes. These and possible underlying mechanisms are important to consider when assessing, treating and providing services for parents with ADHD and their children.

Proposed Journal: Journal of Attention Disorders (see appendix A for journal submission guidelines)

Introduction

What is ADHD?

Attention Deficit/Hyperactivity Disorder (ADHD)[1] is one of the most common neurodevelopmental disorders in children and adolescents. It is characterised by developmentally inappropriate and persistent levels of inattention, hyperactivity and impulsivity. Symptoms can be broken down into subtypes: inattentive subtype, hyperactivity-impulsivity subtype, or the 'combined' subtype, where both inattentive and hyperactivity symptoms are present, (American Psychiatric Association [APA] 2013; see appendix B for full DSM-V diagnostic criteria).

Worldwide prevalence rates in children and adolescents are estimated to be around 5.3% (Polanczyk, De Lima, Horta, Biederman, & Rohde, 2007). Approximately two thirds of children with ADHD are believed to retain impairing symptoms into adulthood (Faraone, Biederman, & Mick, 2006). Prevalence rates in adults are estimated at 2.5% (Simon et al., 2009).

The ratio of ADHD diagnosis in males to females is 4:1 in childhood (Polanczyk et al., 2007), whilst in adulthood the discrepancy almost disappears (Matte et al., 2015). This is thought to be due to referral biases in males, or sex-specific effects of ADHD (Faraone et al., 2015).

ADHD is associated with impairment across the lifespan. For example, in children, core difficulties of hyperactivity and impulsivity may contribute to poor school attainment and difficulties in developing friendships (Carr, 2015). Impulsivity may also lead to increases in risk-taking behaviours and involvement in the criminal justice system

[1] In the UK classification system this is currently referred to as hyperkinetic disorder (World Health Organization, 1992). However, there is now general global consensus with the term ADHD, which will therefore be used in this review.

(British Psychological Society, 2015b), and compromise later relationships, work and health (Carr, 2015).

In adults, symptoms of hyperactivity often diminish, and manifest as restlessness, whilst inattention symptoms persist (Bramham, 2015; Volkow & Swanson, 2013). Difficulties are linked to educational and occupational underachievement, higher rates of divorce, problems with friends and family, higher rates of criminality, and parenting difficulties (Babinski et al., 2011; Biederman et al., 2008; de Graaf et al., 2008; Klein et al., 2012; Lichtenstein et al., 2012; Park, Hudec, & Johnston, 2017).

Further impairment is caused by difficulties in emotional regulation, i.e. the ability to monitor, evaluate and modify emotional reactions (Shaw, Stringaris, Nigg, & Leibenluft, 2014) and common co-morbid neurodevelopmental and mental health disorders. These include intellectual disability (ID)[2], autism spectrum disorder (ASD), conduct disorder (CD), anxiety and depression (Larson, Russ, Kahn, & Halfon, 2011; Thapar, Cooper, Eyre, & Langley, 2013), and also bipolar disorder, personality disorder and substance abuse in adulthood (Friedrichs, Igl, Larsson, & Larsson, 2012). Co-morbid disorders are thought to develop due to shared heritability and the impact of ADHD symptoms on socio-emotional wellbeing (Fayyad et al., 2007; Thapar et al., 2013).

[2]An intellectual disability can be defined as a significant impairment in intellectual and adaptive functioning, which arises before childhood (British Psychological Society, 2015a).

Parental ADHD and child outcomes

Existing literature

For adults with ADHD who go on to have children, there is a well-established link between parental ADHD and childhood ADHD. For example, around 50% of children with parents with ADHD will also have the disorder (Biederman et al., 1995) and many studies have found parental ADHD to predict the severity of child ADHD symptomology (e.g. Agha, Zammit, Thapar, & Langley, 2013; Auerbach, Zilberman-Hayun, Atzaba-Poria, & Berger, 2017; Goos, Ezzatian, & Schachar, 2007; Takeda et al., 2010)

However, the impact of parental ADHD on child outcomes beyond child ADHD, is less well-established. The association between parental mental health disorders and negative child externalising, internalising, social and cognitive outcomes[3] is well known (Ramchandani & Psychogiou, 2009; Stein & Harold, 2015; Stein et al., 2014). It could therefore be hypothesised that an association between parental ADHD and various child psychosocial outcomes, not limited to child ADHD, may also exist. Indeed, well-cited studies have started to explore this association (e.g. Biederman, Faraone, & Monuteaux, 2002).

Underlying mechanisms

Understanding the relationship between parental ADHD and child outcomes is complex and recent research has begun to shed light on the trajectory of child functioning over time. Heuristic models such as that devised by Johnston and Chronis-Tuscano (2017)

[3] Externalising difficulties can include symptoms or diagnoses of ADHD, Oppositional Defiance Disorder and Conduct Disorder; internalising difficulties can include symptoms or diagnoses of depression and anxiety; social outcomes can include social skills such as perspective taking, empathy and co-operation; cognitive outcomes can be conceptualised by IQ, academic ability, etc (Stein et al., 2014).

have attempted to conceptualise this relationship (see figure 1), although acknowledge that it is near impossible to include the multiplicity, complexity, and bi-directionality of the relationship, and all known influential variables. Key underlying mechanisms will be discussed below.

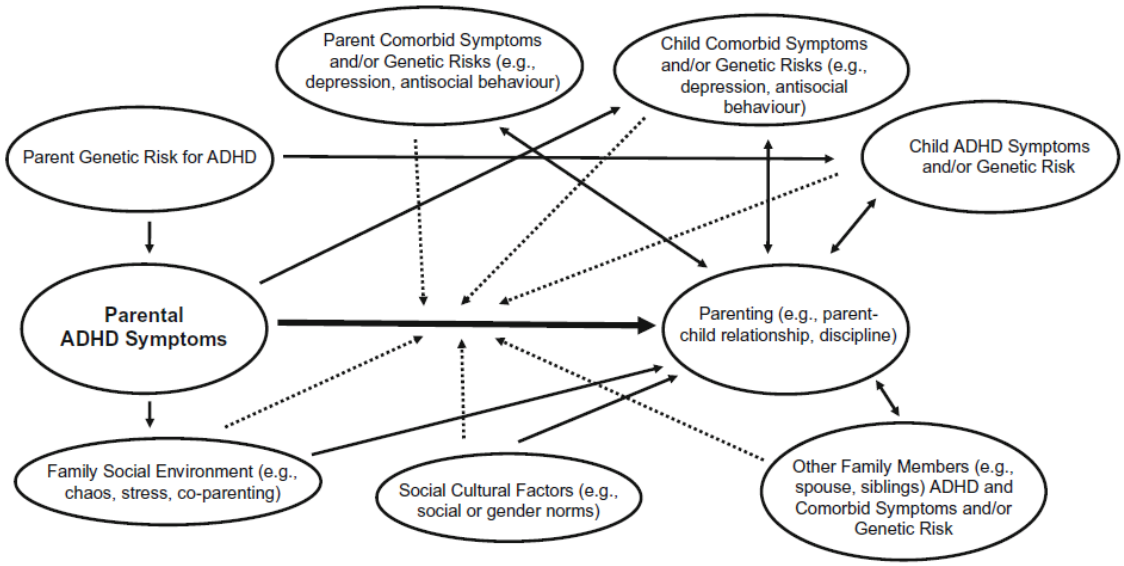


Figure 1. The relations between parental ADHD symptoms and parenting, and child and family functioning, taken directly from Johnston and Chronis-Tuscano, (2017; p.1).

Parental ADHD and genetics

Genetic factors are thought to account for part of the association between parental ADHD and child outcomes; research has consistently shown high heritability rates for ADHD, i.e. the degree of genetic variation of ADHD traits within a population (Faraone et al., 2005; Nikolas & Burt, 2010; Sprich, Biederman, Crawford, Mundy, & Faraone, 2000). A child's environment is also substantial in their development, where genes and environmental factors are closely intertwined (Thapar et al., 2013).

Despite the strong genetic link, the genetic transmission is not a simple pathway between parental ADHD and child ADHD (Thapar et al., 2015). It can be hypothesised that parental ADHD will increase the risk of transmission of other negative child outcomes and co-morbid disorders. This will also be influenced further by the genetic overlap with other co-morbid neurodevelopmental and psychiatric disorders (Lichtenstein et al., 2010; Thapar et al., 2013).

Parental ADHD and parenting

A recent meta-analysis (Park et al., 2017) found that parental ADHD negatively impacted on parenting behaviour, increasing both harsh and lax parenting which may link to ADHD-specific difficulties. Low levels of parenting control and inconsistent emotional responsiveness are in turn associated with child outcomes such as increased internalising symptoms (see Rose, Roman, Mwaba, & Ismail, 2017), antisocial behaviour (Alvarez-Garcia et al., 2016) and poor academic achievement (e.g. Steinberg, Lamborn, Bornbusch & Darling, 1992). It could therefore be assumed that the parenting behaviour seen in parental ADHD may also influence similar child outcomes.

The relationship between parental ADHD and child outcomes is bi-directional, (Johnston & Chronis-Tuscano, 2015). The association between parental ADHD and parenting is moderated by child ADHD, where a match between parent and child ADHD status decreases the association between parental ADHD and harsh parenting (Johnston, Williamson, Noyes, Stewart, & Weiss, 2016; Park et al., 2017).

Parental ADHD and family social environment.

Adult ADHD has been associated with family and marital conflict, a lack of family cohesion, increased psychiatric disorders in spouses and home chaos (Biederman et al.,

2002; Klein et al., 2012; Minde et al., 2003; Mokrova, O'Brien, Calkins, & Keane, 2010). Such factors, in turn, have been associated with not only child ADHD (Auerbach et al., 2017) but also externalising and internalising outcomes, and lower educational attainment (Ackerman & Brown, 2010; Fiese & Winter, 2010). Therefore, parental ADHD may be associated with child psychological outcomes beyond child ADHD and may be moderated by the family social environment.

Parental ADHD and co-morbid difficulties

Given that 85% of adults with ADHD are also likely to experience at least one co-morbid mental health disorder (Kessler, 2006), these may also impact on child externalising, internalising, social and cognitive outcomes (Ramchandani & Psychogiou, 2009; Stein & Harold, 2015; Stein et al., 2014), on top of those difficulties already associated with parental ADHD alone.

Summary

In summary, the intergenerational transmission of mental health difficulties goes beyond one phenotype and parental ADHD may also be associated with child outcomes beyond ADHD. Specifically, internalising, externalising, social and cognitive outcomes are influenced by those factors associated with parental ADHD, such as the strong genetic overlap with mental health difficulties, parenting difficulties, and difficult family environments.

Research investigating parental ADHD is increasing and yet to date, no review exists of the literature considering associated child outcomes beyond child ADHD. High quality research is needed to understand the complex mechanisms at play between parental

ADHD and child outcomes, parsing the direct and indirect contributions of genetics and environment (Johnston & Chronis-Tuscano, 2015), and child ADHD co-morbidities.

Aims of the review

This review aims to:

- Systematically identify, synthesise and evaluate quantitative literature which measures outcomes (i.e. internalising, externalising, social and cognitive) beyond ADHD of children of parents with ADHD.
- Consider, where measured, possible mediating and moderating mechanisms between parental ADHD and the above child outcomes beyond ADHD.
- Consider implications for current models of parental ADHD, and for future research and clinical practice.

Method

Search strategy

A systematic search was conducted on 6.2.2018 using the databases PsycINFO, Medline, Embase, CINAHL (Cumulative Index to Nursing and Allied Literature), AMED (Allied and Complementary Medicine), and Scopus. Key word searches related to parental ADHD and child outcomes (see appendix C for search strategy). Peer-reviewed articles, written in English and published up until 6.2.2018 were included. The search yielded 2233 studies, before duplicates were removed. Reference lists of key papers were also hand-searched, which yielded an additional seven studies.

Inclusion criteria

Studies were included in the review if they: (i) statistically examined the association between parental ADHD and child psychological outcomes as part of the main analysis; (ii) used a measure of current parental ADHD symptoms, rather than retrospective child ADHD measures only; (iii) used a measure of child psychological functioning which could be broadly categorised into externalising, internalising, cognitive and social outcomes as used in similar reviews, (e.g. Stein et al., 2014); (iv) used child participants <18 years of age; (v) used a quantitative design. Studies were excluded if only child ADHD was measured, given that the link between parental and child ADHD is already well-established.

Procedure

The Preferred Reporting Items for Systematic Review and Meta-Analyses (PRISMA) guidelines were followed (Liberati et al., 2009; Moher, Liberati, Tetzlaff, Altman, &

Group, 2009). An initial screening process of the abstracts of 2105 papers led to the exclusion of 2017 papers.

The full-texts of the remaining 88 papers were then screened thoroughly leading to the further exclusion of 67 papers. A total of 21 papers were included in the current review (see figure 2 for further details) and data extracted (see appendix D for data extraction tool).

A checklist was developed to measure study quality (Downs & Black, 1998) and (Downes, Brennan, Williams, & Dean, 2016) (see appendix E).

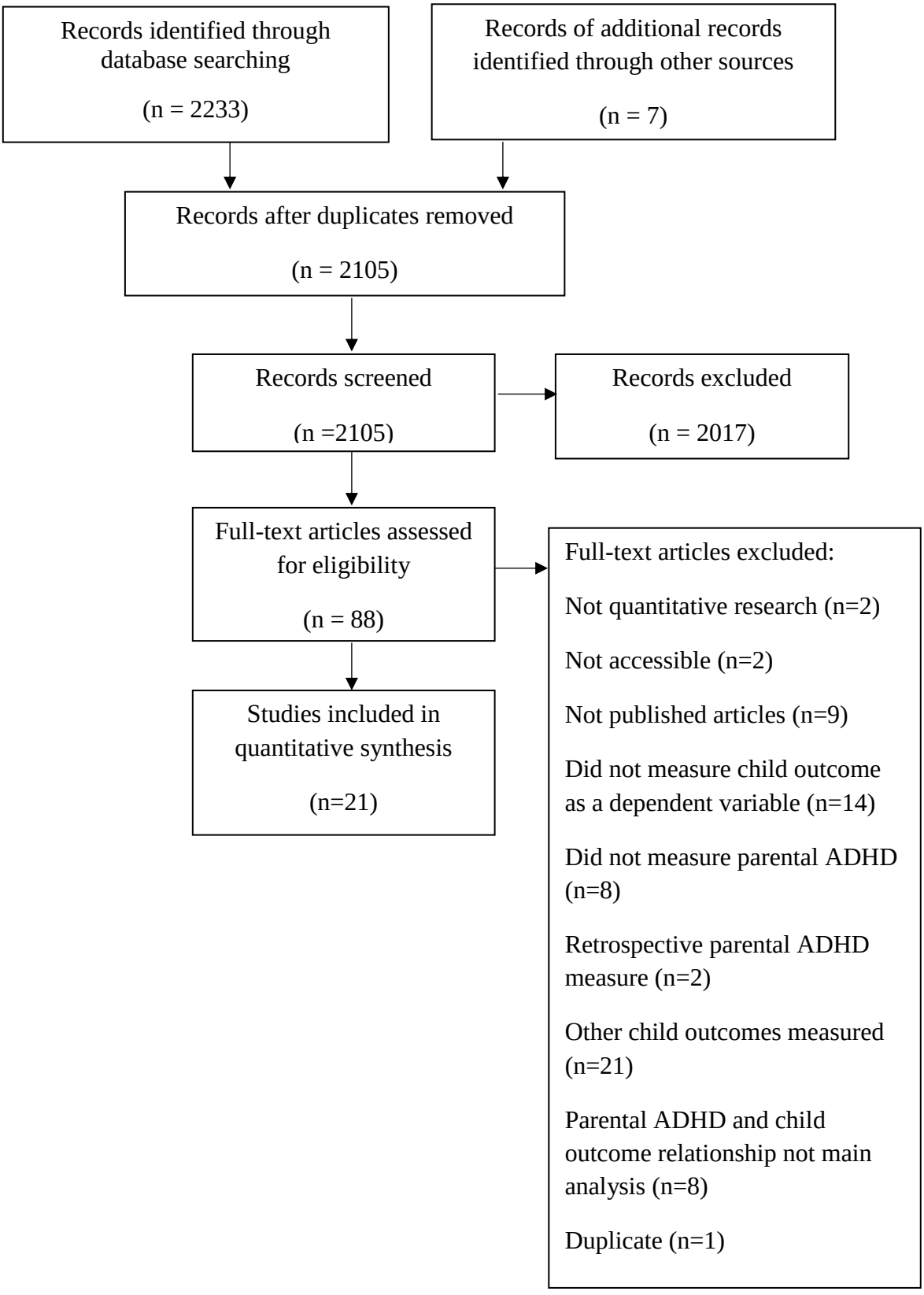


Figure 2. Flow diagram of study selection process

Results

Study characteristics

Detailed study characteristics can be found in table 1.

Fifteen cross-sectional and six longitudinal studies were identified, which included a range of offspring age groups: 17 reported child (aged 3-12 years) outcomes and one reported adolescent (13-18 years) outcomes. Three studies utilised samples encompassing both children and adolescents (Agha, Zammit, Thapar, & Langley, 2017a; Biederman et al., 2002; Segenreich et al., 2015).

Fourteen studies measured externalising outcomes (including Oppositional Defiance Disorder [ODD], Conduct Disorder [CD], aggression), eight measured internalising outcomes (including anxiety, depression, emotional functioning), eight measured cognitive outcomes (e.g. cognitive ability, executive functioning, academic achievement), and six measured social outcomes (e.g. social functioning, skills and behaviours).

Some samples appeared to be drawn from the same research groups, such as the Early Behaviour Development Project (Breaux, Brown, & Harvey, 2017; Breaux, Harvey, & Lugo-Candelas, 2014; Herbert, Harvey, Lugo-Candelas, & Breaux, 2013) and the Study of ADHD Genes and Environment (Agha et al., 2013, 2017a; Agha, Zammit, Thapar, & Langley, 2017b).

Participant[4] numbers ranged from 37 (Romirowsky & Chronis-Tuscano, 2014) to 1099 (Biederman et al., 2002). All studies had a majority of male participants (between 57%

[4] The term 'participant' will refer to the offspring from this point forward, unless otherwise stated.

and 100%). Nineteen studies recruited participants who already had a clinical condition (e.g. ADHD or behavioural difficulties). Of those 19, 11 studies used control groups.

Four of the studies measured maternal ADHD only (Agha et al., 2017a; Efron, Furley, Gulenc, & Sciberras, 2018; Griggs & Mikami, 2011; Zisser & Eyberg, 2012), whilst three considered paternal ADHD only (Herbert et al., 2013; LeMoine, Romirowsky, Woods, & Chronis-Tuscano, 2015; Romirowsky & Chronis-Tuscano, 2014). Fourteen considered both maternal and paternal ADHD.

Caucasian participants ranged from 45.5% (Humphreys, Mehta, & Lee, 2012) to 100 % (Agha et al., 2013). Ethnic background was unreported in nine studies.

Table 1.

Summary of studies considering parental ADHD and child psychological outcomes.

Citation	Design, Recruitment source	Sample		Parental ADHD measure		Child outcome/measure		Main Findings	Mediator/ moderator variables	Confounding variables included
		Child	Parent	Self-report	Interview/ objective measure	Parent/child reported measure	Objective measure			
Agha et al. (2013) *UK*	Cross-sectional Child & adolescent psychiatry & paediatric services	Children with ADHD N= 570 86% male Mean age= 10.78 years (SD = 3.01)	N= 546 mothers, 280 fathers ADHD = 19% mothers, 25% fathers	18-item DSM-IV ADHD checklist ADHD = ≥six symptoms	Not reported	CAPA	WISC-IV	Maternal and paternal ADHD status was associated with increased CD symptom severity but not ODD, depression or anxiety. Maternal ADHD status was associated with CD diagnosis. Paternal ADHD was associated with lower full-scale IQ and working memory abilities.	None reported	Child age and gender used as covariates Adjusting for social class attenuated CD symptoms and diagnosis, and maternal hostility, but not family conflict, cohesion or maternal warmth
Agha et al. (2017a) *UK*	Longitudinal Child & adolescent psychiatry & paediatric services	Children with ADHD N= 143 100% male Mean age time 1= 10.71	N=140 mothers Parents with	18-item DSM-IV ADHD checklist		CAPA, DAWBA		No association was found between maternal ADHD and CD symptom severity at time 1 or 2 or with changes in CD symptom scores. A trend existed between maternal ADHD	None reported	Adjusted for child age, ADHD and CD disorder at time 1, maternal childhood CD symptoms, period between time 1 and 2 and ADHD medication status.

Citation	Design, Recruitment source	Sample		Parental ADHD measure		Child outcome/measure		Main Findings	Mediator/ moderator variables	Confounding variables included
		Child	Parent	Self-report	Interview/ objective measure	Parent/child reported measure	Objective measure			
		years (SD=2.14) Mean age time 2= 13.73 years (SD=1.74)	ADHD = 19%	ADHD = ≥six symptoms				symptoms and CD symptoms.		
Agha et al. (2017b) *UK*	Cross-sectional Child & adolescent psychiatry & paediatric services	Children with ADHD N=568 85% males Mean age =10.77 years (SD=3.01)	N=546 mothers, 280 fathers Parents with ADHD = 23%	18-item DSM-IV ADHD checklist ADHD = ≥six symptoms		Not reported	WISC-IV, Intra-Extra Dimensional, Cambridge gambling task	Parental ADHD associated with poorer performance in working memory and set shifting ability.	None reported	Adjusted for child age, social class, parent education, child IQ, child ADHD and CD severity
Berger et al. (2013) *Israel*	Cross-sectional Hospital maternity ward	N=60 100% boys Mean age = ~5 years.	N=60 Parents with ADHD = unknown	CAARS:S long version	CAARS:O short version (partner rated)		Stop-signal task	Father inattention had significant contribution to reaction time. Father hyperactivity made significant contribution to error rates. No significant correlations were found	None reported	None reported

Citation	Design, Recruitment source	Sample		Parental ADHD measure		Child outcome/measure		Main Findings	Mediator/ moderator variables	Confounding variables included
		Child	Parent	Self-report	Interview/ objective measure	Parent/child reported measure	Objective measure			
								with mother ADHD symptoms.		
Biederman et al. (2002) *USA*	Cross-sectional Paediatric hospital clinics	N=1099 53% males Mean age=12.4 years (range=6-17) Child ADHD group n=280 Child with ADHD sibling n=317 Control group n=240 Control sibling n=260	Parents n=477 Parents with ADHD= 29%	K-SADS	SCID	CBCL GAF	WISC-R /WAIS-R, Arithmetic Subtest of the Wide range achievement test – revised. Gilmore reading test, SAICA	Parental ADHD had deleterious impact on school performance and academic achievement in offspring *without* ADHD but not children with ADHD. No differences found in internalising, externalising, or social outcomes between controls and children with parents with ADHD.	None reported	Model adjusted for offspring ADHD status (if parental ADHD x offspring ADHD non-significant), SES and exposure to parental psychopathology.
Brammer et al. (2016)	Longitudinal, Mental health centres and paediatric	N=230 Age range at time 1 = 5-10 years, (SD=1.1).	N=not reported, 86% mothers	ASRS		CBCL	DISC-IV, DBD (teacher-rated),	Parental ADHD did not predict ODD or externalising behaviour 2 years later. Changes in parental ADHD symptoms over	Child ADHD status did not moderate association between parental ADHD and ODD.	Sex, race-ethnicity, age and parental depression included as co-variates.

Citation	Design, Recruitment source	Sample		Parental ADHD measure		Child outcome/measure		Main Findings	Mediator/ moderator variables	Confounding variables included
		Child	Parent	Self-report	Interview/ objective measure	Parent/child reported measure	Objective measure			
USA	offices, local elementary schools and community locations	Age range at time 2 = 8-11, (SD=1.3) Children with ADHD n=110 Males = 78% Control n=120 Males = 64%	Parent ADHD n= unreported				TRF (teacher-rated)	time did not predict changes in child ODD symptoms or externalising behaviour.	Decreases in parental ADHD symptoms associated with decreases in parent-reported externalizing behaviour *only* in control children (but not when teacher-rated).	Child ADHD status and externalising symptoms were controlled for.
Breaux et al. (2014) *USA*	Longitudinal Birth records, paediatrician offices, child care centres and community centres	Children with behavioural problems N=132 58% male Mean age at time 1 = 3.71 years (SD=3.18). Mean age at time 4= ~6 years	N=123 mothers, n=130 fathers Parental ADHD n= unreported	CSS		BASC-PRS		Higher levels of maternal & paternal ADHD at age 3 were associated with more child same-parent-reported internalising & externalising problems at age 6. Maternal ADHD was associated with poorer child mother-reported social skills at age 6.	Child gender did not moderate these relationships	None reported

Citation	Design, Recruitment source	Sample		Parental ADHD measure		Child outcome/measure		Main Findings	Mediator/ moderator variables	Confounding variables included
		Child	Parent	Self-report	Interview/ objective measure	Parent/child reported measure	Objective measure			
Breaux et al. (2017) *USA*	Longitudinal Birth records, paediatrician offices, child care centres and community centres	N=258 53% male Mean age at time 1 = 3.68years (SD=0.28) Mean age at time 2 = ~6years Behavioural problems at time 1 n=199 Control n=59	Unreported Parental ADHD = 12% mothers, 6% fathers	CSS ADHD = ≥five symptoms		DISC-IV		Maternal (but not paternal) ADHD symptoms correlated with age 3 (but not age 6) ODD symptoms.	Maternal over-reactivity (but not laxness) mediated the relationship between maternal ADHD symptoms and later child ODD symptoms. This was not the case for paternal ADHD. Family adversity did not interact with parental ADHD symptoms to predict child ODD symptoms	Model controlled for early child ADHD and ODD symptoms, family ADHD history, paternal psychopathology
Efron et al. (2018) *Australia*	Cross-sectional Schools	Children with ADHD N=117 80% male	N=166 mothers Parents with	CAARS:S short version		SDQ	SSIS (teacher-rated), SDQ (teacher-rated)	Maternal ADHD associated with increased child conduct problems, emotional and social problems in children without ADHD only. No association was found between maternal	None reported	Model adjusted for child age, gender, maternal education level, single parent status, SES and parent

Citation	Design, Recruitment source	Sample		Parental ADHD measure		Child outcome/measure		Main Findings	Mediator/ moderator variables	Confounding variables included
		Child	Parent	Self-report	Interview/ objective measure	Parent/child reported measure	Objective measure			
		Mean age = 8.9 years (SD=0.4) Control N=146 95% male Mean age = 8.9 (SD=0.4)	ADHD = unreported					ADHD and academic performance.		psychological distress.
Farbiash et al. (2014) *Israel*	Cross-sectional Hospital maternity ward	N=84 100% male Mean age= 4.44 years (SD=0.16)	N= unreported Parental ADHD n =unreported	CAARS:S long version		CBCL		Parental total ADHD was associated with child aggression.	Home chaos mediated Relationship for paternal but not maternal ADHD	Analysis controlled for parental age and years of education.
Griggs & Mikami (2011)	Cross-sectional Schools, paediatric offices &	N=103 72% male Age range: 6-10 years	Mothers n= unreported	CSS		CBCL	TRF (teacher-rated), Playgroup sociometri	Maternal ADHD symptom was associated with mother-reported but not teacher-reported social problems.	None reported	Maternal education, child sex, child medication status, child IQ, observed child aggression

Citation	Design, Recruitment source	Sample		Parental ADHD measure		Child outcome/measure		Main Findings	Mediator/ moderator variables	Confounding variables included
		Child	Parent	Self-report	Interview/ objective measure	Parent/child reported measure	Objective measure			
USA	participant database	ADHD group n=47 Control n=56	Parental ADHD n=10				cs (peer-rated), Observed child prosocial behaviour (observer-rated)			
Herbert et al. (2013) *USA*	Longitudinal Birth records, paediatrician offices, care & community centres	Children with externalising problems N=128 57% male Mean age at time 1 = 3.70years, (SD=0.3), Mean age at time 2 = 6.69, (SD = 4.68)	Fathers n= unreported Parental ADHD =4%	CSS		BASC-PRS, Social Skills Scale, DISC-IV	WISC-IV. WIAT-II-A	Paternal ADHD associated with increased internalising for girls and boys & externalising problems for girls. Paternal ADHD marginally associated with lower cognitive ability for girls but not for boys. Paternal ADHD was not associated with child social functioning.	Paternal ADHD and child social emotional functioning was partially mediated by paternal laxness (but not demands). Paternal ADHD symptoms and child cognitive and academic outcomes were fully mediated by paternal depressive symptoms but not parenting.	Unreported

Citation	Design, Recruitment source	Sample		Parental ADHD measure		Child outcome/measure		Main Findings	Mediator/ moderator variables	Confounding variables included
		Child	Parent	Self-report	Interview/ objective measure	Parent/child reported measure	Objective measure			
									Child gender and child ADHD/ ODD did not moderate any associations.	
Humphreys et al., (2012) *USA*	Cross-sectional. Schools, paediatric offices, self-help groups, referrals from clinical service providers	N=178 72%male Age range= 5-10 years ADHD group n=91, mean age=7.24 years Control group n=87, mean age=7.63 years	Unknown	ASRS		DBD CBCL	DISC-IV	Parental ADHD associated with greater child internalising & externalising problems.		Unreported
LeMoine et al. (2015)	Cross-sectional	Children with ADHD N=102	N=102 fathers	CAARS		DBD		Paternal ADHD symptoms had no direct effect on child conduct problems	Negative parenting fully mediated relationship between paternal ADHD and child	Control variables included child CP, marital status, and marital satisfaction.

Citation	Design, Recruitment source	Sample		Parental ADHD measure		Child outcome/measure		Main Findings	Mediator/ moderator variables	Confounding variables included
		Child	Parent	Self-report	Interview/ objective measure	Parent/child reported measure	Objective measure			
USA	Schools, paediatric offices, parenting listservs, and ADHD-related websites	75% male Age range = 5-12 years	Parental ADHD = 66%	ADHD = t scores ≥ 65					conduct problems.	Controlling for paternal symptoms of ASPD meant that all associations between parental ADHD and child conduct problems were no longer significant.
Minde et al. (2003) *USA*	Cross-sectional Adult ADHD clinic & newspaper adverts	N=59 57% males Mean age = 7.5 years (SD=1.8) Children with ADHD & ADHD parent: n=15, mean age=7.5 (SD=1.8) Children without ADHD &	Parents with ADHD: n=33 and spouses n=23 Controls: n=26, spouses n=20.	CAARS Patient's behaviour checklist, Wender-Utah Rating Scale Parents with ADHD = 33		CBCL SAICA	TRF (teacher-rated) DISC-IV	Children with ADHD with a parent with ADHD had greater internalising, externalising, social functioning difficulties compared to non-ADHD and comparison children.		None reported

Citation	Design, Recruitment source	Sample		Parental ADHD measure		Child outcome/measure		Main Findings	Mediator/ moderator variables	Confounding variables included
		Child	Parent	Self-report	Interview/ objective measure	Parent/child reported measure	Objective measure			
		with ADHD parent n=18, mean age=8.4 (SD=3.1) Control n=2.9 Control mean age = 8.0years (SD=2.9)								
Moroney et al. (2017) *USA*	Longitudinal Mental health centres, paediatric offices, adverts in local elementary schools and the community.	Children with ADHD: n=116, 73% male, mean age at time 1 = 7.23 years (SD=1.14) Control: n=108, 61% male, mean age at time 1 =7.51 years, (SD=1.08) Mean age at wave 2=10.2	N=unknown, 86% mothers at time 1. Parental ADHD = 37%	ASRS ADHD = scores of ≥29		DBD		No direct effect of parental ADHD at time 1 and ODD symptoms at time 3. Increases in parental ADHD symptoms predicted worsening of ODD symptoms across 6 years but not CD.	Negative parenting (but not positive parenting) at 10 years marginally mediated relationship between parental ADHD at 6 years and ODD symptoms at 12 years. Expressed emotion did not mediate any associations.	Model controlled for early ADHD diagnostic status, age, gender and race-ethnicity and parental depression.

Citation	Design, Recruitment source	Sample		Parental ADHD measure		Child outcome/measure		Main Findings	Mediator/ moderator variables	Confounding variables included
		Child	Parent	Self-report	Interview/ objective measure	Parent/child reported measure	Objective measure			
		years (SD=1.3) Mean age at wave 3=12.0 years (SD=1.5)								
Romirowsky and Chronis-Tuscano (2014) *Canada*	Cross-sectional, Local ADHD groups, schools, and health providers	Children with ADHD N=37 70% male Mean age= 8.29years (SD=2.00)	N=37 fathers Paternal ADHD = 13.5%		MINI	DBD	DBD (teacher-rated), K-SADS	Paternal ADHD symptoms not independently associated with child conduct problems.	Paternal involvement moderated relationship between paternal ADHD symptoms and child conduct problems	None reported
Segenreich et al. (2015) *Brazil*	Cross-sectional ADHD clinic and schools	Children with ADHD n=87 Mean age = 11.48 years (SD=2.73) Unaffected siblings n=72 Mean age=12.75	Children with ADHD group: Mothers n=87, Fathers: n=86 Control group: Mothers		Adapted K-SADS	CDI CSTAI		Increased maternal (but not paternal) inattention scores (not hyperactivity or total scores) associated with increased offspring anxiety. No significant correlation between parental ADHD and offspring depression.	None reported	None reported

Citation	Design, Recruitment source	Sample		Parental ADHD measure		Child outcome/measure		Main Findings	Mediator/ moderator variables	Confounding variables included
		Child	Parent	Self-report	Interview/ objective measure	Parent/child reported measure	Objective measure			
		years (SD=4.43). Control n=26, Mean age=13.54years (SD=3.01) Gender unreported	n=13, Fathers n=13, (SD=7.8)							
Thissen, Rommelse, Altink, Oosterlaan, and Buitelaar (2014) *Netherlands*	Cross-sectional, Child psychiatric clinics	Children with ADHD n=350 75% male Mean age=11.5years (SD=2.8) Unaffected siblings n=195 45% male Mean age=11.5 years (SD=3.6)	Mothers n=384 Fathers n=383 Mothers with ADHD n=23 Fathers with ADHD n=23	CAARS:S short version ADHD = z score ≥1.5			WISC/WAIS-III, Motor timing, Time test, Stop task, Digit span, Visuospatial sequencing , Pursuit tracking	Maternal ADHD associated with poorer executive functioning (inhibition) and motor functioning (two motor control paradigms) scores. Paternal ADHD associated with decreased scores on timing (time reproduction) and IQ (verbal and total IQ).	None reported	None reported

Citation	Design, Recruitment source	Sample		Parental ADHD measure		Child outcome/measure		Main Findings	Mediator/ moderator variables	Confounding variables included
		Child	Parent	Self-report	Interview/ objective measure	Parent/child reported measure	Objective measure			
		Control n=271 41% male Mean age=11.6 years (SD=3.2)								
Thissen, Rommelse, Hoekstra, et al. (2014) *Netherlands*	Cross-sectional, Study database	Children with ADHD n=406 71% male Mean age=17.4years (SD=3.4) Unaffected siblings n=206 40% male Mean age=17.4years (SD=4.0) Control group	Parents with ADHD who have ADHD children n=174 Parents without ADHD who have ADHD children n= 278 Control parents n=137		CAARS:O short version		Visual stop task, WAIS-IV	Parental ADHD was not significantly associated with any measure of offspring executive functioning.	None reported	Model controlled for child age, sex and parental age.

Citation	Design, Recruitment source	Sample		Parental ADHD measure		Child outcome/measure		Main Findings	Mediator/ moderator variables	Confounding variables included
		Child	Parent	Self-report	Interview/ objective measure	Parent/child reported measure	Objective measure			
		n=193, 40% male Mean age=16.8years (SD=43.8)								
Zisser and Eyberg (2012) *USA*	Cross-sectional Study on treatment for child ADHD	Children with ADHD: N=54 74% male Mean age = 4.98 years (SD=0.75, range=4-6)	Mothers n=54 Mean age =33.85 years (SD=6.36) Parent ADHD = unreported	ASRS CAARS:S ADHD = unreported	Clinical unstructured interview	CBCL SNAP-IV	YC-DISC	Maternal ADHD symptoms correlated with child ODD symptoms on the SNAP but not the CBCL.	None reported	None reported

Note: ADHD=Attention Deficit Hyperactivity Disorder; ASPD=Anti-Social Personality Disorder; ASRS= Adult ADHD self-report scale; BASC-PRS=Behaviour Assessment System for Children-Parent Report Scale; CAPA=Child and Adolescent Psychiatric Assessment; CAARS:S=Conner's Adult ADHD Rating Scale self-report version; CAARS:O= Conner's Adult ADHD Rating Scale observer screening version; CBCL=Child Behaviour Checklist; CD = conduct disorder; CDI=Child depression inventory; C-DISC=Computerised - Diagnostic Interview Schedule for Children; CSS=Current Symptoms Scale; CSTAI=Child State-trait Anxiety Inventory; CTRS=Conner's Teacher Rating Scale-Revised; DAWBA=development and Well-Being Assessment; DBD=Disruptive Behaviour Disorder Rating Scale; DISC-IV=Diagnostic Interview Schedule-Fourth version; DSM-IV= Diagnostic and Statistical Manual of Mental disorders-fourth edition; GAF=Global Assessment of Functioning; K-SADS= Kiddie Schedule for Affective Disorders and Schizophrenia; MINI= Mini International Neuropsychiatric Interview; ODD= opposition defiance disorder; SAICA=Social Adjustment Inventory for Children and Adolescents; SCID=Structured Clinical Interview for DSM-III-R; SQD=Strengths & Difficulties Questionnaire; SES=socio-economic status; SNAP=Swanson-Nolan and Palham-IV Rating Scale; SSIS= Social Skills Improvement System; TRF= Teacher Report form; UK= United Kingdom; WIAT= Wechsler Individual Achievement Test ; WAIS=Wechsler Adult Intelligence Scale; WISC=Wechsler Intelligence Scale for Children; YC-DISC=Diagnostic Interview Schedule for Young Children

Synthesis of findings

Externalising outcomes

Findings of studies considering externalising outcomes were mixed.

Longitudinal research found associations between parental ADHD and CD symptoms (Agha et al., 2017a) and greater behavioural problems (i.e. symptoms of hyperactivity, aggression and conduct problems) (Breaux et al., 2014; Herbert et al., 2013), even when controlling for child ADHD. Associations with CD, externalising symptoms and child aggression were also supported by cross-sectional research (Agha et al., 2013; Farbiash, Berger, Atzaba-Poria, & Auerbach, 2014; Humphreys et al., 2012).

Mixed results regarding the association between parental ADHD and child ODD symptoms may reflect differences in study quality. Longitudinal, well-controlled studies (Brammer, Galan, Mesri, & Lee, 2016; Moroney, Tung, Brammer, Peris, & Lee, 2017) and one cross-sectional study did not find an association (Agha et al., 2013). Although another cross-sectional study did find a correlation between parental ADHD and child ODD symptoms, this was only found on one of two measures, making results inconclusive (Zisser & Eyberg, 2012).

Studies which considered parental ADHD as a time-varying predictor of child externalising outcomes (i.e. the influence of decreases or increases in parental ADHD over time) also had mixed results. Opposing results were found for ODD symptoms despite the studies using near-identical samples and methodologies; increases in parental ADHD symptoms predicted increases in child ODD symptoms over 6 years in Moroney et al. (2017) but not over 2 years in Brammer et al. (2016). However, descriptive statistics were not provided in the latter, therefore making it difficult to

distinguish the nature of these changes. These differences were not addressed in the articles, despite common authors. Differences may reflect Moroney et al. (2017) measuring changes over a longer period of time.

Decreases in parental ADHD symptoms were not found to predict changes in child CD symptoms over a period of 6 years (Moroney et al., 2017), although the internal consistency of CD measures was low, making it difficult to draw confident conclusions. Decreases in parental ADHD symptoms were associated with decreases in parent-rated externalising behaviour for controls. This was not found for teacher-rated behaviour, making results inconclusive (Brammer et al., 2016).

Moderating and mediating factors

For some studies, parent gender moderated the relationship between parental ADHD and child externalising difficulties, and also moderated the influence of mediating factors. For example, the relationship between fathers with ADHD and child aggression was fully mediated by home chaos, which was not the case for mothers (Farbiash et al., 2014). On the other hand, for children with ADHD, maternal, but not paternal ADHD, was associated with increased likelihood of CD diagnoses (Agha et al., 2013). Furthermore, parental gender may also interact with child gender; in children with 'behavioural problems', parental ADHD symptoms were only associated with increased behavioural problems when parents and children were of opposing gender (Herbert et al., 2013) e.g. paternal ADHD symptoms were associated with behavioural problems in girls but not boys.

Parenting appeared to be a consistent mediating or moderating factor in the relationship between parental ADHD and child externalising difficulties. Father involvement moderated the relationship between paternal ADHD and CD symptoms,

which was only significant when father involvement was high (Romirowsky & Chronis-Tuscano, 2014). The association between maternal ADHD and ODD was fully mediated by over-reactivity (Breaux et al., 2017). This was not the case for paternal ADHD suggesting possible parenting and parent gender differences. Moroney et al. (2017) also found a trend towards mediation of negative parenting between parental ADHD and child ODD. However, paternal symptoms of anti-social personality disorder (ASPD) appeared to have a stronger influence over this relationship; negative parenting no longer mediated the relationship between paternal ADHD and CD problems when controlling for paternal ASPD (LeMoine et al., 2015).

In cross-sectional studies, child ADHD was only found to be a moderating factor in low quality studies. An association was found between maternal ADHD and child CD symptoms only in children *without* ADHD (Efron et al., 2018) whilst Minde et al. (2003) found an association with greater externalising problems for children *with* ADHD only. However, poor study quality, such as a lack of clarity regarding group comparisons (Efron et al., 2018), and small sample sizes mean that these findings should be treated cautiously. On the other hand, in a large-sample study (n=1099), an interaction was not found between child and parental ADHD when considering child externalising symptoms (Biederman et al., 2002).

Internalising outcomes

Fewer studies investigated internalising outcomes and also provided mixed results.

Both longitudinal and cross-sectional studies found parental ADHD (either diagnosed or self-reported) was associated with greater internalising problems (Herbert et al., 2013; Humphreys et al., 2012). In Breaux et al. (2014) maternal ADHD symptoms

were only associated with maternal-rated internalising difficulties, and paternal ADHD symptoms with paternal-rated internalising difficulties, which may reflect rater-biases.

Interestingly, cross-sectional studies which considered the association between parental ADHD and specific internalising difficulties found non-significant results, for both depression (Agha et al., 2013; Segenreich et al., 2015) and anxiety (Agha et al., 2013).

Moderating and mediating factors

As with externalising outcomes, parent gender moderated the relationship between parental ADHD and child internalising outcomes; in one study, only maternal inattention symptoms were associated with increased offspring anxiety (Segenreich et al., 2015). This also suggests that ADHD subtype is a moderating factor.

As with externalising outcomes, child ADHD as a moderating factor depended on study quality. For example, in less robust studies, the association between parental ADHD and child internalising factors was found only for children with ADHD (Minde et al., 2003) and without (Efron et al., 2018). This was not found in a larger, higher quality study (Biederman et al., 2002).

Parenting and parental mental health difficulties also played a role in the relationship between paternal ADHD and child 'social-emotional' symptoms (i.e. both internalising and social skills); the relationship was partially mediated by paternal laxness and fully mediated by paternal depressive symptoms (Herbert et al., 2013).

Social outcomes

The association between parental ADHD and child social outcomes is inconclusive due to sparse study numbers and low-quality research.

Moderating effects appeared for parent gender and parental ADHD subtype. For example, maternal ADHD, but not paternal ADHD, was associated with poorer social skills in children with behavioural problems (Breaux et al., 2014). This is supported by Griggs and Mikami (2011) who found maternal hyperactivity-impulsivity symptoms were associated with poorer social outcomes, and Herbert et al. (2013) who did not find an association with paternal ADHD. However, the opposite parent gender was not considered in these studies. Teacher-reported social outcomes did not support the association in Griggs and Mikami (2011), which may suggest parent-rater bias or differential environmental effects, and therefore results remain inconclusive.

The same low-quality studies suggested child ADHD may moderate this association (Efron et al., 2018; Minde et al., 2003) and therefore conclusions cannot be drawn. This opposed Biederman et al. (2002), who did not find differences in social outcomes between children with and without parents with ADHD, despite using the same measure and design as Minde et al. (2003).

Cognitive outcomes

Few studies found an association between parental ADHD and child cognitive outcomes.

In both cross-sectional and longitudinal studies, no association was found between parental ADHD and child cognitive abilities such as IQ (Agha et al., 2017b; Biederman et al., 2002; Herbert et al., 2013), executive functioning tasks in adolescents (Thissen, Rommelse, Hoekstra, et al., 2014) or academic achievement (Efron et al., 2018; Herbert et al., 2013).

Parental ADHD *was* associated with poorer set-shifting ability and working memory (Agha et al., 2017b).

Moderating and mediating factors

A lack of association may be accounted for by moderating factors, such as parent gender. For example, paternal but not maternal ADHD was associated with decreased scores in IQ (Agha et al., 2013; Thissen, Rommelse, Altink, et al., 2014) and response inhibition (Berger, Alyagon, Hadaya, Atzaba-Poria, & Auerbach, 2013). On the other hand, poorer executive and motor functioning in children was associated with maternal ADHD only (Thissen, Rommelse, Altink, et al., 2014). However, these studies did not control for parental IQ, a well-known predictor of child IQ (Eriksen et al., 2013), and therefore results may not be as valid as possible.

Furthermore, child ADHD was also a moderating factor in specific academic measures. An interaction was found between parental ADHD and child ADHD; children with ADHD performed worse on academic outcomes than children without ADHD. However, for children with ADHD having a parent with ADHD was associated with *better* scores in school functioning compared to those without a parent with ADHD. On the other hand, for a child without ADHD, having a parent with ADHD was associated with *worse* scores in school functioning compared to having a parent without ADHD (Biederman et al., 2002). As noted by the authors, this result may be reflective of a ceiling effect; parental ADHD has little further effect on children with ADHD who are already impaired.

Methodological critique

Design

The majority of the studies (n=15) used a cross-sectional design. Six longitudinal studies provided stronger, but not definitive evidence for causal relationships, where measures were taken over multiple time points and time was controlled for (Agha et al., 2017a; Breaux et al., 2017; Breaux et al., 2014; Herbert et al., 2013) or changes over time in parental and child symptoms were considered (Agha et al., 2017a; Brammer et al., 2016; Moroney et al., 2017). Unfortunately, only Moroney et al. (2017) measured the same outcome over more than two points in time.

Study design therefore is a major limitation and consequently the current literature cannot provide conclusions about the long-term nature of the relationship, nor the directionality, between parental ADHD and child outcomes. This is particularly important given the reciprocal influence between the child and parent, and the fact that child outcomes and ADHD vary with child development and time (NICE, 2008).

Sample

Justification of sample size (i.e. power calculations) was only reported in Farbiash et al. (2014), making it unclear whether statistics in all other studies were under-powered, particularly those with lower sample sizes (e.g. Berger et al., 2013; Minde et al., 2003; Romirowsky & Chronis-Tuscano, 2014; Zisser & Eyberg, 2012).

All studies used a majority of male participants. Gender was unreported in Segenreich et al. (2015). Despite the prevalence of ADHD being higher in males (Polanczyk et al., 2007), this makes generalising findings to the female population difficult.

Measures of Parental ADHD

A key critique to the current evidence is the over-reliance on non-diagnostic measures of parental ADHD (see appendix F for further measure details). Seventeen studies used questionnaires, which, although generally well-validated and feasible for large studies, are *not* considered a diagnostic alternative to a clinical interview (Belendiuk, Clarke, Chronis, & Raggi, 2007; NICE, 2008). Diagnostic interviews were used in 5 studies (Biederman et al., 2002; Minde et al., 2003; Romirowsky & Chronis-Tuscano, 2014; Zisser & Eyberg, 2012), although Segenreich et al. (2015) used an interview which has not been validated for adults. Therefore, one must be extremely cautious when drawing conclusions from questionnaire-based studies regarding parental ADHD in its true clinical form.

Some (n=14) overcame this by considering parental ADHD as a dimensional construct, which reflects current thinking; ADHD can be considered on a spectrum in the general population (NICE, 2008). However, this lack of cut-off may have meant that lower sample sizes were at risk of being under-powered and missing effects of clinically significant ADHD.

Measures of child outcomes

The exclusive use of parent-rated measures of child outcomes occurred in many studies (Agha et al., 2013, 2017a; Biederman et al., 2002; Breaux et al., 2014; Farbiash et al., 2014; Herbert et al., 2013; LeMoine et al., 2015), which may have caused reporting biases. For example, in Breaux et al. (2014) associations were only found if the parental ADHD and the parent-rater matched (e.g. maternal ADHD was only associated with maternal-rated child outcomes).

Studies which used objective measures such as teacher reports (Brammer et al., 2016; Efron et al., 2018; Griggs & Mikami, 2011; Minde et al., 2003; Moroney et al., 2017; Romirowsky & Chronis-Tuscano, 2014; Zisser & Eyberg, 2012), laboratory measures (Agha et al., 2017b; Herbert et al., 2013), and diagnostic interviews (Brammer et al., 2016; Humphreys et al., 2012; Minde et al., 2003) reduced the risk of reported bias. The use of multiple sources is important, given that diagnosis is based on symptoms being present across environments (e.g. home and school; NICE, 2008).

Studies measuring similar outcomes used different measures, making cross-study comparisons more difficult (see appendix F for measure details). For example, out of the eight studies measuring child CD and ODD symptoms, four different questionnaires were used, including the DBD, CBCL, DISC and CAPA.

Studies often used different broad-based questionnaires to measure specific and/or multiple child outcomes (Brammer et al., 2016; Breaux et al., 2017; Farbiash et al., 2014; Griggs & Mikami, 2011; Humphreys et al., 2012; Minde et al., 2003; Zisser & Eyberg, 2012). Whilst broad-band measures allow for a wider sampling of behaviours, this may result in reduced specificity. For example, the definition of 'externalising' problems incorporated outcomes such as CD, aggression and hyperactivity, making it difficult to control for child ADHD symptoms. Furthermore, pooling outcomes may increase the likelihood of finding a significant effect, and may explain why parental ADHD was more likely to be associated with externalising and internalising outcomes compared to specific measures (e.g. anxiety or depression).

The psychometrics properties of measures were not reported in almost half of the studies (n=8) (Agha et al., 2013, 2017a, 2017b; Berger et al., 2013; Biederman et al., 2002; Humphreys et al., 2012; Minde et al., 2003; Segenreich et al., 2015), leading to a

lack of clarity regarding the utility and validity of measures. Poor internal consistency was also reported for CD symptoms in Moroney et al. (2017) at each measurement, suggesting this was a poor measure of CD for the sample.

Measures of child ADHD

Those studies which recruited children with ADHD or behavioural problems (n=17) faced similar issues as described for child outcome and parental ADHD measures. For example, the use of different quality tools such as previous diagnosis and questionnaires makes cross-study comparisons difficult and puts studies at risk of rater-biases.

Analysis

Statistical analyses were appropriate for the majority of studies, although variations in methods made cross-study comparisons difficult.

Correlational analysis in Zisser and Eyberg (2012) did not allow for directional or multiple relationships between variables to be accounted and/or controlled for. Furthermore, the analysis and reporting in Minde et al. (2003) was insufficient; despite adjusting the statistical significance definition to 0.01, the increased risk of type one errors was not completely ruled out, particularly with a small sample. Furthermore, exact statistics were unreported, leaving the reader unclear as to the justification of reported findings and conclusions.

A serious concern of the study analyses was a lack of control for various potentially confounding factors, discussed below, making it extremely difficult to draw conclusions about the individual influence of parental ADHD on child outcomes.

Lack of control for confounding parental factors

Despite the well-established link, only a minority of studies (n=5) measured or controlled for parenting factors (Breaux et al., 2017; Herbert et al., 2013; LeMoine et al., 2015; Moroney et al., 2017; Romirowsky & Chronis-Tuscano, 2014). Other important factors associated with adult ADHD, such as parental conflict, socio-economic status, and the impact on spouses were not controlled for.

Given the high co-morbidity rates between adult ADHD and other psychological difficulties (Friedrichs et al., 2012), and the known impact of parental psychopathology on child outcomes (Thapar et al., 2015) it is also surprising that this was only accounted for in four studies (Biederman et al., 2002; Breaux et al., 2017; Herbert et al., 2013; LeMoine et al., 2015). Indeed, those which included parenting depression and ASPD (Herbert et al., 2013; LeMoine et al., 2015) found significant effects. Clearly there is variance which is unaccounted for.

In those studies which used both maternal and paternal ADHD (n=14), parental gender was not for controlled for in five studies (Agha et al., 2017b; Biederman et al., 2002; Humphreys et al., 2012; Minde et al., 2003; Moroney et al., 2017). This is clearly an important factor, given the gender differences in adult ADHD (Williamson & Johnston, 2015) and parenting roles (Lewis & Lamb, 2003). Indeed, the majority of studies which considered parenting gender (n=7) found differing parenting gender effects. Therefore, another major factor was not accounted for.

Uncontrolled parenting factors make it difficult, therefore, to confidently conclude that effects found across the child outcome domains were solely due to parental ADHD and were not reflective of other important parenting factors. This may explain the lack of consistency between study results.

Lack of control for confounding child factors

Child ADHD and behavioural symptoms were not clearly controlled for in 5 of the studies which used children with clinical symptoms (Agha et al., 2013; Breaux et al., 2014; LeMoine et al., 2015; Romirowsky & Chronis-Tuscano, 2014; Zisser & Eyberg, 2012). Therefore, conclusions cannot be confidently drawn as to whether results reflect the impact of parental ADHD on the child, or are merely a result of co-morbidities associated with child ADHD (Larson et al., 2011). Thus, generalising findings to children who do not have clinical symptoms is difficult.

Often, child gender was not accounted for (Breaux et al., 2017; Breaux et al., 2014; Humphreys et al., 2012; LeMoine et al., 2015; Zisser & Eyberg, 2012) despite gender effects being commonly acknowledged in chid psychological outcomes (Thapar et al., 2015) and in the association between parental ADHD and parenting behaviours (Park et al., 2017). This may have explained some variance within the studies.

Variation in participant ages across studies, from age 4 (Farbiash et al., 2014) to 17 (Thissen, Rommelse, Hoekstra, et al., 2014), made cross-study comparisons and understanding age-specific effects difficult. In fact, only four studies controlled for child age within their analysis (Brammer et al., 2016; Efron et al., 2018; Moroney et al., 2017; Thissen, Rommelse, Hoekstra, et al., 2014).

Discussion

Overview of findings

The evidence-base considering the relationship between parental ADHD and child psychological outcomes beyond ADHD demonstrated mixed results. This is reflective of specific effects according to the child outcome, numerous methodological issues, and between-study heterogeneity. Major methodological concerns included a lack of control for confounding factors, such as parenting, gender, and a reliance on questionnaires.

Generally, an association was found between parental ADHD and increased child externalising problems, including CD and aggression, even when controlling for child ADHD symptoms. The findings of longitudinal studies allow for more definitive conclusions to be made about the directionality of this relationship i.e. parental ADHD leads to increased child externalising difficulties. Results were inconclusive regarding whether changes in parental ADHD impacted on child externalising outcomes.

Interestingly, an association was not found between parental ADHD and child ODD problems. This is surprising considering the overlap between CD and ODD (Dick, Viken, Kaprio, Pulkkinen, & Rose, 2005) and supports those who argue for a significant distinction between child externalising disorders (e.g. Biederman et al., 1996). These results suggest that parental ADHD may impact upon child externalising outcomes differentially.

An association was found between parental ADHD and internalising difficulties, when using broad-based measures. This association was not found for measures of specific disorders such as anxiety and depression. This may reflect the sparsity of good quality evidence or that parental ADHD may be associated with an

increased risk of broader internalising disorders where the child does not meet diagnosis threshold. On the other hand, the fact that maternal inattention was associated with child anxiety may reflect specific parental effects according to ADHD subtype and gender, which may have been missed in other studies considered in this review. As noted by Johnston, Mash, Miller, and Ninowski (2012), further research considering parental subtypes of ADHD is needed to create a clearer picture.

Studies considering the association between parental ADHD and child social outcomes were inconsistent. Social outcomes appeared to be impacted by parent gender, where maternal ADHD was more often associated with poorer social skills. This gender effect is also seen in parental depression literature, where maternal depression has a greater direct influence on child outcomes than paternal depression (Gutierrez-Galve, Stein, Hanington, Heron, & Ramchandani, 2015). However, the scarce number and cross-sectional nature of the studies makes these conclusions tentative.

Research considering cognitive outcomes was also mixed and often too heterogeneous to make direct comparison. Parental ADHD was generally not associated with changes in child IQ. However, this may reflect a lack of specificity in measures, rather than a lack of effect, as ADHD has consistently been associated with lower scores in working memory and processing speed (e.g. Theiling & Petermann, 2016).

Those studies which considered underlying mechanisms of the association between parental ADHD and child outcomes found parenting to be a consistent mediating factor. This supports previous ADHD literature and child outcome literature suggesting the importance of parenting (e.g. NICE, 2013; Park et al., 2017). However, firm conclusions could not be drawn regarding the *type* of parenting which had the most effect on child outcomes (e.g. negative parenting, laxness or over-reactivity).

Studies which considered parent gender found some moderating effects but were not replicated throughout, due to the dearth of literature. For example, maternal ADHD was associated with the increased likelihood of CD diagnosis and anxiety, and poorer social skills and executive functioning. Paternal ADHD on the other hand was associated with decreased IQ scores. This is in line with previous literature regarding gender differences in adult ADHD (Williamson & Johnston, 2015), parenting roles (Lewis & Lamb, 2003) and increased influence of maternal psychopathology (e.g. Gutierrez-Galve et al., 2015). This moderating effect may also interact with child gender where opposing parent-child gender effect was found with externalising outcomes, which may be reflective of parents with ADHD parenting their sons and daughters differently (Park et al., 2017).

Theoretical implications

As parental ADHD was found to be associated with child externalising symptoms and possibly with child internalising symptoms, current models (e.g. Johnston & Chronis-Tuscano, 2017) need to emphasise these child outcomes which are beyond child ADHD, as shown in figure 3. It is unlikely that the additional difficulties these children experience can be explained by co-morbidity alone. The association between parental ADHD and child social and cognitive outcomes on the other hand requires further high quality, longitudinal research before they can be built into parental ADHD models.

The current review highlights the key role of factors such as parenting styles and psychological co-morbidities which support current models of ADHD. Parental gender was also highlighted and has therefore been given greater emphases in figure 3, compared to previous models. Future research is clearly needed, to consider whether

these factors have differential effects according to the child outcome domain, *and* to look at the possible effect of parental ADHD subtype.

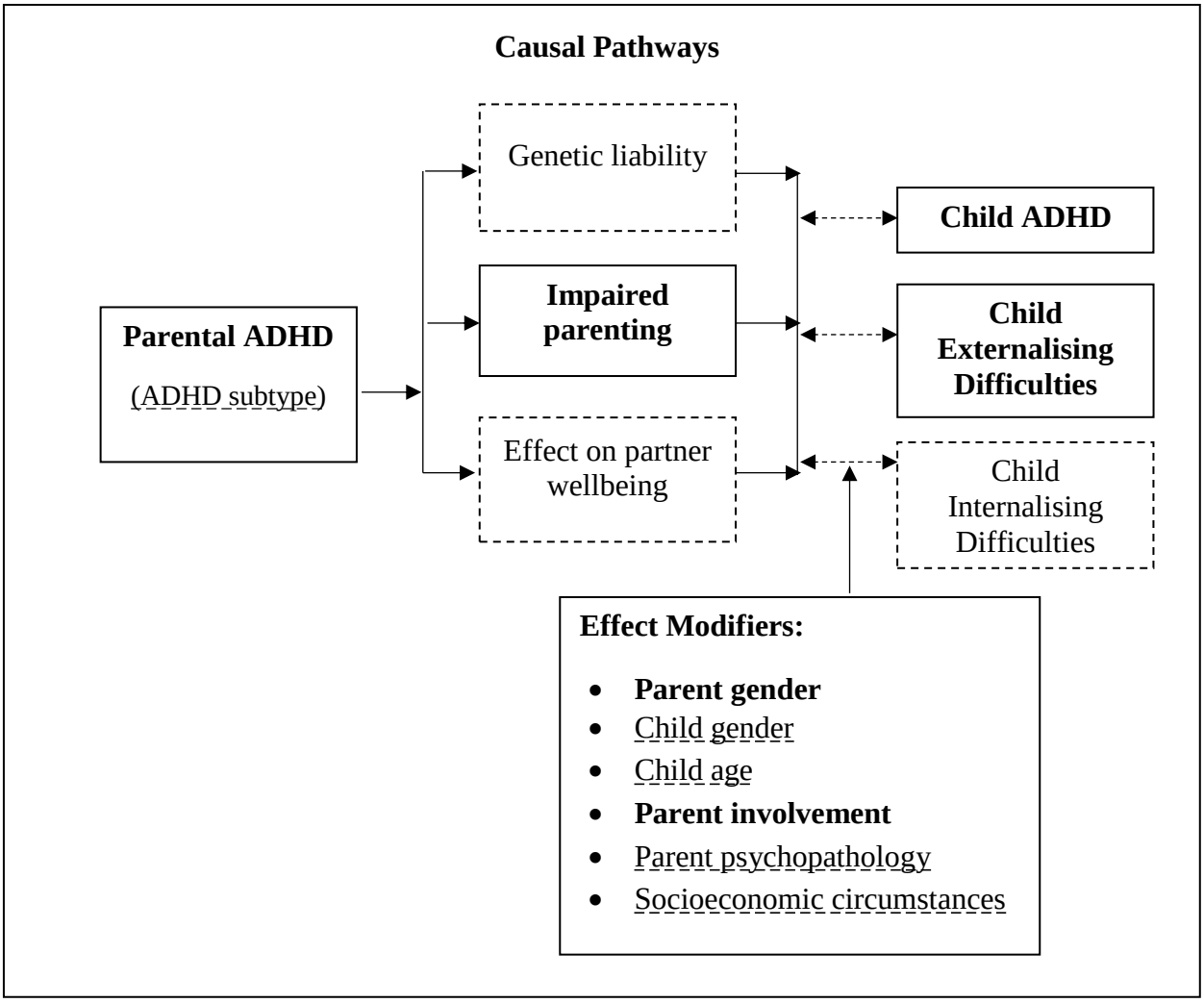


Figure 3. Suggested model of the underlying mechanisms between parental ADHD and child outcomes, based on the current review, Johnston and Chronis-Tuscano (2017) and Ramchandani and Psychogiou (2009), where bold text signifies firm conclusions and dotted lines signify areas for future research.

A key limitation to the literature, and therefore to the current understanding of parental ADHD, is the lack of consideration for developmental effects. As parental disorders can have differential effects on a child according to developmental stage (Ramchandani & Psychogiou, 2009), this needs to be considered in future research.

The dearth of longitudinal research means that causality and bi-directionality cannot be concluded and therefore cannot support this part of the parental ADHD model. Perhaps due to parental ADHD literature being in its infancy, study designs did not allow for

parsing of genetic and environmental effects of parental ADHD and child outcomes, as has been seen when considering child ADHD outcomes (e.g. Auerbach et al., 2017; Harold et al., 2013).

Clinical implications

Clearly further research into associated child outcomes and underlying mechanisms is key to the development of interventions and identification of at-risk parents and children. However, given the clearer associations between parental ADHD and poorer externalising symptoms, prevention and intervention for these families must be a priority.

Better recognition of unidentified or misdiagnosed adult ADHD is vital to be able to provide support if necessary, such as medication or psychological interventions (NICE, 2009), which may then impact on their family.

Future clinical guidelines, such as NICE, may benefit from including details regarding the possible issues and needs of parents with ADHD and their children. For example, parents with ADHD may require psychological interventions that address their own needs *and* those of their children. The latter may include parenting interventions, such as those for children with externalising difficulties (e.g. NICE, 2013), where parents with ADHD may require more support in implementation (e.g. Chronis-Tuscano et al., 2011; Chronis-Tuscano, Wang, Woods, Strickland, & Stein, 2017). Furthermore, given the multiple needs within these families, it is fundamental to provide an integrated service (i.e. CAMHS, adult mental health, social care and education) for the whole family.

Limitations of the review

The current review was limited by the exclusive consideration of 4 child outcomes. Although these covered key psychological outcomes, a broader overview of the literature, such as considering physical health outcomes, may have also been beneficial. This is particularly important as children's health outcomes have also been associated with parenting quality (The Scottish Government, 2012).

A main limitation of the literature reviewed was the over-reliance on questionnaires measuring parental ADHD. This meant that conclusions regarding clinically significant parental ADHD cannot be drawn. The current review may have benefitted from only including those papers which used diagnostic measures of parental ADHD.

The current review was at risk of not including those research papers which did not find a significant result, due to publication bias.

Conclusion

The literature investigating parental ADHD and child psychological outcomes beyond child ADHD found mixed results. More conclusive evidence found an association between parental ADHD and child externalising outcomes, but not for child ODD. Future models of parental ADHD must consider these outcomes. Studies investigating child internalising, social and cognitive outcomes showed inconsistencies which reflected the sparsity of evidence and methodological issues; high-quality, longitudinal future research is needed.

Underlying mechanisms such as parenting, parental mental health and parent gender were also highlighted across the literature and therefore also have implications for models of parental ADHD and treatment. Better recognition of parental ADHD and the

needs of their families is required within services and national guidelines, to be able to provide tailored assessments, interventions and services.

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PAPER B:

The Parenting Experiences of Adults with Autism Spectrum Disorder Who Have a Child with Autism Spectrum Disorder: An Interpretative Phenomenological Approach

Elise Marriott

A thesis submitted in partial fulfilment of the requirements of the degree of

Doctor of Clinical Psychology, validated by the University of Oxford

(Trinity Term)

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Abstract

Having a child with Autism Spectrum Disorder (ASD) has been associated with many difficulties such as increased parenting stress and parental mental health difficulties. Despite ASD being highly heritable, little is known about parents with ASD who have children with ASD. The current study therefore aimed to answer the question, "What are the parenting experiences of adults with ASD who have a child with ASD?" An Interpretative Phenomenological Analysis (IPA) methodology was used. Eight parents with a diagnosis or a high number of symptoms of ASD completed a semi-structured interview regarding their family, parenting and support. Four main themes were identified. The first considered the parent-child relationship, where parents' own ASD traits and needs often helped and hindered parenting. The second considered the positive and negative personal impact of being a parent. The third captured parents finding their home both an accepting yet a challenging place to live. The final theme captured participants' experiences of professional services and how they coped with the lack of support. Findings highlighted the importance of providing accessible, integrated and tailored services for families with ASD and calls for more research into parents with ASD who have children with ASD.

Keywords: Autism, parental autism, parent, child, offspring, Interpretative Phenomenological Analysis

Proposed journal: Autism (see appendix G for journal submission guidelines)

Introduction

Autism Spectrum Disorder

Autism Spectrum Disorder (ASD)[5] is a lifelong neurodevelopmental disorder characterised by two main features: difficulties with social communication and interaction, and restrictive and repetitive patterns of behaviours or interests, difficulties can vary dramatically between people. In order to be diagnosed with ASD, these features must be present from early childhood (American Psychiatric Association, 2013, APA).

In the UK, 1% of children and adults meet diagnostic criteria for ASD (Baron-Cohen et al., 2009; Brugha et al., 2011), although many adults remain undiagnosed (Brugha et al., 2011; Taylor & Marrable, 2011). ASD is more commonly diagnosed in males than females, with a 3:1 male to female ratio (Loomes, Hull, & Mandy, 2017) (see appendix H for further details).

The aetiological mechanisms of ASD remain unclear. Heritability rates (i.e. the proportion of variation in a population that is due to genetic variation) from twin studies are estimated to be between 64-91% (Tick, Bolton, Happé, Rutter, & Rijsdijk, 2016). However, the influence of environmental factors and the gene-environment interaction has also been emphasised (Chaste & Leboyer, 2012). Furthermore, several different psychological and cognitive theories of ASD have been proposed to explain underlying ASD symptoms, including the Theory of Mind and Weak Central

[5] The classification of autism has been through many changes (Johnny Matson & Kozlowski, 2011). ASD is now considered to represent a continuum of mild to severe impairments (APA, 2013), encompassing previous diagnostic labels of autistic disorder, Asperger's Syndrome and pervasive developmental disorder (APA, 2000; World Health Organization, 1992). This paper will therefore refer to these disorders as ASD in line with the most recent diagnostic criteria (APA, 2013).

Coherence theory yet none are thought to provide a satisfactory unitary account (Le Couteur & Szatmari, 2015) (see appendix I for further details).

Impairment and co-morbid difficulties

The autism spectrum is wide and therefore associated impairments (e.g. problems with social, functional, educational and occupational functioning) also vary widely depending on the severity of ASD symptoms and an individual's coping abilities (National Institute for Health & Clinical Excellence [NICE], 2012).

People with ASD experience high levels of co-morbid mental and physical health difficulties (Croen et al., 2015; Russell et al., 2016). Around 50% of individuals with ASD also have an intellectual disability[6] (Baird et al., 2006) and 94.3% of children with ASD demonstrate at least one challenging behaviour[7] (Matson, Wilkins, & Macken, 2008).

Neurotypical parents' experiences of parenting children with ASD

The literature suggests that having a child with ASD can have a profound impact on the parent and family. For example, high levels of parenting stress and parental mental health difficulties have been consistently found in parents with a child with ASD (Hartley, Seltzer, Head, & Abbeduto, 2012; Hayes & Watson, 2013). Parenting stress has been linked with the severity of child behavioural problems (Greenberg, Seltzer, Hong, & Orsmond, 2006).

[6] An intellectual disability can be defined as a significant impairment in intellectual and adaptive functioning, which arises before childhood (British Psychological Society, 2015).
[7] Challenging behaviour has been defined as behaviour "of such an intensity, frequency or duration as to threaten the quality of life and/or the physical safety of the individual or others and is likely to lead to responses that are restrictive, aversive or result in exclusion." (Royal College of Psychiatrists, British Psychological Society, & Royal College of Speech and Language Therapists, 2016, p.8).

In contrast, increased self-efficacy and appropriate support can moderate the impact of child ASD on parenting stress (Benson & Karlof, 2009; Hastings & Brown, 2002). Furthermore, some parents report that besides stress, parenting a child with ASD results in enrichment, growth and joy (Phelps, McCammon, Wuensch, & Golden, 2009; Safe, Joosten, & Molineux, 2012).

Having a child with ASD has both positive and negative impacts on the parent-child relationship (Griffith, Totsika, Nash, Jones, & Hastings, 2012; Hoffman, Sweeney, Hodge, Lopez-Wagner, & Looney, 2009) and on wider family dynamics. For example, higher levels of marital dissatisfaction and an almost two-fold increase in divorce rates (Gau et al., 2012; Hartley et al., 2010) have been reported. On the other hand, other parents reported growing closer as a result (DePape & Lindsay, 2015). The child's inflexibility to change, and obsessive and repetitive behaviours can also be difficult to manage and require families to be extremely organised (Ludlow, Skelly, & Rohleder, 2012; Safe et al., 2012). Associated sibling outcomes have been mixed, with some reporting loneliness, behavioural difficulties and stress (Hastings, 2003, Benson & Karlok, 2003), and others reporting no additional difficulties (Hastings, 2007). Family finances and parental work can also be impacted, where parents report resigning from work to cope with caregiving demands (DePape & Lindsay, 2015).

Parents are also faced with negative social judgement, particularly in regards to their child's challenging behaviour (DePape & Lindsay, 2015), and with social isolation (Griffith, Totsika, Nash, Jones, et al., 2012; Ludlow et al., 2012). Furthermore, these parents must 'navigate the system' of professional services, where a lack of understanding of ASD from others and difficulty accessing services is common. As a result, parents have to become self-sufficient in educating and implementing strategies themselves (DePape & Lindsay, 2015)

Adults with ASD parenting a child with ASD

Existing literature on parental ASD

Given the strong genetic heritability of ASD, there is an increased likelihood of a parent with ASD also having a child with ASD. Research has shown that around 5-80% of parents of children with ASD show sub-clinical threshold traits of ASD, termed the "broader autism phenotype" (Rubenstein & Chawla, 2018). Around 7-18% of parents of children with ASD, obtain scores indicative of an ASD diagnosis on screening measures (Lau, Peterson, Attwood, Garnett, & Kelly, 2016). NICE guidelines also acknowledge the need to provide services for adults with ASD who are caregivers (NICE, 2012).

However, little is known about adults with ASD who are parents. The very limited extant literature suggests that fathers (but not mothers) with a number of ASD symptoms experience increased parenting stress, negative parenting and lower parent efficacy scores (Lau et al., 2016; van Steijn, Oerlemans, van Aken, Buitelaar, & Rommelse, 2013, 2014). Maternal ASD symptoms have also been linked to lower mother-child interactions with their child with ASD (Parr, Gray, Wigham, McConachie, & Couteur, 2015) and less successful parent-mediated psychosocial interventions (de Veld et al., 2017; Parr et al., 2015).

Studies considering the systemic impact of parental ASD with a child with ASD found ASD symptoms in both mothers and fathers had a negative impact on family relationships (i.e. cohesion, expressiveness and conflict; van Steijn, Oerlemans, van Aken, Buitelaar, & Rommelse, 2015). Others found parental ASD did not increase marital or parental dissatisfaction compared to neurotypical parents (Lau & Peterson, 2011).

Possible experiences of parenting with ASD

The existing literature on families with ASD is clearly limited. Given the difficulties experienced by neurotypical parents with children with ASD (DePape & Lindsay, 2015) and the association between parental disorders and parenting difficulties (e.g. Park, Hudec, & Johnston, 2017; Stein et al., 2014), families with ASD may experience further difficulties. For example, difficulties with understanding others' feelings and intentions (Baron-Cohen, 1997; Mazza et al., 2014) may also impact on the ability of a parent with ASD to respond appropriately and sensitively to their child's and family's needs. Difficulties may be exacerbated when parent-child traits are 'mis-matched', as has been found in parental ADHD literature (e.g. Grimbos & Wiener, 2016). Furthermore, adults with ASD are more vulnerable to developing co-morbid mental health problems (Russell, Rodgers, Ukoumunne, & Ford, 2014), the presence of which may also further exacerbate parenting difficulties.

On the other hand, parental ASD may also be advantageous; these parents may have a greater understanding of their child's needs and subsequent ability to support their child. This 'similarity-fit' hypothesis has been suggested in some parental ADHD research (e.g. Johnston, Williamson, Noyes, Stewart, & Weiss, 2016; Psychogiou, Daley, Thompson, & Sonuga-Barke, 2008). Parents with ASD may also be less affected by negative social judgements as reported by neurotypical parents (DePape & Lindsay, 2015) due to their reduced ability to pick up social cues (Baron-Cohen, 1997).

Current study aims

Given the high prevalence of ASD symptoms in parents of children with ASD, the challenges neurotypical parents experience in raising a child with ASD, and the dearth of existing literature regarding families with ASD, there is clearly a need for further research.

The current study therefore aims to answer the question, "What are the parenting experiences of adults with ASD who have a child with ASD?" The current study will use qualitative Interpretative Phenomenological Analysis (IPA) (Smith, Flowers, & Larkin, 2009) to capture the complex and unique experiences of these parents. IPA is particularly well-suited for the exploration of the experiences of individuals with ASD (e.g. Griffith, Totsika, Nash, & Hastings, 2012; Huws & Jones, 2015). It is hoped that findings will inform future research and clinical practice.

Method

Design

An IPA methodology was used to analyse data from semi-structured interviews (Smith et al., 2009; see appendix J for further details and rationale of IPA).

Recruitment

Purposive, homogenous sampling was used, in line with IPA (Smith et al., 2009). Participants were recruited from an NHS Child and Adolescent Mental Health Service (CAMHS) and local ASD charitable organisations. Participants were required to meet the criteria outlined in table 2.

Table 2.

Participant inclusion and exclusion criteria

Inclusion criteria	Exclusion criteria
i. Being over 18	i. Lacking in verbal or cognitive ability to take part in the interview, as identified by self-selection.
ii. Having a diagnosis of ASD, autism, Asperger's syndrome according to the ICD-10, DSM-IV or DSM-V, or symptoms of ASD indicative of a clinical diagnosis, as measured by a score of 32 or above on the AQ (Baron-Cohen, Wheelwright, Skinner, Martin, & Clubley, 2001).	ii. English not being the first language
iii. Having a child/children (aged up to 18 years) with a diagnosis of Autism, Asperger's Syndrome, Pervasive Developmental disorder or ASD, according to the ICD-10, DSM-IV or DSM-V.	

Note. AQ=Autism Quotient; ASD = Autism Spectrum Disorder; DSM-IV= Diagnostic and Statistical Manual of Mental Disorders, Fourth Edition; DSM-V= Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition; ICD-10= International Statistical Classification of Diseases and Related Health Problems, 10th Revision

Procedure

All potential participants meeting inclusion criteria were approached by familiar staff-members and provided with a study information sheet (see appendix K), the AQ screening questionnaire (see appendix L), and a consent form to be contacted by the researcher (see appendix M). After obtaining consent, eligibility was verified. Reasons for a lack of eligibility were discussed if necessary and individuals were signposted to appropriate services if indicated.

Interview adaptations were discussed with eligible participants to ensure participants' comfort. Seven interviews took place at the participant's home, and one took place in a local CAMHS building.

Verbal and written consent was obtained prior to each interview (see appendix N for consent form). Confidentiality was explained and participants were given a right to withdraw at any point up to two weeks post-interview.

At interview, participants completed a demographics questionnaire (see appendix O). Interviews were guided by a semi-structured interview schedule with questions relating to the participant's family, being a parent and support (see appendix P). Interviews were audio recorded and lasted approximately 60 minutes. Participants were reimbursed £15 for their participation.

Following the interview, participants were de-briefed and signposted to appropriate organisations for additional support, if necessary. All participants were offered and subsequently requested an accessible summary of results.

Measures

Autism Spectrum Quotient (AQ; Baron-Cohen et al., 2001)

The AQ (see appendix L) is a 50-item self-report questionnaire, used to measure parental symptoms of ASD indicative of a diagnosis. This ensured the inclusion of parents who may never seek a diagnosis yet would meet criteria. The AQ screens for ASD symptoms such as difficulties in social skills, attention to detail and communication, and has demonstrated good test-retest reliability and internal consistency (Baron-Cohen et al., 2001). A cut-off score of 32 was used to signify symptoms indicative of a diagnosis (Baron-Cohen et al., 2001) which has shown high sensitivity and specificity levels in clinical and non-clinical populations (Ruzich et al., 2015; Woodbury-Smith, Robinson, Wheelwright, & Baron-Cohen, 2005).

Interview schedule

A semi-structured interview schedule (see appendix P) was developed in consultation with a parent with ASD and clinicians working in the field and according to IPA principles (Smith et al., 2009); questions were open-ended and used flexibly, with prompts if necessary, to facilitate the participant's ability to share their experiences.

The schedule was piloted once to ensure question comprehension and that it resulted in adequate, in-depth participant accounts. No significant changes were subsequently made to the schedule and the interview was included in the final analysis.

Data analysis

Interviews were analysed using IPA (Larkin & Thompson, 2012; Smith et al., 2009) (see table 3). Raw data from audio recordings were transcribed and anonymised by the researcher.

Table 3. Stages of IPA analysis

Stage	Overview
1. Analysis of individual transcripts	1a. *Immersion in the data* - transcripts re-read multiple times, initial notes made regarding the interview, the participant, and preconceptions. 1b. *Line-by-line analysis* - structured notes made on striking parts of transcript, such as content, tone and linguistics. Researcher's interpretations noted (see appendix Q). 1c. *Case level-summary* - interpretations clustered into emerging themes and summarised in a table for case-level summary (see appendix R for excerpt).
2. Cross-transcript analysis*	2a. *Creating subordinate themes* - individual participants' emerging themes clustered and compared to produce subordinate themes. 2b. *Creating superordinate themes* - subordinate themes organised into higher-level superordinate themes. *To ensure that participant voices were not lost and as part of the iterative process of IPA (Larkin & Thompson, 2012; Smith et al., 2009), transcripts and audio-recordings were frequently re-visited.

Note. IPA = Interpretative Phenomenological Analysis

Quality measures

Reflexivity

Several processes were undertaken to develop the researcher's reflexivity regarding her own sense-making, beliefs and interpretations of the data. Reflection of such assumptions helped to maintain grounding in the participants' experiences (Larkin & Thompson, 2012; Smith et al., 2009). This was done through an ongoing reflective journal (see appendix S for excerpts), 'bracketing' interviews with peer IPA researchers (see appendix T for excerpts) and discussions with supervisors.

Credibility checks

To ensure quality was maintained, Yardley's quality criteria (Smith et al., 2009; Yardley, 2000, 2017) (as outlined in appendix U) were used.

Credibility checks included an audit trail and parallel analysis with researcher supervisors on multiple transcripts. Coding and analysis was also checked and discussed with an IPA peer research group and an independent IPA expert, and superordinate and subordinate themes was discussed with research supervisors.

Ethical approval

The study proposal was approved by the Oxford Institute of Clinical Psychology Training (See appendix V). The study was sponsored by University of Oxford (see appendix W). Full NHS ethical approval was granted from the NHS South Central Oxford Research Ethics Committee (See appendix X) and the Health Research Authority. Details of ethical considerations can be found in appendix Y.

Results

Contextualising the sample

Eight participants were recruited via third sector ASD organisations (n=6) and CAMHS (n=2), in the same geographical area. Participant characteristics can be seen in table 4. All participants were of white British or white Irish ethnicity. Six participants were either married or co-habiting and two participants were divorced. Seven participants had more than one child. Of their children with ASD (n=9), three also had a diagnosis of ADHD and two had a diagnosis of a learning disability.

Overview of themes

Four superordinate themes were drawn from the analysis. The structure of superordinate and subordinate themes, and their endorsement by each participant can be found in table 5. Further illustrative quotes can be found in appendix Z.

1. The parent-child relationship: 'Intune-ness' vs a 'clash'

This superordinate theme relates to the participants' relationship with their child with ASD, encapsulating both a sensitivity to the child's needs and a 'clash' of parent-child needs, and how parents overcame this clash to provide their child with the parenting they need.

1a. Being 'in tune' with their child with ASD

All participants described a level of knowledge of their child and their child's needs, which was often described as a natural "*instinct*" (Tanya, 166) or "*intune-ness*" (Sarah, 123), suggesting a sense of effortlessness. However, for some this understanding of their child seemed more effortful. Kylie described her son as: "*very violent. But*

apparently it's all to do with his autism." (22), conveying a sense of disbelief and detachment from this understanding of her son's behaviour.

Table 4.
Participants demographic information

Participant						Child with ASD		
Name [a]	**Gender**	**Age range**	**AQ score** [b]	**ASD Diagnosis**	**Co-morbid diagnoses** [c]	**Name** [a]	**Gender**	**Age range**
Kate	Female	21-30	39	No	Yes	Zoe	Female	6-10
Emily	Female	21-30	45	Yes	Yes	Edward	Male	6-10
Sarah	Female	41-50	38	No	No	Jay	Male	6-10
Tanya	Female	41-50	39	No	No	Alfie	Male	6-10
Hilary*	Female	41-50	46	Yes	Yes	Lizzie, Rachel	Female Female	11-15 6-10
Kylie*	Female	31-40	32	No	Yes	Dylan	Male	11-15
Neil	Male	41-50	37	Yes	No	Charlie	Male	6-10
Rosie	Female	41-50	34	No	Yes	Kip	Male	11-15

Note: ADHD = Attention-Deficit/Hyperactivity Disorder; ASC = Autism Spectrum Condition; ASD = Autism Spectrum Disorder; HFA = High Functioning Autism.
* Partner present at interview
[a] Names have been anonymised and a pseudonym used
[b] All participants met cut-off criteria of 32
[c] Details regarding comorbid diagnoses (including ADHD and mental health disorders) have been removed to ensure confidentiality.

Some parents described knowing their child better than their partners. Tanya described her son as: *"very rigid and I just got it. Like Richard will be like, 'But why?' And I'm like, 'Well I understand.'"* (504). This was something Kate appeared to value: "*It's quite nice that I can understand her…that I can translate"* (302), and suggested not only an exclusive connection with her daughter but also a sense of purpose.

All participants related to their own experiences and traits of ASD to gain this understanding of their child, for example:

> *"So, from my own experience of having been a child, and thought that way, and I'm looking at Charlie thinking the same way too. That kind of enabled me to connect a little bit because I kind of understood, firstly not to touch his stuff, but also to ask the sorts of questions. Because I knew what was going on in his head. A little bit about how he was dealing with all these patterns and stuff."* (Neil, 258-262).

This highlights several important advantages for Neil; he was able to connect with his son, and understand his son's cognition and how best to react.

For some, having similar traits and experiences with their child seemed to merge their sense of identities, as described by Sarah regarding the need for routine: "*I don't know if it's him that drives it, or me that drives it, or both together…"* (Sarah, 62).

1b. A 'clash' between parent and child

The majority of parents described moments when they would not be in tune with their child's needs, often resulting in challenging behaviour. For example, Kate described her daughter having a meltdown: "*it's horrible. Because it's out of your control*" (557). This lack of control often seemed to impact parental self-efficacy, as explained by Tanya when

Table 5.
Superordinate and subordinate themes and endorsement by participants

Superordinate and subordinate themes	Total	Kate	Emily	Sarah	Tanya	Hilary	Kylie	Neil	Rosie
1. The parent-child relationship: 'intune-ness' vs a 'clash'									
1a. Being 'in tune' with their child with ASD	8	*	*	*	*	*	*	*	*
1b. A 'clash' between parent and child	7		*	*	*	*	*	*	*
1c. After the 'clash': Being an accommodating parent	8	*	*	*	*	*	*	*	*
2. Changing as a person: The personal impact of being a parent									
2a. Parenting changes you for the better	6		*	*	*	*		*	*
2b. Parenting enables self-reflection	7	*	*		*	*	*	*	*
2c. Negative impact of being a parent	7	*	*		*	*	*	*	*
3. Home is a place of acceptance and distress									
3a. The outside world is threatening	6	*	*	*	*			*	*
3b. 'This is our normal': Family are accepting	7	*	*	*	*	*		*	*
3c. Being 'trapped' in a 'war zone' with a child with ASD	8	*	*	*	*	*	*	*	*
4. Managing the complexities of professional services									
4a. Crying out for help and being rejected: "Why is there nothing out there?"	7	*	*		*	*	*	*	*
4b. Value of being validated and understood by professional services	6	*	*		*	*	*		*
4c. 'Winging it' and 'fighting': Coping with a lack of support	8	*	*	*	*	*	*	*	*

Note. * = endorsed by participant

describing her son's challenging behaviour: "*I do question myself, and I question if I could do it.*" (557).

Parents described a "*clash*" (Sarah, 169; Emily, 77) with their children, particularly when the parent and child had differing needs and were "*pulling in opposite directions."* (Hilary, 84). For example, Emily described an intolerance to her children's touch and feelings of guilt surrounding this:

> *"…if we're a bit close to each other, that's difficult. We do our best…. but I think that's where we probably struggle the most, because I struggle probably most with sensory difficulties. And so that's our main kind of clash. I think other things I can kind of let go. Or let them do their own thing, and I'll do my own thing. Umm…but when you've got somebody on you that you really don't want on you. And it's awful because they're your children…"* (457-462)

This concern was also reflected in Sarah's account: *"…sometimes I have to sort of step back and think, am I missing the fluffy stuff?"* (204). She seemed to reproach herself for neglecting her children's needs while at the same time her contemptuous use of the word "*fluffy*" seemed to excuse herself from this.

1c. After the 'clash': Being an accommodating parent

All participants described differing ways they overcome the 'clash' with their child.

Some parents described the necessity of having to prioritise their child's needs and put their own needs "*…to one side, which, you know, is a daily occurrence in that respect."* (Tanya, 247). This difficulty was illustrated by Emily:

> *"It's really difficult. Because as the parent, you have to put their needs first…And both of them in their own ways are pushing me. She's such a crier and that*

> *really…I find that really difficult to process. And then if Edward's shouting and all I'm really trying to do is…kind of calm myself…There's sort of 3 people who really want their needs met. And they want me to solve it. And they look to you, and actually all you want to do is sit in the corner going "No! [laughs] I can't. I can't do it!"* (145-149).

The majority of parents described being in a dilemma between accommodating their child's needs and their value of being a boundaried parent. For example: "*I don't want to give in to him all the time but it's the easiest way until…we've got a proper full understanding of everything.*" (Kylie, 129), suggesting feelings of not having the adequate resources to challenge her son.

Other parents described having to compromise and create "*rules*" (Sarah, 166) with their children. Rosie described:

> ***"****When you've got a toddler who is autistic and everything is a massive situation, you have to choose your battles, because if you are fighting them on everything, it's really exhausting. So, there are some occasions when like we have to go down in the lift, we have to get off the escalator. We have to. But there are other things where you're like actually, no, this is not, yeah, go ahead, do your thing…"* (384-7)

Some parents described times when they were unable to accommodate their child's need, as illustrated by Kylie's reaction to her son's challenging behaviour: "*I end up shouting at him…which makes it worse…which then makes me worse*" (39), suggesting an escalating cycle of difficulties.

2. Changing as a person: The personal impact of being a parent

All participants discussed the personal impact of being a parent. Some described parenting as changing them for the better and enabling self-discovery. All parents discussed the negative personal impact, such as the exacerbation of mental health difficulties.

2a. Parenting changes you for the better

Six participants described the process of becoming a parent to have changed them for the better. For example: Neil described parenting as "*a blessing. It's the most amazing thing*." (158). Hilary illustrated: "*I am very glad I became a parent. Because it has changed me as a person. Most of it for the better…*" (232)

Some described becoming a parent was a process of development such as being "*more laissez-faire with things*" (Hilary, 204), learning "*patience*" (Neil, 85) and becoming "*a more tolerant and accepting person*" (Tanya, 569). Sarah described having to learn to "*chit chat"* (Sarah, 324) which suggests informal social interactions were not a natural concept to her.

2b. Parenting enables self-reflection

For six participants, having a child with ASD led to the discovery of their own ASD traits. For the majority this was described as a positive experience. Tanya described a sense of empowerment and surprise:

> *"What struck me the most was the lady in [local ASD charity] who was diagnosed in her 60s and the way she was talking…I just got chills. It was just like she was talking about my life. It was just the most amazing…we were there to learn about Alfie… how to be good parents but it ended up being about all about me." (523-526)*

For others, this realisation was accompanied by feelings of anger and injustice for their own childhood. For example, Neil described:

> *"I have to say at the beginning I was incredibly angry. I had all of these issues of not being able to cope at school and not having any friends. Of really being very socially isolated from everybody, of being blamed by your teachers and parents. Frankly for being stupid […] So, I would say at some point, it led to a tremendous self-realisation and truth historically." (430-435)*

Note here that Neil's self-realisation appeared to be a temporal process and enabled him to better manage his difficulties and the impact these had on his family, as he later described:

> *"One of the reasons I wanted to get the ASD diagnosis, is because you can have a lot of temper or a response to things that is disproportionate to the activity, which of course is distressing to everyone else […] So you have to work on…work on that."* (188-193).

Kylie, on the other hand, described "*because of the way I am, with my anger and flying off the handle, I don't know how I'm supposed to stop that. Maybe I need therapy myself. But then I don't believe in that."* (347-348). Here she seemed resistant to self-reflection and the responsibility to manage her difficulties, which may in turn impact on her family.

2*c. Negative impact of being a parent*

All participants discussed the negative psychological impact that being a parent had on them.

Many discussed the relentlessness of parenting and the negative impact this had, as illustrated by Kate: "*You just don't get 5 minutes to stop. And it gets you down. And you*

think why me? I just want a break." (252) and Emily: "*so I spend a lot of time at such a heightened level as well. Because I'm like…just gotta keep going*." (151-152).

For some, parenting had such a negative impact that they felt like they were "*suffocating*" (Rosie, 511). Kylie described: "*Sometimes I don't want to be a parent…Sometimes I wish I could get out and go away, just not bother with anything.*" (59). This suggests overwhelming feelings of wanting to escape, yet she was trapped by the responsibility of parenthood.

Four parents described parenting impacting on their mental health. For example, Rosie described "*a bit of PTSD going on*." (187) when reliving her negative experiences when her son met the same obstacle. Parents described pre-existing issues being exacerbated with parenthood and making it difficult to cope. For example, Hilary described parenting to be *"not so great for my mental health. But that's a lot to do with what was already there in me"* (233) and Kylie: "*I've had depression for years. I just can't bring myself to be happy about anything, you know. So that's hard, on top of looking after kids and Dylan being challenging*." (244).

3. Home is a place of acceptance and distress

This theme represents parents experiencing their home and family as a place of belonging, and acceptance, away from the outside world which is judgemental. However, home was also a very distressing place for the whole family.

3a. The outside world is threatening

Many participants endorsed this subordinate theme which speaks of the perceived threat of the outside world and their struggle of being "*unconventional*" (Rosie, 45).

Participants discussed their own difficulties with the "*pressure to be, like, a certain kind of mother*" (Rosie, 29) and to "*run with the pack*" (Sarah, 136). Sarah described having "*almost like two worlds. If that makes sense. There are things that…that are just parts of me that I don't…share widely*" (27-29), suggesting that Sarah did not feel able to act naturally outside of her home.

Participants also spoke of concerns about societal judgment of their child's challenging behaviours. Kate described: "*all the parents are looking at you like 'Oh my God, she's like…Year 1 and she's doing that!'*" (168) and concern that people "*blame you as a parent*" (33) for her daughter's behaviour. Some participants described isolating themselves from peers to protect their children from judgement: "*I don't talk about how hard things are. Because I don't want them to judge my son."* (Tanya, 370).

On the other hand, both Sarah and Rosie spoke about being "*liberated*" (Sarah, 186) from social norms. Sarah described thinking *"that some of the stuff that we do is…as parents, is for show. For an outside audience, which I'm not interested in"* (218). Rosie also described: *"I'm ok, as I get older, being an unconventional mother. But I'm not ok with the judgement that comes from that"* (374). This suggests that some parents may be in a dilemma between being "*liberated*" from social norms yet still being sensitive to the judgement of others.

3b. 'This is our normal': Family are accepting

Six participants spoke about their family and home as being a place of acceptance of each other, away from a judgemental society: "*this is our normal*." (Hilary,114)

This was also illustrated by Sarah:

> *"It's a very accepting family and there are some really interesting people within it…with some…[smiles] interesting ways of being. [Pause] And I think it's the acceptance because within these 4 walls we are just who we are. Flaws and all. And…I think it's about being appreciated for who you are as a person."* (251-254).

This also conveys a sense that there are "*flaws*" to be accepted, which people outside the family do not accept. This was also conveyed by Emily: "*I don't know how somebody would live with us [laughter]. And that's quite nice, knowing that what we've got is ours. And…we're all weird together*." (line 517). This was particularly powerful as Emily's husband had recently left the family, and perhaps demonstrated that other people couldn't, in fact, cope with living with them.

3c. Being 'trapped' in a 'war zone' with a child with ASD

Despite being a place of acceptance, participants also described the home as being "*chaotic and challenging*" (Hilary, 109) and a tense place to live, where the family were "*on eggshells"* (Kylie, 95). Parents used powerful imagery associated with war, depicting how difficult living with a child with ASD could be. For example, Tanya described her house "*like Beirut*" (419) and "a *bit of a war zone*" (24). Sarah described living with her son with ASD "*like living with a dictator*" (39). Some participants also described feeling "*trapped*" (Emily, 155) and "*like I was being held hostage by my own hom*e" (Tanya, 300), suggesting a sense of physical and emotional entrapment.

The challenges faced with living with a child with ASD dominated the family. Tanya explained: "*the autism seems to dominate most things that we do as a family*" (15) suggesting lack of control of the impact and hopelessness, and that she viewed autism as separate from her son. Kylie described a resentment of the family impact: "*I hate the fact*

that the family's split, if you like, because of Dylan….I haven't got a really good relationship with [older daughter]." (42)

Parents also described the impact the child with ASD had on their other children, such as not getting as much "*attention*" (Kate, 246) or having their needs "*overlooked*" (Neil, 71) which were often associated with feelings of sadness. Tanya described a powerful conversation with her daughter: "*So she has gone to sleep crying before and said, 'Mummy, why is our life so hard?' So that's really difficult*." (71)

4. Managing the complexities of professional services

All participants described the lack of resources for the family and how they tried to overcome this. They also discussed the importance of being validated and understood by professional services.

4a. Crying out for help and being rejected: "Why is there nothing out there?"

All participants apart from Sarah spoke of a relentless cycle of asking services for help and being rejected. Kate described the experience of asking CAMHS and social services for help:

> "*Help! And they're just like, "Well what do you want us to do?" I've spoken to social service. Again, there's just nothing. We're waiting for early help assessment, to try and get support outside of school. You just feel like, "Why is there nothing out there?*" (270-272).

Parents often described their child being rejected from mental health, educational and social services due to their criteria being too high. For example, parents described services instructing them to "*come to us when it's serious*" (Kate, 274), with a sense that services were invalidating their distress. In a conversation regarding her son being unable

to have a school placement, Rosie described a professional telling her "*we all want a Rolls Royce but we don't all get one."* (601-602).

In response to rejection from services, parents reported feeling alone, like they were "*marooned at sea much of the time*" (Tanya, 464) or "*floundering*" (Hilary, 335). Hilary described: "*in the evenings, when it's been a long day and there's no one you can call…because there's nothing. You just feel like…we have nothing."* (310). This ties in with parents again experiencing rejection from society.

4b. Value of being validated and understood by professional services

The majority of participants conveyed the importance of professionals listening to and understanding their child's needs. Parent's described experiences of professionals not hearing or validating the family's difficulties: "*There hasn't been anyone who's known exactly what to do. They're like, 'Gosh! It's really hard isn't it? Anyway, see you in 6 months at the next meeting*.'" (Emily, 386),

or the parent's difficulties:

> "*And there's nobody checking in, going […], 'Are you doing ok? Are you doing fabulously? How about, you come in and just you and me, we have a chat?' They just go, [claps] 'You're doing brilliantly. Very well done. Next! Next person! Rosie is doing brilliantly. Next!"* (Rosie, 559)

Clearly being praised for doing a good job was not useful, and instead Rosie wanted her own difficulties to be recognised.

A common experience was the feeling of being disbelieved by the school regarding their child's needs and behaviour: *"like the fire alarm just going off without warning just…destroys Lizzie for the whole day. And you know, you tried telling the school*

this…but, you know, 'they're fine' patting you on the head patronisingly." (Hilary, 363). This also speaks of a power-imbalance, where the parent is belittled by professionals.

On the other hand, some parents spoke about the value of being listened to and valued as a parent by services and schools. For example, Kylie described her son's school as being "*understanding*" (Kylie, 195) and flexible in regard to his needs. Rosie discussed the importance of the school's open communication with the parent: *"[School] was quite good. If I'm concerned about Kip's mental health or anything he's going through, I can call them... And I will discuss things with him and they will discuss things with me as well*." (491).

4c. 'Winging it' and 'fighting': Coping with a lack of support

When asked about any support they had received and their relationship with services, all participants discussed various ways of coping with a lack of support from professional services.

Most participants spoke of the need to "*fight*" (Emily, 204) services and be an "*ambassador*" (Rosie, 130) for their child so they get adequate support. This was often fuelled by parents being reminded of their own inadequate support as a child: *"…I don't want her to go through life as I have. I want her to be happy. I want her to have that support. I don't want her to go under the radar." (Kate, 448).*

Many participants relied on their partners to get by: "*if [husband] is around obviously that helps because we sort of do the 'divide and conquer.*'" (Hilary, 98) and "*[husband]'s a massive support to me. He is my support*." (Tanya, 431). Most also found that the "*support we do have is from friends and family*" (Neil, 362).

Most parents also showed self-agency in finding or creating their own support and resources to cope.

Parents spoke of having to find their own resources to fill the gap, which often felt like "*...I'm winging it. I've just figured out that's something that works."* (Emily, 398) and "*I'll try other things which I've tried at work which I know have worked with other children. You know like visual timetables and different things. So I've got a toolkit. But if you haven't..."* (Sarah, 403). Neil's wife "*set up ...her own social enterprise, geared up to supporting parents with autism."* (393). The self-agency displayed by Sarah and Neil appeared to be tied to already existing resources, such as Sarah's job as a special needs co-ordinator and Neil's academic background: "*We're health literate parents. I will probably know more about autism than a very large number of people*" (390), illustrating that those who don't have such resources may not be able to cope in such an effective way.

Discussion

The study aimed to explore the parenting experiences of parents with ASD who have a child with ASD. Four superordinate themes emerged from the data which included the experiences of the parent-child relationship, such as when the parent was in tune and out of tune with their child, the personal impact of being a parent, finding the family as both an accepting place *and* a source of distress, and the experiences of coping with the complexities of professional services. Each superordinate theme will be discussed in turn, as well as the limitations and implications of the current research.

The parent-child relationship: 'Intune-ness' vs a 'clash'

All parents demonstrated a level of sensitivity to their child's needs, often using their similar experiences and ASD traits to further understand their child and to adapt their parenting accordingly. This advantage is a novel finding, where these parents have an insight into ASD that a neurotypical parents may not have. Although the level of sensitivity varied amongst participants, it suggests that these parents show Theory of Mind (Baron-Cohen, 1997) with their children, facilitated by their similar experiences (Buckner & Carroll, 2007). However, it is difficult to know whether parents are showing both cognitive *and* affective empathy (Mazza et al., 2014). This is also in keeping with the "goodness of fit" theory where the child's environment (influenced by parental ASD) fits with the child's own characteristics (Chess & Thomas, 2013), as has been found in the parental ADHD literature (Johnston et al., 2016; Psychogiou et al., 2008).

This may also have implications for the parent-child attachment relationship, where the parent's caregiving behavioural system appears to be in conjunction with the child's attachment behavioural system (Bowlby, 1969/1982). However, the assessment

and implications of attachment are complex and should therefore be considered sensitively in future research.

Parents also described being out of tune with their child, particularly when their own symptoms (e.g. hypersensitivity to sensory stimuli) differed from those of their child's, adding to the pre-existing difficulties of raising a child with ASD (DePape & Lindsay, 2015). Furthermore, physical touch differences within some of these families may have implications for the parent's ability to support their child's emotional regulation through touch (e.g. Feldman, Singer, & Zagoory, 2010).

Parents' responses to overcome these differences were important; parents recognised the need to be flexible and prioritise their child's needs over their own. This may be difficult for some parents with ASD where inflexibility is a common trait (NICE, 2012). However, whilst some parents appeared able to overcome this, other parents were not, reflecting a 'similarity-misfit' described in parental ADHD literature (Grimbos & Wiener, 2016).

Changing as a person: The personal impact of being a parent

Some parents with ASD felt that becoming a parent was associated with personal enrichment and growth, mirroring neurotypical parents with a child with ASD (Phelps et al., 2009). Furthermore, parents described learning qualities and skills, and successfully managing situations they may have otherwise avoided.

All parents discovered their own ASD traits following their child's ASD diagnosis. This is commonly seen in child ASD services and may be reflective of the historical under-recognition of ASD traits (NICE, 2012). For some, self-reflection led to an understanding of the systemic impact of their own difficulties and a desire to manage this, which in turn may allow them to cope better with the needs of their child.

The negative psychological impact of parenting reported by all participants supports literature on parenting children with ASD (DePape & Lindsay, 2015). However, parents with ASD appear to be further impacted, having to also manage their own needs associated with ASD and common pre-existing mental health difficulties (Russell et al., 2014).

Home is a place of acceptance and distress

Participants reported experiencing social judgement, both of themselves and of their child. This supports adult ASD (NICE, 2012) and child ASD literature (DePape & Lindsay, 2015) and may also be a barrier for individuals to seek and receive help from professionals. More research is needed to further explore these experiences of social judgement and, although this was not explicitly stated, to explore possible links to these parents feeling stigmatised.

Given their experiences of social judgement, it is not surprising that parents sought comfort and acceptance within their own families. Social isolation has been commonly reported in adults with ASD (e.g. Punshon, Skirrow, & Murphy, 2009) and therefore the experience of acceptance may be rare for some of these parents. Similar experiences have been reported by adults with ASD who reported feeling like they 'fit in' with other individuals with ASD (MacLeod & Johnston, 2007; Punshon et al., 2009).

Despite this acceptance, parents appeared to be in a paradox, where home was also a very distressing and challenging place, due to the presence of their child with ASD and their challenging behaviour. Although challenging home life is also experienced by neurotypical parents (DePape & Lindsay, 2015), parents with ASD may not be able to seek refuge from anywhere else, given their experiences of society, and therefore may be

faced with relentless feelings of physical, emotional and social threat (Gilbert, 2000, 2010).

Although the wide-spread systemic effects of having a child with ASD have been reported by neurotypical parents, such as on siblings (DePape & Lindsay, 2015), family members of parents with ASD may be doubly impacted by having both a parent *and* a child with ASD, and their associated difficulties.

Managing the complexities of professional services

The lack of support for parents with ASD and their families was prominent and replicated neurotypical parent experiences (DePape & Lindsay, 2015). Participants discussed their desperation to find help yet were constantly rejected, often due to the high referral criteria for child services. Parents were left to manage alone, with little help for their child or their own difficulties, leading to feelings of isolation. This not only adds to previous experiences of societal rejection, as discussed earlier, but also shows that these families are suffering without professional support. Those families which did have input from professionals, valued being listened to and validated, rather than patronised or praised.

How parents dealt with the lack of support from services differed. Most relied on their partners, family and friends for support. Those who had existing resources, such as a relevant career or academic background, were best placed to find their own resources, and in an extreme case set up their own third sector organisation, leaving those without such resources left to rely on unresponsive statutory services.

Limitations

Participants were mainly recruited via third sector organisations supporting families with ASD. Although this means those recruited may not have needed input from healthcare services, the more challenged families may have been missed.

The sample was also biased by the fact that seven out of eight participants were women. This may reflect mothers taking on greater care-giving roles and does shed light on the experience of women with ASD; an area which is known to be under-researched. However, findings are not representative of fathers' experiences, as is common in mental health research (Stein et al., 2014) and may have missed gender-specific parenting experiences (e.g. Lau et al., 2016; van Steijn et al., 2013; van Steijn et al., 2014).

The sample was also biased towards the experience of the white British population, and also did not include any parents with intellectual disabilities, despite the high prevalence of intellectual disabilities and ASD (Baird et al., 2006). Generalisation of results is therefore limited beyond white-British, high-functioning parents.

The broad range of the children's ages, ranging from 6-15 years, decreases the homogeneity of the sample, as recommended in IPA (Smith et al., 2009); it could be expected that the experiences of parents with a 6-year-old may differ to those of a parent with an adolescent child. Although it was felt that participants' experiences did not vary dramatically according to child age, research is needed to explore this further, recruiting parents with ASD who have children with ASD of a narrow age range (e.g. adolescents only).

The use of a screening tool for the inclusion criteria also comes with ethical considerations (see appendix Y) and limitations; some parents did not have a diagnosis of

ASD and therefore may not be representative of adults with clinical ASD. However, the cut-off was chosen due to its high sensitivity and specificity rates.

Implications for theory and future research

The key themes found to summarise the experience of parents with ASD who have children with ASD fit within Bronfenbrenner's Ecological Theory (2006) (see figure 4) where both the parent and the child with ASD are at the centre of a system. The parent is impacted by each layer of their own system *and* that of their child; including the microsystem (e.g. the child, the family and household, the school, health services, peers), the exosystem (e.g. current national public service funding which is restricting access to services, and the macrosystem (e.g. societal views of ASD). This conceptualisation not only allows clinicians to understand the multi-layered experience of parents with ASD who have children with ASD, but it is within these multiple systems where future research and intervention must focus.

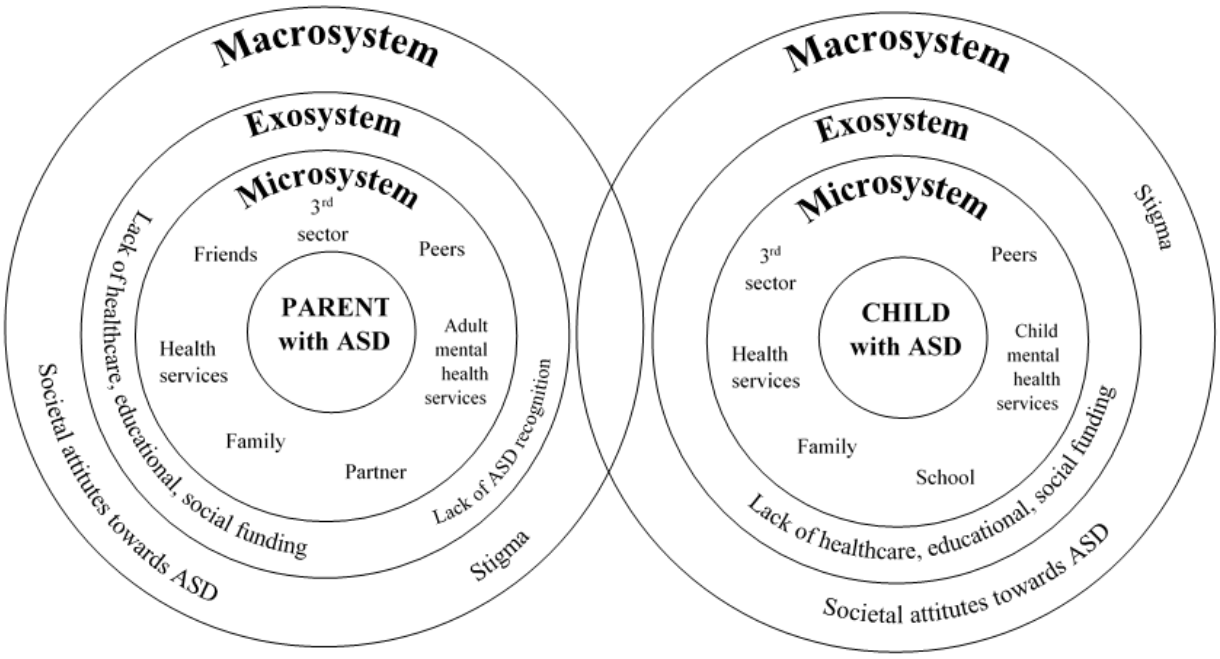


Figure 4. Parent and child systems impacting on parents with ASD who have a child with ASD. A simplified model based on Bronfenbrenner and Morris (2006)

Given the infancy of this topic, future research needs to firstly replicate current findings in an extended sample in the UK and worldwide, and include fathers and individuals with

intellectual disabilities, and those with formal ASD diagnoses. Secondly, quantitative research is needed to consider the multi-system approach. Examples may include, but are not limited to understanding associated parenting factors of parents with ASD as compared to parents without ASD, the mechanisms of the bi-directional parent-child relationship (as seen in parental ADHD; Johnston & Chronis-Tuscano, 2015), the impact on other family members such as siblings, the parent-school relationship, or the impact of targeted ASD interventions on the parent and family which take into account parental ASD as a moderating factor (e.g. de Veld et al., 2017; Parr et al., 2015).

Clinical implications

Multi-system clinical implications for parents with ASD who have children with ASD are fourfold.

Firstly, there is a need for increased recognition of ASD in parents. This would prevent these families from going into crisis, and therefore incurring specialist, high-cost services. The unique strengths and insights in parenting a child with ASD associated with parents with ASD could then be recognised.

Secondly, clinicians in current practice who are working with parents with ASD and their children are recommended to: assess for their associated strengths and challenges; validate and listen to their experiences; use tailored treatment, including systemic interventions with siblings and respite for parents; provide a low-level service for those who do not meet referral criteria.

Thirdly, in line with the ‘experts by experience’ movement, services can do more to not only include these parents and their unique insights in service development and delivery,

but also to encourage more parents to set up the support they require, should they have the self-agency and resources.

Fourthly, services are encouraged to consider the whole family clearly - it is not only the parent with ASD who needs a service, as is currently recommended (NICE, 2012). Families with ASD require a model of care around the whole family, where services (e.g. CAMHS, adult mental health, education, social care) collaborate to provide a connected service. Although this is challenging as there is no current overarching framework linking these services, this recommendation fits with recent government contracts aiming to improve service communication and links for families of children with special educational needs (Department for Education, 2018).

Preventative services are also required. Children with ASD and adults with ASD are costly to public services (NICE, 2012) and early intervention from joined-up services for families with ASD could save future resources.

Conclusion

This study provides important and novel insights into the experiences of parents with ASD who have a child with ASD. Findings suggest that parents' own experiences of ASD traits were both a strength and an additional difficulty when parenting. Parents experienced enrichment and acceptance but also felt the negative personal impact of having a child with ASD. They also described the difficulties living in a challenging home environment and a judgemental outside world, and managing a lack of professional support. Given the infancy of this research area, future research into ASD families is vital. A range of multi-system clinical implications has been highlighted from study findings, including increasing the recognition of parental ASD and providing accessible

and connected professional support services around the whole family rather than just the child with ASD.

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Appendix A - Journal Submission Guidelines



Journal of Attention Disorders
2017 Impact Factor: 3.668

2017 Ranking: 39/142 in Psychiatry (SCI) | 28/142 in Psychiatry (SSCI) | 12/73 in Psychology, Developmental

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Published in Association with American Professional Society of ADHD and Related Disorders

A Journal of Theoretical and Applied Science

EDITOR

Sam Goldstein — University of Utah School of Medicine and School of Nursing

Journal of Attention Disorders (*JAD*) focuses on basic and applied science concerning attention and related functions in children, adolescents, and adults. *JAD* publishes articles including, but not limited to, diagnosis, comorbidity, neuropsychological functioning, psychopharmacology, and psychosocial issues. The journal welcomes manuscripts addressing timely, notable topics in practice, policy, and theory, as well as review articles, commentaries, in-depth analyses, empirical research articles, and case presentations or program evaluations that illustrate theoretical issues or new phenomena.

Submission

Style for all submissions must follow that of the *Publication Manual of the American Psychological Association* (6th ed.). Submission to the journal implies that the manuscript has not been published elsewhere and is not in consideration by any other journal. Submission to the Applied Research section should be no more than 30 double-spaced pages, including an abstract of 150 words or less using a sectional guideline (Objective, Method, Results, and Conclusion), a brief biographical statement for each contributing author, endnotes, references, tables, and figures, all on separate pages. Author names and affiliations should appear on a separate cover page and the manuscript should be formatted for anonymous review.

Journal of Attention Disorders only accepts submissions electronically. Electronic submissions should be sent to http://mc.manuscriptcentral.com/jad. Submissions must be in Microsoft Word. Please ensure that tables are editable files in Word or Excel, not images. Artwork should have a resolution of 300 dpi or higher. Images are best submitted separately from the text document. Please do not embed images into your file, as embedding raster image files (photographs) in Word or similar programs automatically reduces the resolution below what is needed for quality print publication.

Featured Sections

JAD features applied research. *JAD* additionally publishes unsolicited articles in three other sections: Research Into Practice, Research Briefs, and Literature Reviews. The first, Research Into Practice, should focus on well-developed areas of research with an emphasis on application and evaluation of practice. Specifically, the goal of these submissions is to illustrate how relevant conceptual and empirical principles can be implemented in evaluating and practice. Manuscripts should present theoretically sound and empirically documented principles and illustrate how these have been synthesized into practiced and proven interventions.

The journal is also interested in publishing articles in a Research Briefs section promoting the dissemination of new, novel, or otherwise important research information in a format that does not require extensive journal space. Research briefs should be substantially shorter than general articles: no longer than 15 pages, including tables, figures, and references. When submitting a manuscript for consideration as a research brief, the author should so stipulate and agree not to publish a more comprehensive version of the article in another source. Finally, the journal is interested in publishing literature reviews. These reviews should be no more than 50 double-spaced pages. Authors considering writing a literature review should consider contacting the editor before submission. JAD will also publish relevant letters describing interesting cases of developments in the field relative to clinical practice.

The journal also welcomes Letters to the Editor of no more than 300 words. Letters will be published at the editor's discretion. Opinion essays on relevant topics in ADHD are published by invitation only.

Authors who want to refine the use of English in their manuscripts might consider utilizing the services of SPi, a non-affiliated company that offers Professional Editing Services to authors of journal articles in the areas of science, technology, medicine, or the social sciences. SPi specializes in editing and correcting English-language manuscripts written by authors with a primary language other than English. Visit http://www.prof-editing.com for more information about SPi's Professional Editing Services, pricing, and turn-around times, or to obtain a free quote or submit a manuscript for language polishing.

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Appendix B - DSM-V Diagnostic Criteria for ADHD

The following criteria were taken from the DSM-V (pp 59-60; American Psychiatric Association, 2013).

1. **Inattention:** Six (or more) of the following symptoms have persisted for at least 6 months to a degree that is inconsistent with developmental level and that negatively impacts directly on social and academic/occupational activities:

   Note: The symptoms are not solely a manifestation of oppositional behaviour, defiance, hostility or failure to understand tasks or instructions. For older adolescents and adults (age 17 or older) at least five symptoms are required.

   a) Often fails to give close attention to details or makes careless mistakes in schoolwork, at work, or during other activities (e.g., overlooks or misses details, work is inaccurate).
   b) Often has difficulty sustaining attention in tasks or play activities (e.g., has difficulty remaining focused during lectures, conversations, or lengthy reading).
   c) Often does not seem to listen when spoken to directly (e.g., mind seems elsewhere, even in the absence of any obvious distraction).
   d) Often does not follow through on instructions and fails to finish schoolwork, chores, or duties in the workplace (e.g., starts tasks but quickly loses focus and is easily sidetracked).
   e) Often has difficulty organizing tasks and activities (e.g., difficulty managing sequential tasks; difficulty keeping materials and belongings in order; messy, disorganized work; has poor time management; fails to meet deadlines).
   f) Often avoids, dislikes, or is reluctant to engage in tasks that require sustained mental effort (e.g., schoolwork or homework; for older adolescents and adults, preparing reports, completing forms, reviewing lengthy papers).
   g) Often loses things necessary for tasks or activities (e.g., school materials, pencils, books, tools, wallets, keys, paperwork, eyeglasses, mobile telephones).
   h) Is often easily distracted by extraneous stimuli (for older adolescents and adults, may include unrelated thoughts).
   i) Is often forgetful in daily activities (e.g., doing chores, running errands; for older adolescents and adults, returning calls, paying bills, keeping appointments).

2. **Hyperactivity and impulsivity:** Six (or more) of the following symptoms have persisted for at least 6 months to a degree that is inconsistent with developmental level and that negatively impacts directly on social and academic/occupational activities:

   Note: The symptoms are not solely a manifestation of oppositional behavior, defiance, hostility, or a failure to understand tasks or instructions. For older adolescents and adults (age 17 and older), at least five symptoms are required.

   a) Often fidgets with or taps hands or feet or squirms in seat.

b) Often leaves seat in situations when remaining seated is expected (e.g., leaves his or her place in the classroom, in the office or other workplace, or in other situations that require remaining in place).
c) Often runs about or climbs in situations where it is inappropriate. (Note: In adolescents or adults, may be limited to feeling restless.)
d) Often unable to play or engage in leisure activities quietly.
e) Is often "on the go," acting as if "driven by a motor" (e.g., is unable to be or uncomfortable being still for extended time, as in restaurants, meetings; may be experienced by others as being restless or difficult to keep up with).
f) Often talks excessively.
g) Often blurts out an answer before a question has been completed (e.g., completes people's sentences; cannot wait for turn in conversation).
h) Often has difficulty waiting his or her turn (e.g., while waiting in line).
i) Often interrupts or intrudes on others (e.g., butts into conversations, games, or activities; may start using other people's things without asking or receiving permission; for adolescents and adults, may intrude into or take over what others are doing.

B. Several inattentive or hyperactive-impulsive symptoms were present prior to age 12 years.

C. Several inattentive or hyperactive-impulsive symptoms are present in two or more settings (e.g., at home, school, or work; with friends or relatives; in other activities).

D. There is clear evidence that the symptoms interfere with, or reduce the quality of, social, academic, or occupational functioning.

E. The symptoms do not occur exclusively during the course of schizophrenia or another psychotic disorder and are not better explained by another mental disorder (e.g., mood disorder, anxiety disorder, dissociative disorder, personality disorder, substance intoxication or withdrawal). Specify whether: 314.01 (F90.2)

Combined presentation: If both Criterion A1 (inattention) and Criterion A2 (hyperactivity-impulsivity) are met for the past 6 months. 314.00 (F90.0)

Predominantly inattentive presentation: If Criterion A1 (inattention) is met but Criterion A2 (hyperactivity-impulsivity) is not met for the past 6 months. 314.01 (F90.1)

Predominantly hyperactive/impulsive presentation: If Criterion A2 (hyperactivity/impulsivity) is met but Criterion A1 (inattention) is not met over the past 6 months.

(For other specifiers, see DSM-V, pp 60-61).

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Appendix C – Search Strategy and Results

	Search Term	PsycINFO	Medline	EMBASE	CINAHL	AMED	Scopus
Date: 6/2/18							
1.	("parental ADHD" or "maternal ADHD" or "paternal ADHD" or "parents with ADHD" or "mothers with ADHD" or "father with ADHD").ab,ti.	134	94	143	43	6	141
2.	((adult or parent* or maternal or paternal or father or mother) adj2 (attention-deficit hyperactivity disorder or inattention or hyperactivity or impulsivity or attention deficit disorder or ADHD)).ab,ti.	2550	1844	3199	820	46	6664
3.	(Child* or toddler or infant or offspring or boy or girl).ab,ti.	678010	1300733	1798203	291284	17889	3537020

4.	(outcome or develop* or impairment or diagnosis or adjustment or disorder or emotion* or affectiv* or internalis* or depressi* or anxi* or mental health or psychopath* or psycholo* or aggressive or externalising or behav* or angry or ODD or oppositional or conduct or anti-social or difficult or delinquent or learning or cognit* or attention* or memory or language or IQ or ability or relation* or social functioning or attachment).ab,ti.	3235539	7766187	11229808	1159459	103483	3809505
5.	1 or 2	2551	1845	3203	821	47	6664
6.	3 and 4	558522	663321	1003938	169319	10817	671,163
7.	5 and 6	1438	1019	1778	495	36	3,245
8.	Limit 7 to (peer reviews journal and English language)	1015	English language (968)	English language (1684)	470	33	2532
9.	After removing duplicates	2233					

Appendix D – Data Extraction Tool

The following extraction tool was adapted from Cochrane Consumer's and Communication data extraction template (Higgins & Deeks, 2011).

1. General Information		
First author:	Year of study:	Country of study:
Title:		
Journal:		
2. Method		
Design		
Aims		
Hypothesis		
Recruitment (inc method, potential ppts approaches?)		
Inclusion exclusion	Inclusion	Exclusion
Participant characteristics (e.g. age, gender, ethnicity, other demographics)	Child n= Adult n=	
Comparison group?		
Sample size calculation?		
Parental ADHD measure (e.g. symptom/diagnosis)	Details Psychometric properties Validation?	

Child outcomes (inc psychometric properties, validation, etc)	Details
	Emo Behav Cognitive Social
Other outcomes?	
Time points?	
Statistical methods	
3. Results	
Main findings	
Effect size reported	
4. Discussion	
Key conclusions	
Limitations (inc risk of bias)	
Strengths	
Comments (e.g. missing information)	

References: Higgins, J., & Deeks, J. (2011). Chapter 7: Selecting studies and collecting data. In J. Higgins & S. Green (Eds.), Cochrane Handbook for Systematic Reviews of Interventions Version 5.1.0 (updated March 2011)The Cochrane Collaboration. Retrieved from www.cochrane-handbook.org.

Appendix E – Adapted Quality Assessment Checklist

The following quality assessment checklist was adapted from checklists which measured study quality (Downs & Black, 1998) and critically appraised cross-sectional research (Downes, Brennan, Williams, & Dean, 2016).

		Yes	No	Unable to determine
Introduction				
1.	Were the aims/objectives of the study clear?			
2.	Were the main outcomes to be measured clearly described in the Introduction or Methods section?			
3.	Did the theories/concepts adequately justifying the research?			
Method				
4.	Was the study design appropriate for the stated aims?			
5.	Was the sample size justified?			
6.	Were the characteristics of the patients included in the study clearly described?			
7.	Was the sample frame taken from an appropriate population base so that it closely represented the target/reference population under investigation?			
8.	Were the distributions of principal confounders in each group of subjects to be compared clearly described?			
9.	Were measures undertaken to address and categorise non-responders?			
10.	Were the risk factor and outcome variables measures appropriate to the aims of the study?			
11.	Were the risk factor and outcome variables measured correctly using instruments/ measurements that had been trialled, piloted or published previously? (Vakid and reliable)			
12.	Is it clear what was used to determined statistical significance and/or precision estimates? (eg, p values, CIs)			
13.	Were the methods (including statistical methods) sufficiently described to enable them to be repeated?			
Results				
14.	Were the basic data adequately described?			

15.	Does the response rate raise concerns about non-response bias?			
16.	If appropriate, was information about non-responders described?			
17.	Were the results internally consistent?			
18.	Were the results for the analyses described in the methods, presented?			
19.	If any of the results of the study were based on "data dredging", was this made clear?			
20.	Was there adequate adjustment for confounding in the analyses from which the main findings were drawn?			
21.	Did the study have sufficient power to detect a clinically important effect where the probability value for a difference being due to chance is less than 5%?			
Discussion				
22.	Were the authors' discussions and conclusions justified by the results?			
22.	Were the limitations of the study discussed?			
Other				
23.	Were there any funding sources or conflicts of interest that may affect the authors' interpretation of the results?			
24.	Was ethical approval or consent of participants attained?			

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Appendix F – Table of Study Measures

Outcome	Measure	Abbreviation	Measuring/Subscales	Reference	Used in study by
Adult ADHD questionnaires	Adult ADHD Self-Report Scale	ASRS	Inattention, hyperactivity- impulsivity	Kessler et al. (2005); Kessler et al. (2007)	Brammer, Galan, Mesri, and Lee (2016); Biederman, Faraone, and Monuteaux (2002); Humphreys, Mehta, and Lee (2012); Moroney, Tung, Brammer, Peris, and Lee (2017); Zisser and Eyberg (2012)
	Conner's Adult ADHD Rating Scale self-report	CAARS:S	Inattention, hyperactivity, impulsivity, self-concept	Conners et al. (1999)	Berger, Alyagon, Hadaya, Atzaba-Poria, and Auerbach (2013); Efron, Furley, Gulenc, and Sciberras (2018); Farbiash, Berger, Atzaba-Poria, and Auerbach (2014); LeMoine, Romirowsky, Woods, and Chronis-Tuscano (2015); Minde et al. (2003); Thissen, Rommelse, Altink, Oosterlaan, and Buitelaar (2014); Zisser and Eyberg (2012)
	Conner's Adult ADHD Rating Scale observer-rated	CAARS:O	Inattention, hyperactivity, impulsivity, self-concept	Conners et al. (1999)	Berger et al. (2013); Thissen, Rommelse, Hoekstra, et al. (2014)
	Current Symptoms Scale	CSS	Inattention, hyperactivity- impulsivity	Barkley and Murphy (2006)	Breaux, Harvey, and Lugo-Candelas (2014);

					Breaux, Brown, and Harvey (2017); Griggs and Mikami (2011); Herbert, Harvey, Lugo-Candelas, and Breaux (2013)
	Wender-Utah Rating Scale		Unreported	Ward, Wender, and Reimherr (1993)	Minde et al. (2003)
	18-item DSM-IV ADHD checklist		Unreported	American Psychiatric Association (2000)	Agha, Zammit, Thapar, and Langley (2013, 2017a, 2017b)
Diagnostic/clinical interviews	Child and Adolescent Psychiatric Assessment	CAPA	Disruptive behaviour disorders subtests used	Angold and Costello (2000)	Agha et al. (2013, 2017a)
	Development and Well-Being Assessment	DAWBA	ADHD, and conduct-oppositional disorders sections used	Goodman, Ford, Richards, Gatward, and Meltzer (2000)	Agha et al. (2017a)
	Diagnostic Interview Schedule-Fourth version	DISC-IV	ADHD, ODD subscales used	Shaffer, Fisher, Lucas, Dulcan, and Schwab-Stone (2000)	Brammer et al. (2016) Breaux et al. (2017) Herbert et al. (2013); Humphreys et al. (2012) Minde et al. (2003)
	Kiddie Schedule for Affective Disorders and Schizophrenia	K-SADS	Unreported	Kaufman et al. (1997)	Biederman et al. (2002); Romirowsky and Chronis-Tuscano (2014) Segenreich et al. (2015)(adapted)

	Mini International Neuropsychiatric Interview	MINI	Measured: ADHD, antisocial personality disorder, alcohol dependence, and non-alcohol substance dependence	Sheehan et al. (1998)	Romirowsky and Chronis-Tuscano (2014)
	Structured Clinical Interview for DSM-III-	SCID	Unreported	Spitzer, Williams, Gibbon, and First (1990)	Biederman et al. (2002)
	Diagnostic Interview Schedule for Young Children	YC-DISC	Unreported	Strong, Lucas, and Lucas (2006)	Zisser and Eyberg (2012)
Child broad-band outcome measures	Strengths and Difficulties Questionnaire	SDQ	Emotional problems, peer problems, conduct problems, hyperactivity Prosocial	Goodman (1997)	Efron et al. (2018)
	Behaviour Assessment System for Children	BASC	**Externalising:** Hyperactivity, aggression, conduct problems **Internalising:** Anxiety, depression, somatization **Behavioural Symptoms:** Atypicality, withdrawal, attention problems **Adaptive Skills:** Adaptability, social skill, leadership, activities of daily living, functional, communicaion	Reynolds and Kamphaus (1998)	Breaux et al. (2014); Herbert et al. (2013)

	Child Behaviour Checklist Teacher Report Form	CBCL TRF	**Syndrome subscale** *Internalising problems:* Anxious/depressed, withdraw/depressed, somatic complaints *Externalising problems:* Rule-breaking, aggressive behaviour *Other:* Attention problems, social problems, thought problems **Competency subscale** *Activities*: e.g. # of sports, jobs, activities *Social*: e.g. # of friends, behaviour with others *School*: e.g. mean performance, school problems	Achenbach and Edelbrock (1991)	Brammer et al. (2016) Biederman et al. (2002); Griggs and Mikami (2011) Farbiash et al. (2014); Humphreys et al. (2012); Minde et al. (2003); Zisser and Eyberg (2012)
	Disruptive Behaviour Disorder Rating Scale	DBD	ADHD, ODD, CD	Pelham, Gnagy, Greenslade, and Milich (1992)	Brammer et al. (2016); Humphreys et al. (2012); Minde et al. (2003); Moroney et al. (2017); Romirowsky and Chronis-Tuscano (2014)
	Global Assessment of Functioning	GAF	Overall measure of psychological, social, occupational functioning	American Psychiatric Association (2000)	Biederman et al. (2002)

	Wechsler Adult Intelligence Scale;	WAIS	Verbal Comprehension Index, Working Memory Index, Perceptual Organisation Index, Processing Speed Index	Wechsler (1981, 2008)	Biederman et al. (2002); Thissen, Rommelse, Altink, et al. (2014) WAIS-III); Thissen, Rommelse, Hoekstra, et al. (2014)
	Wechsler Intelligence Scale for Children	WISC	Verbal Comprehension Index, Working Memory Index, Perceptual Organisation Index, Processing Speed Index	Wechsler (1974, 2003)	Agha et al. (2013, 2017b); Biederman et al. (2002); Herbert et al. (2013); Thissen, Rommelse, Altink, et al. (2014)
Child narrow-band outcome measures	Cambridge gambling task		Decision making and delay aversion	Rogers et al. (1999)	Agha et al. (2017b)
	Child Depression Inventory	CDI	Depression	Kovacs (1992)	Segenreich et al. (2015)
	Child State-Trait Anxiety Inventory	CSTAI	Anxiety	Spielberger (1973)	Segenreich et al. (2015)
	Gilmore reading test		Academic achievement	Gilmore and Gilmore (1968)	Biederman et al. (2002)
	Intra-Extra Dimensional		Executive Functioning	Cambridge Cognition (1996)	Agha et al. (2017b)
	Motor timing		Reaction time	Van Meel, Oosterlaan, Heslenfeld, and Sergeant (2005)	Thissen, Rommelse, Altink, et al. (2014)
	Observed child prosocial behaviour		Pro-social behaviour	Griggs and Mikami (2011)	Griggs and Mikami (2011)
	Pursuit tracking		Motor precision	De Sonneville (1999)	Thissen, Rommelse, Altink, et al. (2014)

	Social Adjustment Inventory for Children and Adolescents	SAICA	Adaptive functioning	Orvaschel and Walsh (1984)	Biederman et al. (2002); Minde et al. (2003)
	Stop task		Inhibition	Logan, Cowan, and Davis (1984)	Thissen, Rommelse, Altink, et al. (2014); Thissen, Rommelse, Hoekstra, et al. (2014)
	Stop-signal task		Inhibition	Berger et al. (2013)	Berger et al. (2013);
	Swanson-Nolan and Palham-IV Rating Scale	SNAP	Inattention, Hyperactivity/impulsivity, ODD	Swanson (1992)	Zisser and Eyberg (2012)
	Social Skills Improvement System	SSIS	Academic competence subscale used	Gresham and Elliott (2008)	Efron et al. (2018)
	Visuospatial sequencing,			De Sonneville (1999)	Thissen, Rommelse, Altink, et al. (2014)
	Wechsler Individual Achievement Test	WIAT	Academic achievement	Wechsler (1992)	Herbert et al. (2013)
	Wide range achievement test – revised.		Arithmetic subtest only	Jastak and Jastak (1965)	Biederman et al. (2002)

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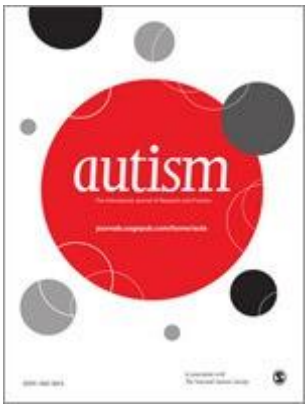
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Appendix G - Submission Guidelines for Proposed Journal



Autism

2016 Impact Factor: 3.684
2016 Ranking: 10/70 in Psychology, Developmental
Source: 2016 Journal Citation Reports® (Clarivate Analytics, 2017); Indexed in PubMed: MEDLINE

Published in Association with **The National Autistic Society**

The International Journal of Research and Practice

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Autism | **Autism Spectrum Disorders** | **Developmental Psychology**

This Journal is a member of the **Committee on Publication Ethics**

Please read the guidelines below then visit the Journal's submission site http://mc.manuscriptcentral.com/autism **to upload your manuscript. Please note that manuscripts not conforming to these guidelines may be returned.**

Only manuscripts of sufficient quality that meet the aims and scope of Autism will be reviewed.

There are no fees payable to submit or publish in this journal.

As part of the submission process you will be required to warrant that you are submitting your original work, that you have the rights in the work, that you are submitting the work for first publication in the Journal and that it is not being considered for publication elsewhere

and has not already been published elsewhere, and that you have obtained and can supply all necessary permissions for the reproduction of any copyright works not owned by you.

1. What do we publish?

1.1 Aims & Scope

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

1.2 Article Types

The Journal considers the following kinds of article for publication:

1. Research Reports. Full papers describing new empirical findings;
2. Review Articles

   (a) general reviews that provide a synthesis of an area of autism research;

   (b) critiques - focused and provocative reviews that may be followed by a number of invited commentaries, with a concluding reply from the main author.

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

3. Short Reports. Brief papers restricted to a maximum of 2,000 words with no more than two tables and 15 references. Short reports could include other approaches like discussions, new or controversial ideas, comments, perspectives, critiques, or preliminary findings. The title should begin with 'Short Report'.
4. Letters to the Editors. Readers' letters should address issues raised by published articles. The decision to publish is made by the Editors, in order to ensure a timely appearance in print. Letters should be no more than 800 words, with no tables and a maximum of 5 references.

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

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Autism operates a strictly anonymous peer review process in which the reviewer's name is withheld from the author and, the author's name from the reviewer. The reviewer may at their own discretion opt to reveal their name to the author in their review but our standard policy practice is for both identities to remain concealed. Each new submission is carefully read by

one of the Editors to decide whether it has a reasonable chance of getting published. If the Editor thinks it does not have this chance, at least one other Editor will be consulted before finally deciding whether or not to send the manuscript out for review. *Autism* strives to do this within two weeks after submission, so that authors do not have to wait long for a rejection. Feedback is also provided on how to improve the manuscript, or what other journal would be more suitable. Each manuscript is reviewed by at least two referees. All manuscripts are reviewed as rapidly as possible, and an editorial decision is generally reached within (e.g.) 6-8 weeks of submission.

As part of the submission process, you will be asked to provide the names of 2 peers who could be called upon to review your manuscript. Recommended reviewers should be experts in their fields and should be able to provide an objective assessment of the manuscript. Please be aware of any conflicts of interest when recommending reviewers. Examples of conflicts of interest include (but are not limited to) the below:

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

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2.2 Authorship

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2.3 Acknowledgements

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

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

2.4 Funding

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

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

2.4.1 National Institutes of Health (NIH) funded articles

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

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

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

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

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

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

2.8 Reporting guidelines

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

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

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6. On acceptance and publication

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

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7. Further information

Any correspondence, queries or additional requests for information on the manuscript submission process should be sent to the Autism editorial office as follows:

Katie Maras
Department of Psychology
University of Bath, UK
Email: **katiemaras.autism@gmail.com**

Appendix H - Further Details Regarding ASD Symptomology and Gender Bias

ASD symptomology

Difficulties in social interactions and communication include deficits in social or emotional reciprocity (e.g. difficulties sharing interests or emotions, failing to initiate or respond to interactions, abnormal social approach); communicative behaviours (e.g. poorly integrated verbal and nonverbal communication, eye contact, body language, use of gesture and facial expression); developing and maintaining peer relationships (e.g. adjusting behaviour to situations, making/interested in making friends) (APA, 2013; Jones, Gliga, Bedford, Charman, & Johnson, 2014).

Restrictive behaviours associated with ASD are apparent in insistence on sameness, inflexibility with regards to routines and ritualised behaviour, and highly restricted interests with great intensity or focus. Repetition can manifest itself in rhythmic motor movements, speech, routine and rituals (Leekham et al., 2011). Individuals with ASD can also show unusual reactivity to sensory information, such as hyper or hypo-reactivity to pain, temperature, sounds, textures and fascination with smells, touching of objects, lights and movements (APA, 2013; Leekam, Prior, & Uljarevic, 2011).

ASD & Gender

There are a number of theories postulated regarding the ASD gender imbalance. Some believe it may be due to diagnostic gender-biases, where ASD in females is under-recognised (Dworzynski, Ronald, Bolton, & Happé, 2012). Other theories suggest that males are at greater risk of ASD due to factors such as having a Y chromosome, lacking a protective paternal X chromosome, being exposed to increased foetal testosterone, or

physiological structural and functional sex differences in brain anatomy (Baron-Cohen et al., 2011; Werling & Geschwind, 2013).

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Appendix I - Theories of ASD

Aetiology of ASD

Along with twin studies reporting a strong genetic contribution to ASD aetiology (Hallmayer et al., 2011), family studies estimate sibling recurrence risk at around 19% (Ozonoff et al., 2011). Research into susceptible ASD genes and chromosomal abnormalities has not yet been definitive (Le Couteur & Szatmari, 2015).

Environmental risk factors are also thought to be important, but again research has not been definitive. Risk factors include, but are not be limited to, obstetric complications, exposure to some environmental chemicals, advanced parental age, and prenatal parental mental health conditions (Hisle-Gorman et al., 2018; Hultman, Sandin, Levine, Lichtenstein, & Reichenberg, 2011).

Neurological differences in ASD have also been widely replicated. For example, individuals with ASD have shown differences in brain development, structure, function and connectivity, with implications for social cognition and executive processing (Ecker, Bookheimer, & Murphy, 2015; Philip et al., 2012).

Theories of Underlying Cognitive and Emotional Processes

Theory of mind

Some have hypothesised that the social difficulties associated with ASD can be explained by impairment in 'theory of mind' (Baron-Cohen, 1997) i.e. the ability to recognise and understand thoughts, beliefs and intentions of others to make sense of and predict their behaviour. Research suggests that some individuals with ASD have theory of mind deficits (Mathersul, McDonald, & Rushby, 2013). However, others have suggested that

individuals with ASD who have an IQ within normal ranges may not be as impaired in theory of mind as once thought (Scheeren, de Rosnay, Koot, & Begeer, 2013).

Theory of mind is theorised to be an essential cognitive part of empathising, i.e. the ability to identify and respond appropriately to others' emotions (Baron-Cohen & Wheelwright, 2004). Some have suggested that individuals with ASD show more difficulties in cognitive empathy (i.e. the ability to correctly identify and predict the mental state of others) rather than affective empathy (i.e. the ability to offer appropriate emotional responses to the affective state of others) (Mazza et al., 2014).

Extreme Male Brain

Baron-Cohen (2002) proposed that individuals with ASD have intact or even superior systematising abilities (i.e. the ability to analyse input-operation-output relationships and infer the rules governing these systems), which are indicative of an extreme male brain profile and hypo-developed empathising abilities, which are indicative of an extreme female brain profile. These abilities are believed to underlie associated repetitive, restrictive and obsessional behaviours and islets of ability (Baron-Cohen, Knickmeyer & Belmonte, 2005) (Baron-Cohen, Knickmeyer, & Belmonte, 2005) and reflect extremes of the male neuroanatomy (Baron-Cohen et al., 2011).

Diminished social motivation

Deficits in social communication in ASD has also been explained by a reduction in social motivation, i.e. mechanisms biasing an individual to engage in a social world (Chevallier, Kohls, Troiani, Brodkin, & Schultz, 2012; Dawson, Webb, & McPartland, 2005). Research has found that ASD has been associated with inattention to social stimuli (e.g. Klin, Jones, Schultz, Volkmar, & Cohen, 2002) and a reduction in the number of friends

and self-reported pleasure in social situation (Chamberlain, Kasari, & Rotheram-Fuller, 2007; Chevallier et al., 2012). However, others have found that people with ASD have a desire for friendship, but don't know how to go about this (e.g. Bauminger & Kasari, 2000).

Executive functioning theory

Executive functioning refers to a range of skills such as working memory, planning, initiating and monitoring behaviours, impulse control, set shifting (Ozonoff, 1997). Some have postulated that individuals with ASD are impaired in executive functions such as the generalisation of learning, which has been used to explain behaviours associated with ASD such as inflexibility and restricted repetitive behaviours (Onzonoff, 1997).

Weak central coherence theory (WCC)

Central coherence has been defined as the intuitive, top-down ability to use multiple pieces of information to form a coherent picture (Happé, 1997). The WCC postulates that individuals with ASD have a weak central coherence and a tendency to focus on localised rather than global information (i.e. a bottom-up approach), causing them to become fixated on technicalities. This has been supported in children and adults with ASD (Happé & Frith, 2006). WCC has been used to explain characteristics of ASD such as pedantry, the desire for sameness, restrictive repetitive interests, hyper-sensitivity to sensory stimuli but also the islets of ability such as superior performance in certain perceptual abilities (Frith & Happé, 1994).

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Appendix J - Further Information about IPA and Rationale

IPA was developed from phenomenology (i.e. the study of experience), hermeneutics (i.e. the practice of interpretation) and ideography (i.e. the study of the particular rather than the general). IPA therefore provides a systematic method to explore individual's in-depth subjective experiences in a particular context (Larkin & Thompson, 2012; Smith, Flowers, & Larkin, 2009).

IPA also addresses double hermeneutics, i.e. the acknowledgement that the researcher is making sense of another's experience and therefore will be drawing on their own context, experiences, beliefs and assumptions. Researchers are encouraged to acknowledge these biases to enable a true grounding in their participants' experiences (Larkin & Thompson, 2012).

IPA was chosen over other qualitative methods in the current study as it allows a detailed yet flexible insight into how individuals make sense of their experiences, rather than how they construct their account (i.e. discourse analysis), or developing an exploratory account (i.e. grounded theory; Smith, 2011). Furthermore, IPA methods are particularly suitable for those with communication difficulties, such as ASD, when appropriate adaptations are used (Smith, 2004). IPA has been used successfully with children and adults with ASD (e.g. Cridland, Jones, Caputi, & Magee, 2014; Griffith, Totsika, Nash, Jones, & Hastings, 2012; Huws & Jones, 2015; Punshon, Skirrow, & Murphy, 2009)

A semi-structured interview was used to elicit narratives, thoughts and feelings about a phenomenon to gain a rich account. A small sample size was used, as recommended, which allowed the researcher to gain detailed participant accounts (Smith et al., 2009). Preece (2002) noted that some characteristics of ASD, such as concrete thought processes, lack of personal insight and high levels of social anxiety may make research

with these individuals more difficult. The researcher accommodated for these possible characteristics, drawing on her experience with this client group to modify the approach, such as taking "a stronger role in guiding [participants] than is usual in IPA interviews" (Smith, 2004, p. 49). It was also necessary with some participants to spend more time building rapport and elicit concrete examples of experiences to then go on to explore in more detail (e.g. Tierney, Burns, & Kilbey, 2016).

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Appendix K - Study Information Sheet

Oxford Institute of Clinical Psychology Training
An NHS Course Validated by the University of Oxford

Isis Education Centre, Warneford Hospital, Oxford, OX3 7JX
Tel: 07957 608479
Email: elise.marriott@oxfordhealth.nhs.uk

PARTICIPANT INFORMATION SHEET

What are the experiences of adults with a high number of Autism Spectrum Disorder (ASD) symptoms, in parenting a child with an ASD diagnosis?

Thank you for reading this letter. My name is Elise Marriott, I am a Trainee Clinical Psychologist. I am completing my training at the University of Oxford. As part of my doctoral training, I am interested in finding out more about the experiences of parents who have a high number of symptoms of Autism Spectrum Disorder (ASD) who have a child or children with a diagnosis of ASD.

Please read this information sheet before considering whether you would like to take part in the study. If there is anything that is not clear or if you have any questions, please contact me (elise.marriott@oxfordhealth.nhs.uk).

What is the purpose of the study?

The aim of the study is to understand more about the experience of adults who have a high number of symptoms of ASD or autism, in parenting a child who has ASD, autism, Asperger's syndrome or pervasive developmental disorder. This study is aiming to gain a better understanding of the advantages and challenges of having many symptoms of Autism yourself while parenting a child with ASD. This might allow clinicians and services working with similar families to yours to provide better care and support. We aim to interview approximately 12 parents for this study. In the interview, I will ask about your experiences of being a parent, including your experiences of parenting a child with ASD.

Why have you been invited?

You may have a high number of symptoms of Autism Spectrum Disorder (ASD) and you also have a child with a diagnosis of with ASD, autism, Asperger's syndrome or pervasive developmental disorder.

Do I have to take part?

No, you do not have to take part in this research. Your participation is entirely voluntary.

If you do decide to take part, you will be asked to sign a consent form. However, you can change your mind and withdraw from the study without giving a reason, at any point before the interview, during the interview and 2 weeks after the interview. This will not affect any clinical care or support from local organisations you are currently receiving or will receive in the future.

What will happen to me if I decide to take part?

If you wish to take part in the study the following will happen:

1) I will ask you to complete an 'Expression of Interest' form, included with this letter, if you are happy for me to contact you.

2) I will ask you to complete a questionnaire to measure symptoms of ASD, to check whether you can take part in the study*. You will then be asked to post the 'expression of interest' form and questionnaire back to me in the envelope included in your information packs.

*Please note, a high number of symptoms on this questionnaire is not equivalent to a diagnosis of ASD. If you are concerned about your score on this questionnaire or would like to find out more please do not hesitate to contact me. They will provide you with a list of services which may be beneficial to you.

3) On receipt of the 'Expression of Interest' form as well as the questionnaire, I will contact you (via telephone or email) to discuss whether you are suitable to take part in the study.

4) If you are suitable, you will be given 48 hours to consider whether you would like to take part. If you are happy to take part after the 48 hours, I will contact you (via telephone or email) to arrange an interview. The interview can take place wherever you are comfortable, for example at home or at a local NHS service. We can also think about ways to make the interview as comfortable as possible, for example bringing a friend, minimal lighting, etc.

5) The interview will take approximately 1 hour. During this time, I will ask you to fill out a demographics questionnaire (e.g. about your age, gender, ethnic background, child's diagnosis). I will also ask you about your experiences of being a parent, including your experiences of parenting a child with ASD and what you think impacts on your parenting. You can say as little or as much as you would like. This interview will take place in a comfortable setting for you. For example, this could be your home. All your answers will be anonymised.

6) After the interview has finished, I will discuss with you how you found the interview and make sure you are OK. I can also provide you with details about which services are available which you might find helpful.

6) Once the study is completed, after a few months, you will be given the option of receiving a summary of the findings. We also aim to publish the results of this studying a journal for healthcare professionals. The answers you provide in the interview will be anonymised in the write up of the study.

What are the possible benefits of taking part?

Little is currently known about what it is like to parent a child with ASD whilst being an adult with ASD or having a high number of ASD symptoms. This study is likely to lead to a better understanding of the advantages and challenges of having many symptoms of ASD yourself while parenting a child with ASD. This will allow clinicians and services working with similar families to yours to provide a better care and support.

This study may give you the opportunity to share and think about your experiences. Some people find this enjoyable and helpful.

Will I be reimbursed for taking part?

You will receive £15 should you choose to take part in the interview, to thank you for your participation and expertise, and to cover travel expenses. Unfortunately, individuals who accompany you to the interview, will not be able to be reimbursed.

Are there any possible disadvantages or risks from taking part?

Sometimes talking about difficult experiences associated with parenting can be distressing. Before starting the interview, it will be agreed with myself (Elise Marriott) how you will let me know if you would like to stop the interview. Anything that you have found uncomfortable during and after the interview can also be discussed further. Information will also be available about other supportive services that will be able to help you.

It is understandable that for some people, taking part in research can be anxiety-provoking. However, lots of steps will be put in place for it to be a comfortable experience for you. We can also discuss any requirements or adjustments you would prefer to make taking part in the study as comfortable as possible.

What will happen if I don't want to carry on with the study?

Your participation is entirely voluntary. You can change your mind and withdraw from the study without giving a reason, at any point before the interview, during the interview and 2 weeks after the interview. This will not affect any clinical care or support from local organisations you or your child are currently receiving or will receive in the future.

If you decide to withdraw from the study before, during, or up to 2 weeks after the interview, your data will be automatically removed from the study. If you decide to withdraw after 2 weeks after the interview, your data already collected will be

retained and used in the study. This is because the data will have already been analysed. No further data will be collected and you will not have to take part in any other research procedure.

What will happen to my information?

The interview will be recorded on an audio recorder with a password. I will then write up the conversation and take out any identifiable information (e.g. your names or personal words), so that no one who reads the report will know who you are and that you have taken part. I will destroy the audio recordings when the study has ended. All of your information will be kept securely on NHS and University of Oxford computers, and your interview will be anonymised and kept confidential.

However, if you were to say anything that may mean that you, your child or another person was at risk of being harmed or hurting someone else, it may be necessary to break confidentiality. For example I may need to have a discussion with the local safeguarding service.

When the results are written up, sometimes direct quotes are used to illustrate important points. However, no-one will be able to identify these quotes, as any identifiable information will be removed. Please let me know if you do not want me to write some of your words in the study report.

Following the completion of the study (which is estimated to be around September 2018), you will be given the option as to whether you would like to receive a summary of the results. This will mean that I will need to keep your contact details (i.e. you name and address or email address) to be able to send the results to you, should you request this.

Responsible members of the University of Oxford and the relevant NHS Trust(s) may be given access to the research data for monitoring and/or audit of the study to ensure that the research is complying with applicable regulations.

What if there is a problem?

The University of Oxford, as Sponsor, has appropriate insurance in place in the unlikely event that you suffer any harm as a direct consequence of your participation in this study.

If you wish to complain about any aspect of the way in which you have been approached or treated during the course of this study, you should contact myself. You may also contact the University of Oxford Clinical Trials and Research Governance (CTRG) office on 01865 572224, or email **ctrg@admin.ox.ac.uk**.

What will happen to the results of this study?

The results of the study will be shared with relevant healthcare teams (e.g. local organisations who support individuals and families with ASD). The study will also be published in a journal for professionals working with individuals and families with ASD.

I will send a summary of the results of the study to you via post or email, unless you state otherwise.

Who is sponsoring the study?

The study is sponsored by the University of Oxford.

All research in the NHS is looked at by an independent group of people, called a Research Ethics Committee, to protect participants' interests. This study has been reviewed and given favourable opinion by the South Central Oxford A Research Ethics Committee.

What do I do now?

If you wish to participate in the study please complete the 'Expression of Interest Form' and questionnaire and return it to myself via the stamped-addressed envelope provided or via email to (elise.marriott@oxfordhealth.nhs.uk).

Further information and contact details:

If you have any further questions, please contact:

Elise Marriott
Trainee Clinical Psychologist
Oxford Doctoral Course in Clinical Psychology, Isis Education Centre, Roosevelt Drive,
Headington, Oxford, OX3 7JX.
Email: elise.marriott@oxfordhealth.nhs.uk
Telephone: 07957 608479

Thank you for considering taking part.

Appendix L - Autism Quotient

The Adult Autism Spectrum Quotient (AQ)

Ages 16+

SPECIMEN, FOR RESEARCH USE ONLY.

For full details, please see:

S. Baron-Cohen, S. Wheelwright, R. Skinner, J. Martin and E. Clubley. (2001). The autism spectrum quotient (AQ): Evidence from Asperger Syndrome/High Functioning Autism, males and females, scientists and mathematicians. *Journal of Autism and Developmental Disorders, 31,* 5-17.

Name:..... Sex:.....

Date of birth:..... Today's Date.....

How to fill out the questionnaire

Below are a list of statements. Please read each statement very carefully and rate how strongly you agree or disagree with it by circling your answer.

DO NOT MISS ANY STATEMENT OUT.

Examples

E1. I am willing to take risks.	definitely agree	slightly agree	slightly disagree	definitely disagree
E2. I like playing board games.	definitely agree	slightly agree	slightly disagree	definitely disagree
E3. I find learning to play musical instruments easy.	definitely agree	slightly agree	slightly disagree	definitely disagree
E4. I am fascinated by other cultures.	definitely agree	slightly agree	slightly disagree	definitely disagree

1. I prefer to do things with others rather than on my own.	definitely agree	slightly agree	slightly disagree	definitely disagree
2. I prefer to do things the same way over and over again.	definitely agree	slightly agree	slightly disagree	definitely disagree

3. If I try to imagine something, I find it very easy to create a picture in my mind.	definitely agree	slightly agree	slightly disagree	definitely disagree
4. I frequently get so strongly absorbed in one thing that I lose sight of other things.	definitely agree	slightly agree	slightly disagree	definitely disagree
5. I often notice small sounds when others do not.	definitely agree	slightly agree	slightly disagree	definitely disagree
6. I usually notice car number plates or similar strings of information.	definitely agree	slightly agree	slightly disagree	definitely disagree
7. Other people frequently tell me that what I've said is impolite, even though I think it is polite.	definitely agree	slightly agree	slightly disagree	definitely disagree
8. When I'm reading a story, I can easily imagine what the characters might look like.	definitely agree	slightly agree	slightly disagree	definitely disagree
9. I am fascinated by dates.	definitely agree	slightly agree	slightly disagree	definitely disagree
10. In a social group, I can easily keep track of several different people's conversations.	definitely agree	slightly agree	slightly disagree	definitely disagree
11. I find social situations easy.	definitely agree	slightly agree	slightly disagree	definitely disagree
12. I tend to notice details that others do not.	definitely agree	slightly agree	slightly disagree	definitely disagree
13. I would rather go to a library than a party.	definitely agree	slightly agree	slightly disagree	definitely disagree
14. I find making up stories easy.	definitely agree	slightly agree	slightly disagree	definitely disagree
15. I find myself drawn more strongly to people than to things.	definitely agree	slightly agree	slightly disagree	definitely disagree
16. I tend to have very strong interests which I get upset about if I can't pursue.	definitely agree	slightly agree	slightly disagree	definitely disagree
17. I enjoy social chit-chat.	definitely agree	slightly agree	slightly disagree	definitely disagree

18. When I talk, it isn't always easy for others to get a word in edgeways.	definitely agree	slightly agree	slightly disagree	definitely disagree
19. I am fascinated by numbers.	definitely agree	slightly agree	slightly disagree	definitely disagree
20. When I'm reading a story, I find it difficult to work out the characters' intentions.	definitely agree	slightly agree	slightly disagree	definitely disagree
21. I don't particularly enjoy reading fiction.	definitely agree	slightly agree	slightly disagree	definitely disagree
22. I find it hard to make new friends.	definitely agree	slightly agree	slightly disagree	definitely disagree
23. I notice patterns in things all the time.	definitely agree	slightly agree	slightly disagree	definitely disagree
24. I would rather go to the theatre than a museum.	definitely agree	slightly agree	slightly disagree	definitely disagree
25. It does not upset me if my daily routine is disturbed.	definitely agree	slightly agree	slightly disagree	definitely disagree
26. I frequently find that I don't know how to keep a conversation going.	definitely agree	slightly agree	slightly disagree	definitely disagree
27. I find it easy to "read between the lines" when someone is talking to me.	definitely agree	slightly agree	slightly disagree	definitely disagree
28. I usually concentrate more on the whole picture, rather than the small details.	definitely agree	slightly agree	slightly disagree	definitely disagree
29. I am not very good at remembering phone numbers.	definitely agree	slightly agree	slightly disagree	definitely disagree
30. I don't usually notice small changes in a situation, or a person's appearance.	definitely agree	slightly agree	slightly disagree	definitely disagree
31. I know how to tell if someone listening to me is getting bored.	definitely agree	slightly agree	slightly disagree	definitely disagree
32. I find it easy to do more than one thing at once.	definitely agree	slightly agree	slightly disagree	definitely disagree
33. When I talk on the phone, I'm not sure when it's my turn to speak.	definitely	slightly	slightly	definitely

	agree	agree	disagree	disagree
34. I enjoy doing things spontaneously.	definitely agree	slightly agree	slightly disagree	definitely disagree
35. I am often the last to understand the point of a joke.	definitely agree	slightly agree	slightly disagree	definitely disagree
36. I find it easy to work out what someone is thinking or feeling just by looking at their face.	definitely agree	slightly agree	slightly disagree	definitely disagree
37. If there is an interruption, I can switch back to what I was doing very quickly.	definitely agree	slightly agree	slightly disagree	definitely disagree
38. I am good at social chit-chat.	definitely agree	slightly agree	slightly disagree	definitely disagree
39. People often tell me that I keep going on and on about the same thing.	definitely agree	slightly agree	slightly disagree	definitely disagree
40. When I was young, I used to enjoy playing games involving pretending with other children.	definitely agree	slightly agree	slightly disagree	definitely disagree
41. I like to collect information about categories of things (e.g. types of car, types of bird, types of train, types of plant, etc.).	definitely agree	slightly agree	slightly disagree	definitely disagree
42. I find it difficult to imagine what it would be like to be someone else.	definitely agree	slightly agree	slightly disagree	definitely disagree
43. I like to plan any activities I participate in carefully.	definitely agree	slightly agree	slightly disagree	definitely disagree
44. I enjoy social occasions.	definitely agree	slightly agree	slightly disagree	definitely disagree
45. I find it difficult to work out people's intentions.	definitely agree	slightly agree	slightly disagree	definitely disagree
46. New situations make me anxious.	definitely agree	slightly agree	slightly disagree	definitely disagree
47. I enjoy meeting new people.	definitely agree	slightly agree	slightly disagree	definitely disagree
48. I am a good diplomat.	definitely	slightly	slightly	definitely

	agree	agree	disagree	disagree
49. I am not very good at remembering people's date of birth.	definitely agree	slightly agree	slightly disagree	definitely disagree
50. I find it very easy to play games with children that involve pretending.	definitely agree	slightly agree	slightly disagree	definitely disagree

Developed by:
The Autism Research Centre
University of Cambridge

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Appendix M - Consent Form to be Contacted

EXPRESSION OF INTEREST IN RESEARCH

Title of study: What are the experiences of adults with a high number of Autism Spectrum Disorder (ASD) symptoms, who have a child with ASD?

I am interested in taking part in the study and would like to be contacted by the researcher (Elise Marriott) to discuss potential involvement. I understand that I am under no obligation to participate.

Name: ……

Contact Details:

Telephone number:	
Email Address:	

I would prefer to Elise to contact me by:

- Phone call ☐
- Text message ☐
- Email: ☐

Signed: ……..

Date: ……..

Please return to this to member of the team, or directly to the researcher:

Elise Marriott

Oxford Institute of Clinical Psychology Training, Isis Education Centre, Roosevelt Drive, Headington, Oxford, OX3 7JX.

If you would like to ask any further questions, please contact me on:

Email: elise.marriott@oxfordhealth.nhs.uk

Telephone: 07957 608479

THANK YOU

Appendix N - Participant Consent Form



Oxford Health NHS
NHS Foundation Trust

CONSENT FORM

Title of study: What are the experiences of adults with a high number of Autism Spectrum Disorder (ASD) symptoms, who have a child with ASD?

Please make sure you have read the Participant Information Sheet before considering taking part in the study.

Please ask any questions before filling out this form.

Please read and respond to each question below:

	Please write your initials in the boxes if you agree:
I confirm that I have read the information sheet dated 30/1/17 (version 3) for this study.	
I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily.	
I understand that my participation is voluntary and that if I change my mind at any time I can ask for my details and data to be removed from the study at any time before, during and 2 weeks after the interview. I know that I do not have to give any reasons to be removed and this will not affect any care or support I or my child receives.	
I understand that relevant sections of the data collected during the study may be looked at by individuals from University of Oxford, from regulatory authorities [and from the NHS Trust(s)], where it is relevant to my taking part in this research. I give permission for these individuals to have access to my records.	
I agree to audio recording and the use of anonymised quotes in research reports and publications.	
I would like a summary of the results sent to me after the study has been written up and approved.	

I agree to take part in this study.	

_____	_____	_____
Name of Participant	*Date*	*Signature*
_____	_____	_____
Name of Person taking Consent	*Date*	*Signature*

**1 copy for participant; 1 copy for researcher site file*

THANK YOU

Appendix O - Demographics Questionnaire



Oxford Health NHS
NHS Foundation Trust

Oxford Institute of Clinical Psychology Training
An NHS Course Validated by the University of Oxford

Isis Education Centre, Warneford Hospital, Oxford, OX3 7JX
Tel: 01865 226341

DEMOGRAPHIC QUESTIONNAIRE

Title of study: What are the experiences of adults with a high number of Autism Spectrum Disorder (ASD) symptoms, in parenting a child with an ASD diagnosis?

Please complete this questionnaire below, to provide us with more information about yourself.

1. **What is your age?** _____

2. **What is your gender identity?**

☐ Man ☐ Woman ☐ Prefer not to say

☐ Another gender identity (please specify) _____

3. **What is your marital status?**

☐ Divorced or separated ☐ Married/civil partnership/cohabiting
☐Single ☐ Widowed ☐ Prefer not to say

4. **What is your ethnic group?**

☐ Prefer not to say

Asian

☐ Asian British ☐ Asian English ☐ Asian Scottish ☐ Asian Welsh ☐ Bangladeshi ☐ Indian ☐ Pakistani ☐ Chinese ☐ Middle Eastern ☐ Any other Asian background – please specify _____

Black

☐ Black British ☐ Black English ☐ Black Scottish ☐ Black Welsh
☐ African ☐ Caribbean ☐ Any other Black background – please specify _____

Mixed/multiple ethnic groups

☐ White and Asian ☐ White and Black ☐ African White
☐ Black Caribbean ☐ Any other mixed background – please specify _____

White

☐ British – English ☐ British – Scottish ☐ British – Welsh
☐ Any other British White background – please specify _____
☐ Irish ☐ Any other White background – please specify _____

Other ethnic group

☐ Arab Latin American ☐ Any other ethnic group – please specify _____

Which of the following have you been diagnosed with? Please specify (Select all that apply)

☐ A learning disability (e.g. dyslexia)

☐ A mental health difficulty – please specify

☐ Autism, Autistic Spectrum Disorder, Asperger's Syndrome, - please specify

☐ A long-standing illness or condition – please specify

☐ A disability or impairment not listed above – please specify

☐ Prefer not to say

5. **How many children do you have?** _____

6. **Has/have your child/children been diagnosed with the following? Please specify (Select all that apply)**

☐ A learning disability (e.g. dyslexia)

☐ A mental health difficulty – please specify

☐ Autism, Autistic Spectrum Disorder, Asperger's Syndrome, - please specify

☐ A long-standing illness or condition – please specify

☐ A disability or impairment not listed above – please specify

☐ Prefer not to say

Appendix P - Semi-Structured Interview Schedule

INTERVIEW SCHEDULE

Title of study: What are the experiences of adults with a high number of Autism Spectrum Disorder (ASD) symptoms, who have a child with ASD?

Introduction

1. **Can you tell me about who's in your immediate family?**

   Possible prompts: Who do you live with? Draw genogram if needed.

Experience of parenting

1. **What is it like to be a parent?**

Possible prompts Is there anything you find particularly challenging? Or there anything you find particularly positive?

2. **Do you think this has changed over time?**

Possible prompts: Is there anything that has improved/got worse with time?

Experience of parenting a child with ASD

3. **Can you tell me about what it's like to parent a child with autism/ASD/Asperger's syndrome?**

Possible prompts: Is there anything you find particularly challenging? Is there anything you find particularly positive? E.g. differences in X's social communication, restrictive/repetitive behaviours, challenging behaviours, life transitions.

4. **Has parenting X changed over time?**

Possible prompts: Is there anything that has improved/got worse as X has got older?

General Prompts for each question:

- Can you tell more about that?
- What did you mean by that?
- What is that like?
- How do you feel about that?
- What thoughts did you have about that?
- What does that mean to you?
- How did you understand/make-sense of that?
- How did you experience that?

Experiences of support

5. **What's your experience of support in parenting?**

Possible prompts: is there anything/anyone/any service that has helped you? Are there any anything/anyone/any service that have been unhelpful to you?

6. **Is there anything else that you feel is important for me to understand about your experiences of being a parent?**

Summary:

7. **Do you have any questions?**
8. **How has it been talking to me today?**

Appendix Q - Example of Researcher's Initial Interpretations

reflect back at you what you're putting in. So when they do something kind I think actually I can't be doing a bad job because they just echo you don't they [I: *yeah*]. they mirror what you've put in. So I guess the difference between me and my friends is that the A*ness isn't the bit that I want echoed. I know that they're clever and I know they'll achieve. I'd rather them be nice. which is a really...un...celebrated word. It's underrated. Because I need people to be kind to J. You know he's very obviously...had needs. He doesn't function at school without 1:1. He doesn't...he's having to learn everything about the outside world in a very tackle specific way. So...it's important that people are kind. So that's what it's like as a parent I guess.

Is there anything you've found particularly challenging about being a parent?

Yes. Not within the confides of the house. That bits easy because luckily for me children really blossom when they've got routine and consistency. And I found that quite easy to implement. I'm not one of these sort of spontaneous...you know. I can do fun as long as I've planned it. They don't need to know I've planned it. So we can go sledging and do all those things but I'll just place it where it fits best. Um...so things that are more difficult were when I had S I was only 19 and still working out lots of lots of things. And so making doctors appointments and all of those sorts of things. [Pause]. I'm fine with it now. Those....I can do it for them much more easily than I can do it for myself. So in effect it's a good thing...much braver.

What was it about those things that were challenging for you?

Appendix R - Excerpt of Case-level Emerging Themes

Participant: Emily

Sense of participant/overview

- Very together and frank about difficulties
- Sense that family are all in it together
- Strong will to keep going and adapt to the children, despite professionals not always being helpful
- Reflective of own difficulties and needs – currently going through diagnosis procedure

What I don't want to lose

- Triangle – all pulling in different directions
- Sense of equality between her and children – we're in it together
- Sadness/going against mother instinct - not being able to have physical contact with children

Emerging themes	Line	Examples
<u>We are in it together/equal/have our difficulties to manage</u>		
• We need respite from each other/feeling trapped	118	"And we've got this kind of triangle of people….Often need a break from each other. But we haven't really got anywhere to go."
	169	"when do they get sort of time when they're not…at a heightened state?"
• Having children = connection	440	"And it's really nice to have those people that are kind of yours. And you're really important to them"
	455	
• Child difficulty = everybody's difficulty	167	"he likes to have his breakfast and his medication in a certain way. And when I get that the wrong way round then that's…very difficult for everybody."
• Children provoke each other	172	"he wants to irritate her. And…provoke her. So he's in on her space And then everyone's screaming."
• Parent or 'we' has to manage children's differing needs	8-10	"we're trying to curb it"
	54	"She's always checking them and doing everything. And…whereas he's not…really that bothered"
	124	"Both of them are quite different in the fact that E wants to be out doing loads of

		stuff and A just likes to be at home. So the winter is the worst for us."
• We're all in it together	517	"And that's quite nice, knowing that what we've got is ours. And…we're all weird together. You know… it is very difficult parenting a child with needs…when you have needs yourself. Yes, we are all very similar but at different times we're all over the place."
• Parent and child developing together	443	"And sort of growing with E"
• Parent learns from the child	216	"So I was trying to learn…but actually I had to learn from him."
• Understanding child is an ongoing process	220	"So that's how it's changed really. Just listening to them. "
<u>Parenting is relentless</u>		
• Parent never has respite from children/feeling trapped	137	"So he'll take her….but doesn't take E. So…they…so I never kinda have that time."
	155	". So…I just kind of end up…feeling really stressed. And actually feeling kind of trapped sometimes. Because I haven't got someone to kind of go…"let me…help you""
• Relentlessness of parenting which impacts the child	152	"And…so I spend a lot of time at such a heightened level as well. Because I'm like…just gotta keep going."
	340	Because no it's not easy because I'm very tired and I'm trying to meet the kids' needs all the time. But also…it just is just what needs to be done. So I just get on with it."
	388	"It's just a case of going day to day, seeing what the latest challenge is."
• Perseverance	185	"You just kind of keep going."
	338	"And so…I'm just kind of doing it…I'll just do it. I'll just keep going [laughs]."
	341	"because I'm very tired and I'm trying to meet the kids' needs all the time."
• As a parent you need to keep going, despite your own difficulties	63	". And I'm trying to kind of…. struggling with that…But as the parent you just got to kind of keep going."
• Love for children gets through the difficulties	438	"But…you are pushed to your absolutely limits but then you…or I love them unconditionally anyway."
• School is the only respite	185	"You just kind of keep going. And I think because they're at school, it's OK. I can kind of do what I like to do."

Appendix S - Excerpts of Reflective Journal

Developing the Interview Schedule

"Developing the interview schedule has been a particularly frustrating process. Despite reading about the IPA approach, I could not understand why my questions were still causal and assuming.

It wasn't until a meeting with my research tutor that it clicked that parents with ASD may not feel their parenting is impacted by their own symptoms, as I had been assuming, and that this in itself was incredibly interesting! I realised that I had been hypothesising about all the challenges that these individuals may face, perhaps due to my experiences of working in CAMHS. However, given that this is such an under-researched area, this could be completely wrong. This led me to reconsider the services I am recruiting from, and put equal emphasis on trying to recruit from third sector organisations, where participants may not be struggling as much."

"I am concerned about not getting rich accounts from the interviews, which is partly a reflection of my anxiety about doing a semi-structured interview and perhaps an assumption that individuals with ASD will not be reflective and provide a rich account when faced with open-ended questions. However, I am trying to remember that the interview schedule can be adapted and the pilot study will be very revealing!"

Deciding Inclusion Criteria

"I have been finding the process of deciding how to measure ASD challenging (i.e. diagnosis of ASD only vs screening tool), particularly as anecdotally many

parents with ASD symptoms may not get a diagnosis. This made me consider using a screening tool, i.e. is a screening tool a valid measure of ASD? Would parents without diagnosis consider inclusion as confirmation of a diagnosis? I consulted my current and previous supervisors in this field who agreed that it would be ethically challenging. This led me to thoroughly research the use of ASD screening tools, and think about those people who don't have a diagnosis of ASD but may indeed meet the criteria, such as the service user who I had been consulting with regarding my project. Would those voices be lost?

"After researching, I felt like I had a good argument for using a screening tool. For example they had been used previously with parents with ASD and are discussed in NICE guidelines (2012). I felt that managed sensitively, it would be appropriate to use a screening tool, and would increase the inclusivity of the project."

Following Research Ethics Committee (REC) panel

"During the REC, much of the conversation was drawn to use of a screening tool and how participants would react when finding out that they had ASD symptoms indicative of a diagnosis. I felt like I had put enough procedures into place to manage this, such as getting familiar clinicians to recruit only those who had already considered that they had traits of ASD, including information in the participant information sheet, etc.

This made me consider a possible assumption of the REC panel; finding out about a diagnosis of ASD is a negative thing. Surely this is a reflection of society's attitude to the condition? This made me even more motivated to hear the voices of these parents, who may in fact have unique strengths in parenting their children."

Recruitment

"Having had difficulty recruiting from CAMHS services, I have been aware of my attempts to strengthening relationships with other 'gate-keepers' from 3rd sector organisations. It made me think that despite this being a frustrating process, how this is part of the 'sensitivity to context' that Yardley (2000) discusses. Building relationships with these individuals has been very important (and slow!) as these are very busy clinicians, and they are protective over the clients that they see. These clinicians also encouraged me to be more flexible in my methods of contact, e.g. most parents preferred conversations via email rather than the phone. This opened the door to many more potential participants."

"It feels great to talk to potential participants, not only to make contact with individuals I have been considering for over 2 years but also to hear their enthusiasm about the project. It's made me reflect on how easy it can be to lose enthusiasm for a research project, without contact with those you are researching and subsequent enthusiasm! This also makes me think about the real benefits of having a service user to consult on *every* step of the project to ensure this voice and motivation is not lost."

Reflections following first interview

"It has been great to finally get going and hear a parent's experience! However, this participant clearly found being a parent to her daughter with ASD very challenging. I found the interview jumped around a lot which may have been a reflection of my anxiety regarding doing the first interview, or the fact that the participant's narrative or ideas were not fully formed yet.

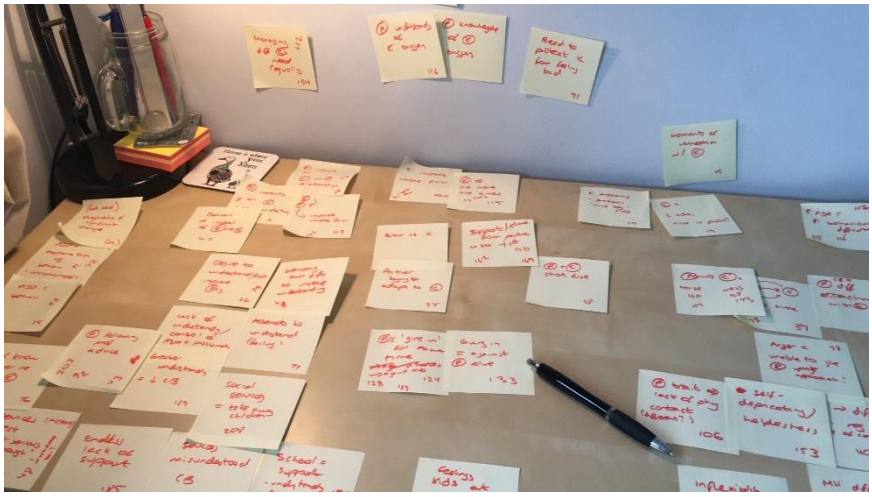
I found myself asking some closed questions, which shut conversations down. I found it very difficult to take a researcher's position rather than a psychologist's position. There were so many times where I wanted to jump in to reassure, give advice or reflect back what the participant had told me. Leaving long pauses for the participant helped and made me reflect on trying this more in my clinical work! It's interesting how just doing research can influence clinical practice."

Reflections following interview seven

"This interview was such a stark contrast to interview six who was very rigid in her thinking and not very reflective. The participant was very reflective and the focus was more on him and how he must improve himself/his anger issues rather than on the child, as many others have been. I wondered whether this was a reflection of the fact he was the only male, or that he had just received his ASD diagnosis and it was therefore at the forefront of his mind. It again made me reflect on how much this influenced all participants' experiences; something I had not considered when considering my sample and making as homogenous as possible. Interestingly, despite there being such stark differences, participant six and seven did have some similarities - they both had anger issues perhaps triggered by their children and wanted to improve these.

This participant was clearly very intellectual and it seemed like this very much helped the family. But I wondered whether there would be any downsides of this; i.e. the participant's desire to be the perfect Dad?"

Emergent themes analysis participant three



"I am currently in the process of looking for emergent themes (as can be seen in the image).

I am feeling anxious about not doing the participants justice. I am finding it helpful to discuss such anxieties with my IPA research group, as these seem mutual. I am struck by how complex, laborious and subtle the IPA process is. I think the fact that analysis involves so much of my interpretation can also be anxiety provoking, as how will you ever know it's correct? I feel this is why reflection, supervision and quality checks are so important, reflection can get lost when feeling stressed and short of time. I am trying to keep in mind that good quality IPA involves higher-level interpretation, rather than merely descriptive analysis, which I feel I am drawn towards."

Looking across transcripts



"I have started the cross-transcript journey which feels overwhelming and daunting! My initial cross-transcript themes seem very descriptive, and I am still aware of the articles and books I have read

which encourage those deeper levels of interpretation. I feel very immersed in the data but am struggling to helicopter myself out of it!

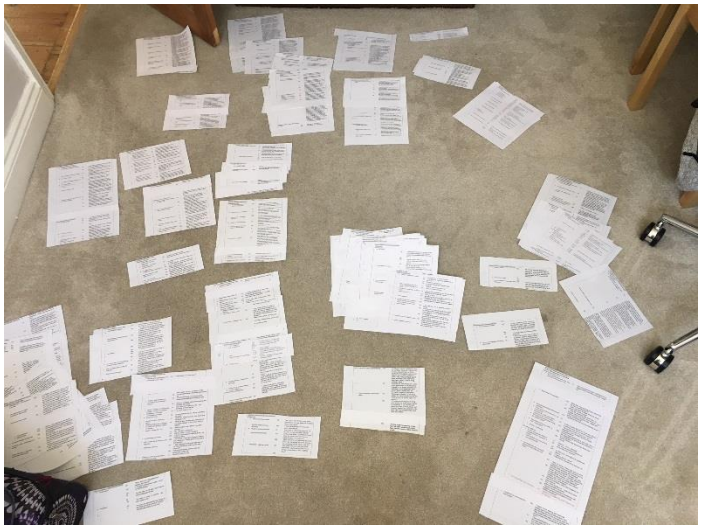
My meeting with my IPA supervisor was very helpful. She helped me to draw on some psychological concepts to see if these fit with my data. I have started to consider different ways to group the emergent themes, as can be seen in the image below. It is hard to move away from my emergent themes and still hold the participants in mind!"

Finding super-ordinate themes

"I feel I have come full circle with my analysis and super-ordinate themes. I spent time 'helicoptering' and look across accounts at commonalities such as 'acceptance' or 'loss of control.' However, it did not form a narrative of the data.

I decided to go back to my emerging themes and corresponding quotes for each person (see image) and looked for commonalities across transcripts this way. This reassured me that I was still staying close to the data. I have actually found that I have come back to some of my original as these sat most comfirtably with the data, e.g. parent-child relationship theme.

Talking the themes through with a peer helped me to think about the narrative of my themes. They made me question which themes I needed to keep and which were less interesting and didn't tell us anything new. E.g. the lack of parenting efficacy is perhaps



something that all parents feel. It felt like this theme was not specific enough and just clumped together subordinate themes that didn't really sit well together. This is something I need to discuss in supervision.

Meeting with IPA supervisor to discuss main themes

"The meeting with my supervisor to discuss my second round of main themes was really helpful. We discussed those parts of the themes that didn't quite fit or didn't make sense. For example the theme of 'parenting efficacy' actually weaved its way throughout the themes rather than a stand alone themes.

It also made me realise that my theme regarding services is too descriptive. I have spent some time going back to the data and my emerging themes to see what the key ideas were.

Eventually it seemed that the themes were reflective of the multiple layers of Bronfenbrenner's theory, which felt great and lead to me feeling more confident in my themes; they were telling a story that was not only grounded in the data but also reflected a substantial psychological theory."

Meeting with dissertation supervisors to discuss main themes

"Gaining a clinician's perspective on my themes has been really helpful. It was interesting that they did not like the theory driven labels for my superordinate themes and were very much interested in titles that were grounded in the data. It made me reflect on the usefulness of my study, which is surely one of the most important parts of the research, and the importance of my implications, as they are the clinicians that will be using this to inform their practice. This also made me refer back to the Yardley (2017) criteria for qualitiative research.

Their enthusiasm for the findings has also given me more motivation. It is easy to get lost in the enormity of the task."

Write up

"I have found the process of writing up also a key part of my analysis. It has made me think about the narrative of my themes and go back to the transcripts on multiple occasions, reflecting IPA's true iterative process!

I have found this part rewarding, to be able to see the vast amounts of data I originally had telling a more coherent picture. I hope that I am doing the participants and their experiences justice!"

References

National Institute for Health & Clinical Excellence. (2012). *Autism: The NICE guideline on recognition, referral, diagnosis and management of adults on the autism spectrum*: The British Psychological Society & The Royal College of Psychiatrists.

Yardley, L. (2000). Dilemmas in qualitative health research. *Psychology and Health, 15*(2), 215-228.

Yardley, L. (2017). Demonstrating the validity of qualitative research. *The Journal of Positive Psychology, 12*(3), 295-296. doi:10.1080/17439760.2016.1262624

Appendix T - Excerpts from Bracketing Interview with Peer IPA Research Group

Researcher: My project is about parents who have got a high number of ASD symptoms and their experience of parenting a child with autism diagnosis.

***Peer*: What brought you to this topic? Previous experiences or…?**

Researcher: Part of it was, I worked in a service that worked a lot with these parents, in a neuropsychiatry team. We'd had quite a lot of conversations about the fact that there was just no literature about these parents, because adults with autism that are being, like the parent age of autism…at the parent age now, they typically wouldn't have had a diagnosis back in the day. So it's only now that they are starting to get diagnosed and it's since their children have been diagnosed and they're like oh, maybe I've got it too. But there's no literature on it.

***Peer*: How do you know their traits? Have you got a measure?**

Researcher: The AQ. I did originally wanted to use participants who have a diagnosis, but quite a lot of them don't. They haven't needed to seek a diagnosis, so, I wanted to capture everybody. So I am using the AQ. The autism quotient.

Have you got any ideas on what you might find? Any thoughts on what you might find?

Researcher: I think I'm going to find a lot of negative experiences. I have an assumption that it will be challenging for parents who have got autism or a high level of symptoms of autism to also parent a child with autism. So I already came with that assumption that it will be difficult, but there's also the possibility that it's a very positive experience. For example, the parent and the child might have similar symptoms, so the parent can understand the child and can understand what they need. Maybe, maybe not. So I've definitely swayed towards negative, that I might find negatives.

Peer: What do you think you might find that might be negative, difficult?

Researcher: Parents might find it difficult to understand what their child needs, if their child is struggling to communicate, and then the parent also struggles to communicate. Also things like…parents who don't have ASD symptoms but who have children with ASD, they find it difficult to negotiate things like social services and support, they need quite a lot of knowledge and skills to navigate their way through those systems and then having an added layer of complexity of ASD symptoms might make it more difficult for them. They might seek less social support.

Peer: Have you got any ideas about ... I'm just thinking about actually interviewing parents themselves with traits of autism? Have you got any thoughts about that or any concerns?

Researcher: I've thought quite a lot about it. I'm thinking about how easy it will be for them to answer such open questions that are IPA style. And I've had to balance IPA questions with what I think a parent will be able to answer. So I'm concerned that perhaps my questions are too open, and that has made me think quite a lot about my follow-up questions. So I will start broad and then if they are struggling, I will narrow it down and make them as closed as they need to be.

I've also thought quite a lot about how to make the environment as comfortable as possible with them. And all through the process, contacting them with whatever means is most comfortable for them; or I'm going to have a conversation with them beforehand, like how to make it a comfortable experience; do you need a clock? Do they not need the lights on? Do they want someone else there with them? How will they let me know if they're distressed? So I think I'm a bit anxious about how it will go. Yeah.

What might draw your curiosity away from being a neutral researcher?

Researcher: [pause] maybe I'm more likely to go down a negative route, or something that they found challenging, or I think my skills as a trainee, as a therapist would draw me away from the researcher positions…. Or maybe I'll try to formulate in the interview, about what's going on and that's not necessarily IPA. I'm just trying to draw out the meat of their experience, aren't I, rather than being like, "Oh that's because…" like you do in a clinical interview. So yes, I think that will.

What do you think this project says about you as a person or as a psychologist?

Researcher: Well, this is a generic one, but I think it's important for people's voices to be heard. These parents' voices aren't often heard in services or in research. There aren't any services for these parents, which says it all. I feel like it shows that I care that something is done, that they get help, if they need it. But that's an assumption in itself, that they might need help.

So as you're asking about parenting, not being a parent yourself, how do you think that will influence? I wonder, if in a way, not being a parent yourself helps to see things from a more naive perspective, not to make assumptions, to think about your own experience?

Yeh…do you know I hadn't even considered that. I suppose I only have my own experience of being parented to draw from. And my parents didn't have any major mental health difficulties or anything like that…so perhaps I'll be tempted to ask questions in line with my own experiences but might be totally different from theirs.

But then from my experience, when a new parent meets up with another new parent, they just know what questions to ask, they ask about specific details and it gets the conversation flowing more. So maybe the fact I'm not a parent will mean that they don't

feel like they've got a common ground with me. Or it will mean I will be more curious, and make less assumptions, because I don't know what it's like to be a parent…

Have you got a sense of what your participants might think about you? What assumptions they might make about you?

Well, they'll probably make a lot of assumptions about the fact that the University of Oxford's stamp is on the top of all the participant information sheets, which might be intimidating. Or some people with autism who I worked with liked to know that you are an academic person. So they might assume about my intelligence, or that I'm young, a white middle class woman who doesn't have a clue about what they're going through. So that might make it more difficult.

Appendix U - Quality Criteria for Qualitative Research

The following quality criteria for qualitative research were used based on Yardley (2000, 2017) and adapted for IPA (Smith et al., 2009).

Sensitivity to context

This is demonstrated by actions such as:

- Purposive sampling
- Showing awareness of participant context
- Using verbatim quotes
- Referencing the literature
- Showing awareness of sociocultural settings

Commitment and rigour

This is demonstrated by actions such as:

- Attentiveness during data collection
- Appropriate sampling
- Showing expertise and skills in IPA
- Carrying out an in-depth analysis

Transparency and coherence

This is demonstrated by the reader's ability to see:

- the stages of the research process
- how the interpretation was derived from the data
- the degree of fit between with IPA principles

Impact and importance

This is demonstrated by producing useful and important results to the reader.

References

Smith, J. A., Flowers, P., & Larkin, M. (2009). *Intepretative phenomenological analysis: Theory, method and research*. London, UK: SAGE Publications Ltd.

Yardley, L. (2000). Dilemmas in qualitative health research. *Psychology and health, 15*(2), 215-228.

Yardley, L. (2017). Demonstrating the validity of qualitative research. *The Journal of Positive Psychology, 12*(3), 295-296. doi:10.1080/17439760.2016.1262624

Appendix V - Proposal Approval from Oxford Institute of Clinical Psychology

Oxford Health NHS
NHS Foundation Trust

The Oxford Institute of Clinical Psychology Training

UNIVERSITY OF OXFORD

Oxford Doctoral Course in Clinical Psychology
An NHS Course validated by the University of Oxford

Isis Education Centre, Warneford Hospital, Oxford OX3 7JX
Tel: +44(0)1865 226431
Website: www.oxicpt.co.uk

3rd July, 2017

Elise Marriott
Trainee Clinical Psychologist
Oxford Doctoral Course in Clinical Psychology
Isis Education Centre
Warneford Hospital

Dear Elise,

Thank you very much for your very thorough response to the Research Sub Committee letter. You now have full approval for your research study provided you make a change to one section of your interview schedule, as follows:

The section 'factors impacting on parenting' implies causality, and does not really fit well with an IPA approach. I wondered whether you could rephrase this to 'What's it like to be a parent?'

We wish you all the very best with your research.

Yours sincerely,

Myra

Dr Myra Cooper
Chair, Research Sub-Committee

c.c. James Stacey
Olivia Hewitt
Nienke Verkuij

Senior Research Tutor and Interim Deputy Programme Director:
Dr Myra Cooper, M.A. (Hons)., M.Phil., D.Phil., C.Psychol.
Tel: (01865) 226375 myra.cooper@hmc.ox.ac.uk

emarriottdissapp

Appendix W - Agreement of University of Oxford Research Sponsorship

RESEARCH SERVICES
Clinical Trials and Research Governance
Joint Research Office
Block 60
Churchill Hospital
Headington
Oxford
OX3 7LE

UNIVERSITY OF OXFORD

CTRG Clinical Trials and Research Governance

To whom it may concern

Date: 22/09/2017

Dear Sir/Madam,

Title: What are the experiences of adults with a high number of autism spectrum disorder (ASD) symptoms who have a child/children with ASD.

PID: 13071

Protocol Date/Version: 22.09.2017 version 2

The above study has been designed by Miss Elise Marriott and colleagues at the University of Oxford and funded by the Oxford Institute of Clinical Psychology Training. I confirm that the University will accept the role of Research Sponsor of this Study and will comply with the requirements of the Department of Health Research Governance Framework for Health and Social Care 2005, in so far as these apply in the United Kingdom.

Insurance-provided indemnity arrangements are in place for the project:
Newline Underwriting Management Ltd., at Lloyd's of London.

Sponsorship is confirmed subject to the condition that the following are sent to Clinical Trials and Research Governance for review prior to submission to the Research Ethics Committee. Failure to do so may compromise insurance cover for the project.

- Any minor or substantial amendments
- Any extension to the study end date
- Addition of any new research site or patient identification centre

In addition, annual progress reports, the end of study notification and final report must be copied to Clinical Trials and Research Governance.

Lastly, where they exist, University Core SOPs must be followed by default for all clinical research sponsored by the University. Further information can be found here: https://www.admin.ox.ac.uk/researchsupport/ctrg/resources/

Any communications relating to Research Sponsorship should be directed to the undersigned, whose contact details are given in this letter.

Yours faithfully

pp

Elaine Chick
Deputy Head of Clinical Trials and Research Governance

Tel: +44 (0)1865 572221 · Fax: +44 (0)1865 572228 · Web: www.admin.ox.ac.uk/researchsupport/ctrg/
Email: Heather.house@admin.ox.ac.uk or Elaine.Chick@admin.ox.ac.uk

Appendix X - Ethical Approval Granted from the NHS South Central Oxford Research Ethics Committee

NHS
Health Research Authority

South Central - Oxford A Research Ethics Committee
Bristol Research Ethics Committee Centre
Whitefriars
Level 3 Block B
Lewins Mead
Bristol
BS1 2NT
Telephone: 0207 1048 045

Please note: This is the favourable opinion of the REC only and does not allow you to start your study at NHS sites in England until you receive HRA Approval.

15 December 2017

Miss Elise Marriott
Isis Education Centre
Warneford Hospital
Oxford
OX3 7JX

Dear Miss Marriott

Study title:	**What are the experiences of adults with a high number of autism spectrum disorder (ASD) symptoms who have a child/children with ASD?**
REC reference:	**17/SC/0577**
Protocol number:	**N/A**
IRAS project ID:	**231035**

Thank you for your letter of 02 December 2017, responding to the Committee's request for further information on the above research and submitting revised documentation.

The further information has been considered on behalf of the Committee by the Chair.

We plan to publish your research summary wording for the above study on the HRA website, together with your contact details. Publication will be no earlier than three months from the date of this opinion letter. Should you wish to provide a substitute contact point, require further information, or wish to make a request to postpone publication, please contact hra.studyregistration@nhs.net outlining the reasons for your request.

Confirmation of ethical opinion

On behalf of the Committee, I am pleased to confirm a favourable ethical opinion for the above research on the basis described in the application form, protocol and supporting documentation as revised, subject to the conditions specified below.

Conditions of the favourable opinion

The REC favourable opinion is subject to the following conditions being met prior to the start of the study.

Management permission must be obtained from each host organisation prior to the start of the study at the site concerned.

Management permission should be sought from all NHS organisations involved in the study in accordance with NHS research governance arrangements. Each NHS organisation must confirm through the signing of agreements and/or other documents that it has given permission for the research to proceed (except where explicitly specified otherwise).

Guidance on applying for NHS permission for research is available in the Integrated Research Application System, www.hra.nhs.uk or at http://www.rdforum.nhs.uk.

Where a NHS organisation's role in the study is limited to identifying and referring potential participants to research sites ("participant identification centre"), guidance should be sought from the R&D office on the information it requires to give permission for this activity.

For non-NHS sites, site management permission should be obtained in accordance with the procedures of the relevant host organisation.

Sponsors are not required to notify the Committee of management permissions from host organisations

Registration of Clinical Trials

All clinical trials (defined as the first four categories on the IRAS filter page) must be registered on a publically accessible database within 6 weeks of recruitment of the first participant (for medical device studies, within the timeline determined by the current registration and publication trees).

There is no requirement to separately notify the REC but you should do so at the earliest opportunity e.g. when submitting an amendment. We will audit the registration details as part of the annual progress reporting process.

To ensure transparency in research, we strongly recommend that all research is registered but for non-clinical trials this is not currently mandatory.

If a sponsor wishes to request a deferral for study registration within the required timeframe, they should contact hra.studyregistration@nhs.net. The expectation is that all clinical trials will be registered, however, in exceptional circumstances non registration may be permissible with prior agreement from the HRA. Guidance on where to register is provided on the HRA website.

It is the responsibility of the sponsor to ensure that all the conditions are complied with before the start of the study or its initiation at a particular site (as applicable).

Ethical review of research sites

NHS sites

The favourable opinion applies to all NHS sites taking part in the study, subject to management permission being obtained from the NHS/HSC R&D office prior to the start of the study (see

"Conditions of the favourable opinion" below).

Non-NHS sites

Approved documents

The final list of documents reviewed and approved by the Committee is as follows:

Document	*Version*	*Date*
Copies of advertisement materials for research participants [Recruitment Poster]	3	19 October 2017
Evidence of Sponsor insurance or indemnity (non NHS Sponsors only) [Insurance Certificate]	1	22 September 2017
Interview schedules or topic guides for participants [Interview Schedule]	2	19 September 2017
IRAS Application Form [IRAS_Form_23102017]		23 October 2017
IRAS Application Form XML file [IRAS_Form_23102017]		23 October 2017
IRAS Checklist XML [Checklist_23102017]		23 October 2017
IRAS Checklist XML [Checklist_02122017]		02 December 2017
IRAS Checklist XML [Checklist_14122017]		14 December 2017
Letter from funder [Letter from funder]	1	21 July 2017
Letter from sponsor [Letter from Sponsor]	1	22 September 2017
Non-validated questionnaire [Demographic Questionnaire]	1	04 September 2017
Other [Professional Information Sheet]	2	19 September 2017
Other [Summary CV for NV]	1	19 September 2017
Other [Expression of Interest Form]	2	19 September 2017
Other [Letter to Dr Hugh Davies - reply to provisional opinion]	1	02 December 2017
Participant consent form [Consent form]	3	21 November 2017
Participant information sheet (PIS) [Participant Information Sheet]	3	19 September 2017
Participant information sheet (PIS) [Participant Information Sheet]	4	28 November 2017
Research protocol or project proposal [Study protocol]	2	22 September 2017
Research protocol or project proposal [Clinical Study protocol]	3	28 November 2017
Summary CV for Chief Investigator (CI) [Chief Investigator CV]	1	27 July 2017
Summary CV for supervisor (student research) [CV for supervisor JS]	1	21 September 2017
Validated questionnaire [ASD screening questionnaire (Autism Quotient)]	2	

Statement of compliance

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

After ethical review

Reporting requirements

NHS
Health Research Authority

The attached document *"After ethical review – guidance for researchers"* gives detailed guidance on reporting requirements for studies with a favourable opinion, including:

- Notifying substantial amendments
- Adding new sites and investigators
- Notification of serious breaches of the protocol
- Progress and safety reports
- Notifying the end of the study

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

User Feedback

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

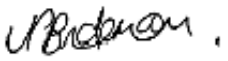
HRA Training

We are pleased to welcome researchers and R&D staff at our training days – see details at http://www.hra.nhs.uk/hra-training/

17/SC/0577	**Please quote this number on all correspondence**

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

Yours sincerely



Dr Hugh Davies
Chair

Email: nrescommittee.southcentral-oxforda@nhs.net

Enclosures: "After ethical review – guidance for researchers"

Copy to: *Ms Heather House, University of Oxford*
Ms Victoria Rush, Oxford Health NHS Foundation Trust

Appendix Y - Further ethical considerations

Recruitment

Participants were recruited via a staff member/clinician within a local ASD or CAMHS organisation, who deemed the individual to be suitable according to the inclusion criteria. Clinicians were carefully briefed regarding the study and possible benefits, burdens and risk associated with participation. For example, clinicians were discouraged to approach those parents who had not considered that they may have a high number of ASD symptoms, as this may have caused undue distress.

The use of an ASD screening tool

A screening tool was used to ensure that those who did not have a diagnosis of ASD but who may have met diagnostic criteria were included. Screening tools have been successfully used in the existing literature considering parents with ASD (Lau, Peterson, Attwood, Garnett, & Kelly, 2016) and are recommended in NICE guidelines (2012) as a screening tool to lead to a further adult ASD diagnostic assessment.

It was made very clear to participants that this screening tool did not equate to a diagnosis and was only used for research purposes. This was reiterated in the Participant Information Sheets, via recruiting clinicians, during the initial screening conversation and at multiple points during the participation process.

For those participants who did not meet inclusion criteria, the researcher dealt with any issues sensitively, explaining why the individual was not be suitable, managing any distress or disappointment, and providing resources and signposting to appropriate services (e.g. ASD diagnostic services).

Consent

Thorough information was provided about the purpose of the study. Written consent to take part in the study was also gained prior to participation, including consent to use anonymised transcripts. Capacity to consent to participation was assessed at each contact with the participant, and all potential participants were deemed to have capacity to participate. Should any issues have arisen, the researcher would have sought advice from their supervisors, before continuing with an individual's participation.

Participants were given the right to withdraw at any point before, during and 2 weeks after the interview had taken place. This was clarified in the Participant Information Sheets, and prior to the interview. No participants wished to withdraw.

Risks, burdens and benefits

Participation may have been at risk of distress as a result of discussing potentially difficult experiences in the semi-structured interview. A number of procedures and measures were put in place to minimise or manage this at all stages of participation, as shown in table 6. However, participation may have been the first opportunity that participants had had to discuss their experiences, and therefore may have benefited from taking part in the study. Indeed, all participants reported that the interview had been a positive experience. Neil reported it to have been "*excellent, cathartic*" (line 462).

Table 6.
Steps taken to minimise participants' distress

Stage of research	Steps taken to minimise distress
1) Recruitment	• Researcher highlighted risks and benefits to recruiting clinicians prior to research. • Participants informed of risks and benefits of participation and offered multiple opportunity to discuss this prior to consenting to participate.

	• Participants were reassured participation would not affect any care the parent or child was receiving at that time. • Distress regarding inclusion/exclusion criteria was sensitively managed.
2) Development of the Interview Schedule	• Interview schedule developed with parents with ASD, who did not have any concerns. • No issues highlighted during pilot interview
3) Preparation for interview	To ensure the participant was as comfortable as possible the researcher: • Offered a number of ways of contact with the researcher, e.g. via telephone, email, text message. • Discussed with participants how to make interviews as comfortable as possible, e.g. carrying interviews out in a familiar environment, having a familiar person accompany them. • Made a plan with participants regarding how they would communicate any distress.
4) During the interview	• The semi-structured interview was used flexibly according to participant responses, e.g. spending more time establishing rapport, discussing less emotive topics, using specific examples if open-ended questions were too difficult. • The researcher continuously assessed for distress during the interview and offered breaks if necessary
5) Post-interview	• Participants were debriefed and the experience of the interview was discussed. • Where necessary, participants were signposted to appropriate services (E.g. local Autism support groups). • Participants were offered a lay summary of the study results which will be disseminated following write-up.

Confidentiality

Confidentiality was maintained within the 'Caldicott Principles' framework and carefully explained to participants. Confidential information was only seen by researcher and study supervisors, and in accordance with the Data Protection Act (1998, The Office of Public Sector Information, UK Government) and NHS policy. All data was anonymised, where identifiable information was removed and participants were given a pseudo-name.

Electronic data was stored in a secure data file on an encrypted data stick, only accessible to the study investigators. In the case where identifiable information is necessary to be held, was stored electronically and password protected. Data will be kept for up to a period of 5 years before being destroyed.

Confidentiality of email records with participants was maintained in accordance of the Data Protection Act and NHS confidentiality policy. A secure NHS email address was used and accessed only by the researcher. Email records will be deleted immediately following study completion.

Participants were informed that if they disclosed any information which was considered risky, e.g. that an adult or child was at risk of being harmed/hurting someone else, that the researcher had a duty of care to inform the relevant party, e.g. local safeguarding teams, the police, etc. No risk information was disclosed during interviews.

Dissemination of results

All participants were offered a summary of the study. The researcher will also disseminate study findings to local services, and will aim to publish the research in a peer-reviewed journal.

References

Lau, W. Y., Peterson, C. C., Attwood, T., Garnett, M. S., & Kelly, A. B. (2016). Parents on the autism continuum: Links with parenting efficacy. *Research in Autism Spectrum Disorders, 26*, 57-64. doi:10.1016/j.rasd.2016.02.007

National Institute for Health & Clinical Excellence. (2012). *Autism: The NICE guideline on recognition, referral, diagnosis and management of adults on the autism spectrum*: The British Psychological Society & The Royal College of Psychiatrists.

Appendix Z - Example Table of Illustrative Quotes for Superordinate Theme 1

The parent-child relationship: 'intune-ness' vs a 'clash'

Subordinate	Key quotes
Knowing child needs	Neil: "*So for my own experience of having been a child, and thought that way, and I'm looking at [child] thinking same way too. That kind of enabled me to connect a little bit because I kind of understood, firstly not to touch this stuff, but also to ask the sorts of questions. Because I knew what was going on in his head. A little bit about how he was dealing with all these patterns and stuff."* (line 258-262) Emily: "*…it's helpful because of the way that I am…I can go 'well that's going to be too much them. I'm not even going to attempt that*.'" (line 75) Emily: "*Because of the way that I am…it's very sort of…their needs just fit in with the family*." (58) Rose: "*But I've been through that and knew what it was like. I spent most of my childhood and my teenager years, feeling that panic. So I was just like, ok from my experience I'm going to teach you. I didn't learn this sort of self-care stuff until I was way too old and I want to give you the tools while you're way younger*." (271) Tanya: "*I get a lot of [child's] behaviours I just have an instinct."* (line 166). Sarah: "*I think it's just an intune-ness that something [husband] doesn't naturally tune into.*" (123) Sarah: *"He likes what he likes."* (line 87) Kate: "*There's nothing wrong with her. It's just the way she is. And she can't change that*" (line 88) Tanya: "*And I think sometimes when [child] is in the zone, you can't reason with him. And just accepting that communicating with him when he's ready*." (line 321)

	Hilary: "*they are who they are and they're brilliant*." (391) "Kate: "*It's quite nice that I can understand her…that I can translate."* (line 302) Sarah: "*I do get it…more naturally than [husband]"* (line 139). Neil: *"I can see a few things in there that other people probably couldn't."* (line 355) Tanya: "*he can be very rigid and I just got it. Like [husband] will be like 'but why'? And I'm like, well I understand*." (504) Rosie: "*So I was teaching him all this stuff from a young age, and people are going, 'is that appropriate?' And I'm like,' I think it's really appropriate*" (87) Sarah: "*I don't know if it's him that drives it, or me that drives it, or both together…*" (line 62)
Clash of needs	Sarah: "*a clash of compulsions*" (169) Emily: "*And then if [child]'s shouting and all I'm really trying to do is…kind of calm myself…there's sort of 3 people who really want their needs met. And they want me to solve it. And they look to you, and actually all you want to do is sit in the corner going "No! [laughs] I can't!..I can't do it*!" (line 147) Emily: "*If we're a bit close to each other, that's difficult. We do our best….but I think that's where we probably struggle the most, because I struggle probably most with sensory difficulties. And so that's our main kind of clash."* (line 458) Emily: "*And it's awful because they're your children and people want their kids on me all the time*." (461) Hilary: *"It's chaotic because because we're four individuals pulling in opposite directions sometimes."* (line 84) Neil: "*there is more understanding, but that doesn't necessarily lead to a happier household because you both got those needs*" (456) Kylie: "*I end up shouting at him. Which makes it worse. Which then makes me worse*." (line 39)

	Emily: *"But if everybody's kind of heightened….I'm heightened as well. And we've got this kind of triangle of people….Often need a break from each other. But we haven't really got anywhere to go."* (line 118) Neil: "*you're right in the middle of a social situation where your help is needed with the children, so you can't just walk away into a darkened room for 10 minutes and recalibrate. You have to be there. That can lead to, if it's not managed well, those sort of tensions can build on each other***"** (146) Sarah: *"But sometimes I have to sort of step back and think am I missing the fluffy stuff"* (line 204) Tanya: "*if it's particularly disruptive…I sometimes wonder if, you know, am I equipped? Can I do this?"* (209) Neil: "*one of the unknown questions is having an autistic child with an autistic parent going to inflame the situation…" (451)*
Overcoming the clash	Emily: "*Going back to what you said about the fact that sometimes there's like a triangle of you 3, when you're all heightened. What's that like?* *It's really difficult. Because as the parent, you have to put their needs first…And both of them in their own ways are pushing me. She's such a crier and that really…I find that really difficult to process. And then if E's shouting and all I'm really trying to do is…kind of calm myself…there's sort of 3 people who really want their needs met. And they want me to solve it. And they look to you, and actually all you want to do is sit in the corner going "No!" [laughs] I can't..I can't do it."* (line 143) Sarah: "*There's just some of the more day-to-day stuff can be a little bit…ugh OK. Need to get this sorted. Because if they have to get their eyes checked and I don't feel like going into town that day…it's tough. I have to do it…"* (line 300) Rose: "*I just think choose your battles and compromise. There are times when you have to deal with the situation, but other times you can compromise and just let it go. Be easy." (427)* Neil: "*Over time you worked out what you can do to support those situations and diffuse them. But it changes of course. So what was true a year ago in terms of helping…back chain how put on your trousers*" (100)

	Tanya: ““*I really needed a wee. But I had to put all of that to one side, which you know is a daily occurrence in that respect*” (line 247) Hilary: ““*And us all trying to work with each other*.” (85) Kylie: “*Now I've been told it's all down to his autism. I try and think now, before saying that stuff.* ” (286) Emily: “*Because you can’t just let kids…there has to be boundaries*” (line 251) Emily “if *it was just all gonna be the way I thought it should be…we’d never get anywhere. But it’s a fine balance. Because you can’t just give them what they want. You have to be like…put…restrictions*.” (line 250) Tanya: “*And I was at that point where I thought I really don't know what to do. Does autism rule? We have to, you know,…there's so many times over the years that we've not been allowed to speak or move or do stuff because he just was just so overloaded. So I wasn't sure what to do*” (292) Kylie: “*I don't want to give in to him all the time but it's the easiest way until until…we've got a proper full understanding of everything*.” (129) Rose: “*When you've got a toddler who is autistic and everything is a massive situation, you have to choose your battles, because if you are fighting them on everything, it's really exhausting. So there are some occasions when like we have to go down to the lift, we have to get off the escalator. We have to but there are other things where you're like actually, no, this is not, yeah, go ahead, do your thing, you know*” (383) Emily: “*So I was trying to learn…but actually I had to learn from him*.” (line 266) Tanya: “*he's very good at telling us what we should have done to help him in that moment*.” (324)