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Exploring the experiences of parents whose son or daughter has received a diagnosis of Asperger's syndrome in adulthood

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Contents

Systematic Literature Review

UK parents' experiences of their child receiving a diagnosis of Autistic Spectrum Disorder: A systematic review of the qualitative evidence

Abstract

The purpose of this article is to systematically identify, appraise and synthesise qualitative research concerning UK parents' experiences of their child receiving a diagnosis of Autistic Spectrum Disorder (ASD). Eleven articles were located through a systematic search of five databases, reference lists, citations and grey literature which were then critically appraised and their results synthesised using a meta-ethnographic approach. Five constructs were created to synthesise the results of the reviewed studies which explored parental pre-diagnostic and diagnostic experiences, their reactions to, and how they adapted to the diagnosis, and their perceptions of post-diagnostic support. The quality of included studies was variable and so suggestions are made to improve reporting of future research. The findings should be considered by professionals working with children, particularly those directly involved in diagnosing ASD.

Key Words

Systematic literature review, Qualitative research, Autism Spectrum Disorder, Diagnosis, Parents, Metasynthesis

Introduction

Autism Spectrum Disorder (ASD) is an umbrella term used to describe a range of inter-related neurodevelopmental conditions with shared core symptomology of impaired social interaction and communication abilities and stereotyped or restricted patterns of activities, interests and behaviours which have a significant impact on the individual's functioning. ASD falls under the category of Pervasive Developmental Disorders in the Diagnostic and Statistical Manual (DSM-V) (American Psychiatric Association, 2013) and the International Classification of Disease (ICD-10) (World Health Organisation (WHO), 1993).

The prevalence of ASD in childhood is estimated to be roughly 1% and is more common in boys than girls with a ratio of 3 – 4:1 (Baird et al. 2006; Green et al. 2004).

Although many parents are aware of differences in their child's development from 18 months old (Howlin & Moore, 1997), ASD is often not diagnosed until school entry age (Brett et al., 2016). Factors such as proximity to services and limited service availability may impede early diagnosis (National Autistic Society (NAS), 2003).

The National Institute for Health and Care Excellence (NICE) (2011) and NAS (2003) recommend that a number of items should be included in all ASD diagnostic assessments: Questions about the parent's/carer's concerns; a chronology of the child's life and a description of their current functioning; assessment of social and

communication skills and behaviours through interaction and observation, assessment cognitive abilities, medical history and physical examination. It is also important to consider differential diagnosis and comorbidity.

Diagnosis can alter the family context and result in parents experiencing a loss of their own identity, sense of self, and their role (Atwood & Gallo, 2010). They may also experience ambiguous loss (Boss, 2004) related to the discrepancy between their original hopes and expectations for their child and the new reality, and identity ambiguity due to changes in the parent-child relationship and the lack of boundaries and clarity of the identities of the parent and child. It is important to understand parent perceptions of the process and responses to diagnosis in order to make improvements and provide the best possible support to help parents accept and adapt to their child's condition.

Although there is one existing review concerning the parental experience of having a child diagnosed with ASD (Chua, 2012), this was not systematic, it was mixed-methods and included studies from all over the world. Therefore, the current review will focus only on the experiences of UK parents to gain a better understanding of the diagnostic process in this specific cultural context and will draw together the detailed accounts of parents contained in qualitative studies in order to inform practice.

The aims of this review were to:

1. Systematically identify qualitative research concerning the experiences of UK parents of their child receiving a diagnosis of ASD or AS;
2. Appraise the quality of the identified studies;
3. Synthesise the results of these studies using a meta-ethnographic approach.

Methods

The review was approached from a critical realist epistemological position which assumes that knowledge of reality is mediated by our beliefs and perceptions (Maxwell & Mittapalli, 2007).

Inclusion criteria

Articles were included if they were:

- written in English
- reported original qualitative research using a recognised qualitative methodology
- explored UK parents' experiences of their child receiving a diagnosis of AS or ASD before the age of 18 years old.

Studies employing mixed methods were included only if it was possible to extract qualitative data separately. If the research included professionals or children

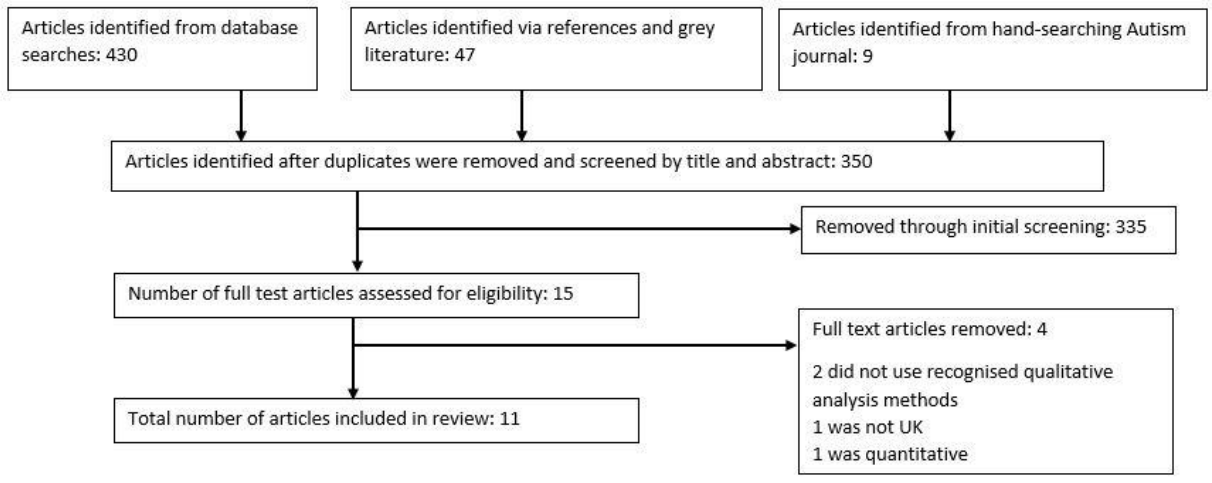
themselves, studies were only included if the data from parents could be extracted separately. There were no specific exclusion criteria so long as the above inclusion criteria were met.

Search procedure

A systematic search using Medline, CINAHL, PsychInfo, Embase, Autism databases was conducted on 3rd July 2017. These databases were selected as they were deemed to be relevant to the field concerned. The search terms used in PsychInfo were: parent* OR mother OR father OR maternal OR paternal OR guardian OR carer; experience OR view OR opinion OR attitude OR perception OR reaction OR response; diagnosis OR recognition OR assessment OR evaluation; autism OR ASD OR ASC OR AS OR Asperger OR "autistic spectrum disorder" OR "autistic spectrum condition" OR "autism spectrum disorder" OR "autism spectrum condition"; Qualitative OR mixed methods. Equivalent search terms were used in all databases. If the database had an option of selecting by geographical area, "UK and Ireland" was selected.

In order to optimise the search, reference lists of the articles selected and articles citing the included studies were searched to identify further studies. The journal Autism was also hand-searched for further articles as a number of the articles selected had been published in that journal. Grey literature databases OpenGrey, Grey Literature Report and EThOS were also searched to overcome publication bias. See Figure 1 for a flow chart of the search procedure.

Figure 1: Flow chart detailing the selection of studies



Critical appraisal

An expanded version of the Critical Appraisal Skills Progamme (2017) tool with 17 quality criteria was used to provide more evidence about quality of studies. A score of zero was given if the criteria was not met, one if it was unclear and two where it

was definitely met. This review used quality appraisal to further explore studies rather than to exclude them.

Synthesis of findings

Currently, there is no standard method for synthesising qualitative studies, but as meta-ethnography (Noblit & Hare, 1988) is argued to be the most well-developed method for this purpose and originated in the interpretive paradigm similarly to most methods of qualitative research (Britten et al., 2002), this method was selected for performing the meta-synthesis.

Meta-ethnography involves induction and interpretation of data with the aim of synthesising ideas and concepts across studies. The three different methods of synthesis in meta-ethnography are reciprocal translation which is used when concepts across studies are similar and can be grouped together either by using an existing concept or by developing a new overarching concept; refutational synthesis which involves exploring and explaining conflicting and contradictory accounts; and line of argument synthesis which involves drawing together all of the concepts identified (Noblit & Hare, 1988) into a coherent whole.

Data are collected into first, second and third order constructs (Britten et al., 2002). First order constructs are participant's accounts of their experiences, second order constructs are the studies authors' interpretations of participant's accounts expressed as themes and concepts, and third order constructs are themes and constructs developed from the second order constructs by the researcher conducting the synthesis.

Results

Data abstraction

Eleven studies were included in the review. Table 1 contains the general characteristics of the studies. Each study is assigned a number that will be used to refer to it throughout the review. The total number of participants is 342, with 217 fathers and 125 mothers. No participants were identified as non-parental carers or guardians. All except two studies (8, 9) used semi-structured interviews to collect data, with one (9) using a textual response to an open question on a postal survey and the other (8) using focus groups. All studies used one-off interviews except one (11) which interviewed at two time-points. Thematic Analysis (or variants of) was the most commonly used method of analysis. All studies used audio recording and verbatim transcriptions, except 3 and 10 which used field notes and 9 which relied on a written response.

Table 1: General characteristics of included studies

Study Number	Authors, year, location	Aims	Qualitative data collection method and recording method	Sample	Data analysis method	Key findings
1	Abbott et al., 2012	To investigate the experiences of parents of receiving a diagnosis of ASD for their child in a CAMHS service	Semi-structured interview (SSI) Audio-recorded	9 mothers and 4 fathers of children diagnosed by the service	Inductive Thematic Analysis	• Feedback session was anxiety-provoking and had a significant emotional impact. • Structured and focussed approach was valued. • The parent-clinician relationship was highly important. • Waiting for the assessment was frustrating.
2	Avdi et al., 2000	To explore how parents whose child was undergoing assessment for ASD in a Child Development Centre(CDC) constructed professionals with regards to expertise, knowledge and power.	SSI Audio-recorded	3 mothers and 2 fathers of children undergoing assessment at the CDC	Discourse Analysis	• Professionals were represented as withholding information and scrutinizing parents and child as well as providing help, guidance and support. • Parents admired the professionals expertise and were grateful for the service they received.

3	Braiden et al., 2010	To provide insight into parents' experiences of the process of diagnosis of ASD for their child.	SSI Field notes	11 mothers whose child had received an ASD diagnosis in the previous 18 months.	Long Table Approach	• Diagnostic process was a stressful and challenging time. • Diagnostic process was hard to understand and parents did not know which professionals were involved or what their roles were. • Parents were unaware of potential support available following diagnosis. • Levels of satisfaction with the process were variable.
4	Craig, 2015	To explore young people and their parent's experiences of assessment, receiving and living with a diagnosis of ASD.	SSI Audio-recorded	4 mothers	Interpretive Phenomenological Analysis	• Long journey to diagnosis and struggles to make sense of child's difficulties. • Diverse emotional responses to receiving diagnosis. • A number of factors influenced acceptance of diagnosis. • Having a diagnosis gave access to support and helped with adjusting future expectations.

5	Evans, 2010	To examine parents' responses to their child's diagnosis of ASD, their future expectations for their child, and to identify factors influencing their uptake of early intervention programmes.	SSI Audio-recorded	12 mothers and 3 fathers of children diagnosed with ASD in last 2 years.	Thematic Analysis	• Parents' responses to their child's diagnosis could be broadly categorised as positive or negative, and were influenced by prior expectations about child's difficulties. • Fathers had more difficulties with accepting diagnosis than mothers and employed different coping strategies. • Some parents wanted time to process the diagnosis before becoming involved in any support or intervention.
6	Griffith et al., 2013	To obtain the views of parents/carers about the diagnostic process and follow up to identify gaps in service provision.	SSI Audio-recorded	7 mothers and 3 fathers whose children were assessed by autism services in North Wales in 2009.	Thematic Content Analysis	• Majority of parents were positive in their appraisal of the diagnostic teams. • Frequent criticisms were the lack of support during and after the assessment, and the brief amount of time some clinicians spent directly assessing the child.

7	Midence & O'Neill, 1999	To explore parent's experiences of their child's diagnosis of autism in North Wales	SSI Audio-recorded	3 mothers and 3 fathers of children with a diagnosis of ASD	Grounded Theory	• Highlighted need for early diagnosis and better recognition of developmental problems in young children by health professionals. • Once diagnosis was given, parents were better able to understand their child's behaviour, accept the condition and the child's limitations, and make realistic plans for the future. • Parents considered that autism was an integral part of their child that they couldn't imagine not being there.
8	Osborne & Reed, 2008	To gain parental perceptions of the ASD diagnostic process across several local authorities and to elicit ideas about what would improve the process.	Focus group interviews Audio-recorded	76 mothers and 18 fathers of children diagnosed with ASD in the preceding 7 years.	Content Analysis	• Parents wanted a quicker and easier process with a more coherent structure and content. • Parents suggested that information leaflets provided at the time of diagnosis could be valuable. • Following a period of adjustment to the diagnosis, parents suggested that they would like more information about the range of intervention and educational programmes available and local support groups.

9	Potter, 2016	To explore father's reactions to their child receiving a diagnosis of autism	Textual response to open question on a survey	184 fathers of children diagnosed with ASD.	Inductive Thematic Analysis	• Some fathers had not felt sufficiently included in the diagnostic process. • The delivery of the diagnosis was criticised for being unduly brief with a lack of sensitivity and a focus on negative aspects. • A lack of adequate information and support at the time and following diagnosis was highlighted.
10	Russell & Norwich, 2011	To ascertain how parents influence which children with autistic symptomology receive a formal ASD diagnosis and to examine the function of an ASD diagnosis for parents and whether it affects their perception of ASD	SSI Field notes	15 mothers and 2 fathers, 8 of whom were not pursuing a diagnosis and nine whose children had received an ASD diagnosis.	A modified form of constant thematic analysis incorporating elements of comparative method	• Parents either retain the 'normal' status of their child by resisting diagnosis or 'normalize' them through identification of ASD and attempts to change society's attitude by reframing and de-stigmatising ASD. • Parental reactions to ASD diagnosis involves four stages: pre-diagnosis, diagnosis, post-diagnosis and acceptance and adaptation. • Parents adopted medical and social models of disability strategically in order to reposition themselves and their children.

11	Slator, 2012	To illuminate the process of parental meaning-making of a diagnosis of ASD.	SSI's at 2 time points Audio-recorded	5 mothers and 2 fathers of children diagnosed with ASD in last 3 years.	A combination of structural and thematic narrative analysis	• Narratives of many parents were saturated with themes of struggles and battles with services. • Strong theme of social isolation due to a lack of understanding and awareness of the difficulties associated with ASD by others. • The narratives of understanding, greater self-belief and confidence in their role as parent and their ability to integrate multiple roles and hope grew over time.

Quality appraisal

The overall quality of the studies was variable, with total scores ranging from 21 (8) to 34 (4 and 5) (see Table 2). It is important to acknowledge that those studies receiving the highest quality scores were both doctoral theses and so were not restricted by word counts imposed by journals.

All studies reported their aims clearly, appropriately used qualitative methodologies to meet the aims of their research and clearly reported their method of data collection, as well as their findings. All clearly used appropriate samples, with the exception of 3, which provided scant detail about the recruitment process. All studies contained contradictory accounts, and all but two (3 and 8) provided sufficient data to support the themes reported.

Only five studies (1, 2, 4, 5, 11) provided information about the role of the researcher, for example the potential to introduce bias when formulating research questions and collecting and analyzing data. This is problematic because of the subjective nature of qualitative analysis, and so without this information it is difficult to fully evaluate these studies.

Reporting of ethical approval and standards was variable. The majority of studies (1, 4, 5, 6, 9, 10, 11) stated that approval had been obtained, but study 3 did not seek it as the research was deemed to be an evaluation. Three (1, 7, 8) provided no information to assess ethical standards, and information provided by the remaining studies (except 4 and 5) was limited.

The findings of all studies were clearly presented and contributed to developing understanding of parents' experiences of their child undergoing diagnostic assessment for ASD. Four studies (6, 8, 9, 10) failed to discuss the credibility of their findings. Six of the studies (2, 4, 5, 7, 9, 11) identified new or further research ideas.

Table 2: Quality appraisal of included studies

Study number											
Quality criteria	**1**	**2**	**3**	**4**	**5**	**6**	**7**	**8**	**9**	**10**	**11**
Clear statement of aims	2	2	2	2	2	2	2	2	2	2	2
Qualitative methodology appropriate	2	2	2	2	2	2	2	2	2	2	2
Research design appropriate	2	2	2	2	2	2	2	2	1	2	2
Recruitment strategy explained	2	1	1	2	2	2	1	2	2	2	1
Recruitment strategy appropriate	2	2	1	2	2	2	2	2	2	2	2
Data collection method clear	2	2	2	2	2	2	1	2	2	2	2
Form of data clear	2	2	2	2	2	2	2	2	2	2	2
Critical examination of researcher role and potential for bias	2	2	0	2	2	0	0	0	0	0	2
Ethics committee approval mentioned	2	0	1	2	2	2	0	0	2	2	2
Sufficient information to assess ethical standards	0	1	1	2	2	1	0	0	1	1	1
Detailed description of analysis	2	2	2	2	2	2	2	0	1	1	2
Sufficient information to support themes	2	2	1	2	2	2	2	1	2	2	2
Contradictory data taken into account	2	2	2	2	2	2	2	2	2	2	2
Clear statement of findings	2	2	2	2	2	2	2	2	2	2	2
Discussion of credibility of findings	2	1	2	2	2	0	2	0	0	0	2
Clear contribution to existing knowledge and understanding	2	2	2	2	2	2	2	2	2	2	2
New areas of research highlighted	0	2	0	2	2	0	2	0	2	0	2
Total	**30**	**29**	**25**	**34**	**34**	**27**	**26**	**21**	**27**	**26**	**32**

Results of synthesis

Using the synthesis process described above, five main third-order constructs were developed from the results of the included studies to answer the question about UK parents' experiences of their child receiving an ASD diagnosis. These were pre-diagnosis concerns, confusion and dilemmas; the diagnostic assessment process; reactions to diagnosis, post-diagnosis acceptance and adaptation; and post-diagnostic support. Third order constructs and sub-themes are presented (see Table 3) with identification of studies contributing to each. These are elaborated on with supporting evidence from first and second order constructs.

Table 3: Cross-comparison of studies

	Study number										
Third order constructs and subthemes	1	2	3	4	5	6	7	8	9	10	11
Pre-diagnosis concerns, confusion and dilemmas											
Recognition of differences/concerns			*	*			*	*	*	*	
Confusion				*			*				
Dismissal of concerns by others			*			*	*				*
Dilemma around seeking diagnosis									*	*	*
Diagnostic assessment process											
Timing	*		*		*	*		*	*		
Communication and interaction with clinicians	*	*	*	*	*	*		*	*		
Structure and content of assessment	*		*			*					
Reactions to diagnosis											
Relief	*			*	*		*	*	*		
Negative emotions	*			*	*		*		*	*	
Gender differences					*				*		
Post-diagnosis acceptance and adaptation											
Gaining information				*			*			*	*
Time				*							
Incorporating the diagnosis into understanding of child				*			*				*
Post-diagnostic support											
Benefits and positives of support			*	*	*	*	*	*	*	*	
Lack of post-diagnostic support			*	*	*	*		*	*		*
Active support seeking					*	*		*	*	*	*
Improvements and desired support						*		*			

Pre-diagnosis concerns, confusion and dilemmas

Parents in seven studies (2, 4, 5, 8, 9, 10, 11) discussed their own or professionals' recognition of their child's differences in language, communication and behaviour. For parents who reported having no concerns, this recognition came as a shock, whilst for those who had an awareness, there was tension between wanting professionals to corroborate their concerns and simultaneously hoping they would deny evidence of any impairment.

In two studies, (4, 7) parents described their struggles to make sense of their child's behaviour and their resulting feelings of guilt and self-blame:

> I worried so much that I didn't give this child any faith to grow and I was arresting her development, and I believed it until the day they diagnosed her. (Midence & O'Neill, 1999, p.278)

Parents in four studies (4, 7, 8, 12) who had recognised differences described their struggle to make themselves heard by professionals such as GP's:

> …You were called a liar. We went to the doctor time and time again, and they said no, there is nothing wrong with this child. The GP wrote in the medical records: her mother is neurotic…. (Midence & O'Neill, 1999, p. 279)

Parents in three studies (10, 11, 12) described experiencing a dilemma around whether to seek a diagnosis for their children or not and discussed weighing up the pros and cons of the different courses of action.

The diagnostic assessment process

Six studies (1, 4, 6, 7, 9, 10) discussed issues related to timing of the referral or assessment process. Whilst some parents were satisfied with the length of time they had to wait for a referral, others found the process overly long, slow and frustrating. There were similarly mixed opinions about the time it took for assessments to be completed.

> I'm very, very bitter at the delay that we've had with our son (Osborne & Reed, 2008, p. 316)

Communication and interaction with clinicians was discussed by parents in eight studies (1, 3, 4, 5, 6, 7, 9, 10). On the whole, parents were positive about these interactions and clinicians were reported to be relaxed, approachable, patient, open, honest and transparent. Parents valued being listened to and appreciated when clinicians were positive about their child, expressed optimism about the child's future and their abilities as a parent:

> It's nice that somebody says you're doing a good job - it makes you feel a little bit happier. (Abbott et al., 2012, p. 378)

They were also complimentary about how the clinicians had interacted with their children during assessments.

Although parents in study 2 held some positive views of clinicians, they also constructed them as having privileged access to information and carefully controlling its disclosure. They were also portrayed as judging and scrutinizing of parents, and the power they held as being potentially threatening which impacted on parents' ability to be honest:

> When you've got a child like this, you start feeling that you are losing control, the last thing you want to do is tell other people about it because there is a big stigma attached to it, if you say, "I thought I was going to kill him" people will say "she should have her kids taken off her" and that's really, really frightening. (Avdi et al., 2000, p. 333)

Some parents were satisfied with the way in which their child's diagnosis was communicated, describing clinicians as sensitive and professional, whereas others expressed disappointment. For some, this was about the method in which the diagnosis was given (for example, a brief letter or telephone call), whilst for others, it was about the perceived lack of empathy and sensitivity of the clinician.

Study 10 was the only one to explicitly discuss father's perceptions of the diagnostic process. Fathers in this study reported that they had felt excluded and largely ignored in favour of the child's mother:

> I felt unheard – all the focus was on his mum. (Potter, 2016, p. 101)

Studies 1, 4 and 7 reported parents' views on the structure and content of the assessment. Some reported satisfaction with the comprehensiveness of the history taking, the opportunity to review the assessment process in detail, and the chance to observe some direct assessments. Conversely, some parents reported that they thought clinicians did not spend enough time interacting with and observing their child or were disappointed that they were not shown recordings of the assessments.

Reactions to receiving the diagnosis

Parents in six of the studies (1, 2, 5, 6, 8, 9, 10) reported experiencing relief and vindication when their child received a diagnosis as it offered an explanation for their difficulties, confirmed their suspicions or offered reassurance that their child's difficulties were not due to inadequate parenting.

However, parents in six studies (1, 2, 5, 6, 8, 10, 11) expressed experiencing strong negative emotional responses to the diagnosis, even when there had been prior concerns. Parents described feelings of loss, grief, shock, anger and confusion, and several used visceral language to describe the intensity of their physical responses:

> …like being hit with a sledgehammer… (Evans, 2010, p. 54)

Gender differences in parents' responses to diagnosis were highlighted in studies 6 and 10 with fathers seeming to find it harder to reconcile themselves to having a child with ASD.

Post-diagnosis: Acceptance and adaptation

Four studies (5, 8, 11, 12) discussed how parents came to accept and adapt to their children's diagnoses of ASD. Gaining information about ASD had increased parents' confidence in understanding their child's behaviour and developing strategies for managing this. Some parents discussed the importance of incorporating the ASD diagnosis into their child's identity:

> …We cannot imagine her without it, not any more. Autism is an integral part of her, it is not a problem any more. (Midence & O'Neill, 1999, p. 281)

Only one study (5) mentioned the role of the passage of time in developing acceptance.

Support and information provision

The types of support parents received during the diagnostic process and in the post-diagnostic period was very varied and individual. Parents in studies 4, 5, 6, 7, 8, 9, 10 and 11 who had received information and support were appreciative and spoke positively particularly about support from professional services

Parents in six studies (4, 5, 6, 7, 9, 10, 12) reported that they felt like they had been abandoned by services after the diagnosis and were highly disappointed and frustrated by the lack of support. In studies 6, 7, 9, 10, 11 and 12, parents described the lack of readily available and easily accessible support and their ongoing efforts to secure this

> It would be nice if once you fell into the category you automatically, everything got fed through to the relevant parties, so maybe they would come to your door and say "Look, we are here to help you, instead of you having to find out which doors you might get some help from and then go banging on them, you know, begging almost. (Evans, 2010, p. 67).

Parents in studies 7 and 9 made recommendations for improving support such as providing more guidance on accessing support; receiving support during and after diagnosis from a keyworker; better communication, continuity and joint-working between services; professionals to be more available and easily contactable; more training for professionals such as GPs, teachers and nursery staff in recognising ASD and supporting children with ASD; and better access to and availability of respite care.

Discussion

The aim of this review was to synthesise qualitative accounts of UK parents' experiences of their child being diagnosed with ASD. Five themes, with subthemes, were identified to capture this experience. Participants' experiences varied widely even within individual studies, and so themes reflect these contrasting views.

There was evidence from some of the reviewed studies that parents experienced major dilemmas before seeking an ASD diagnosis for their child. Parents appeared to experience conflict between wishing to hold on to the "normal" status of their child due to the perceived threat that the label could lead to damaging prejudices and discrimination by others (Scheff, 1974) and may even create self-fulfilling prophecies (Nadesan, 2013), and the belief that having a label could help them to better understand and manage their child, provide access to support and may be used to deflect blame that their child's behaviour was the result of inadequate parenting (Hinton & Wolpert, 1998). Baron-Cohen et al. (2008) advocate for changing the terminology we use to describe ASD from "disorder" to "condition", and Kapp et al. (2013), who are proponents of the neurodiversity movement, argue that increased awareness of ASD and celebrating it as a positive, valid and equal but different identity may decrease stigma and encourage parents to seek diagnosis.

Fewer professionals recognised concerns about children than parents did and worryingly, there were also some reports of parents being labelled as neurotic or overly anxious for expressing concerns. This lack of recognition or dismissal of concerns can significantly delay the start of intervention programmes, which have been found to be more effective the earlier they are implemented (Lord, 2000). To remedy this, NAS (2003) make a number of recommendations including the development of a team of skilled practitioners for professionals to discuss behaviours of concern with and continuous ASD awareness training for education and health professionals involved with children. Most importantly,

they argue that concerns about a possible ASD at any age should lead to the triggering of a referral to the local pathway. Implementation of these recommendations should be audited by services to assess their effectiveness.

The waiting time for a referral and completion of the assessment was argued to be too long by some parents, which again creates a delay in children receiving the intervention and services they may require. NAS (2003) recommend that first contact with parents following a referral to the CDS or CAMHS should be within six weeks of the referral date and that the General Developmental Assessment should be completed in 13 weeks, then if a Multi-Agency Assessment is required, this should be completed in no more than 17 weeks. Again, it is recommended that services internally audit their timeframes to ensure they are meeting these goals.

The communication of the ASD diagnosis and method of delivery was found to be dissatisfactory by some parents. NICE (2011) guidelines recommend that the diagnosis should be made in person, without delay and clinicians should be sensitive and use recognized good practice when doing this. They should also provide information about what ASD is and how it is likely to impact on the child and produce a written report. Online training for clinicians delivering the diagnosis of Down Syndrome to parents was found to increase knowledge and reduce discomfort (Kleinert et al., 2009), and so the development of a similar approach may be of benefit for clinicians diagnosing ASD. This could be informed by Nissenbaum et al.'s (2002) recommendations for delivering a diagnosis. It is also important for clinicians to hold in mind power differentials between themselves and clients during interactions and work to reduce these (Avdi et al., 2000).

Although most parents reported satisfaction with the content of the assessment, some parents expressed disappointment that it had not been as comprehensive as they had hoped. Both NAS (2003) and NICE (2011) provide detailed guidelines about what should and shouldn't be included in ASD assessments. Audits should be undertaken by services to ensure this is the case and parents should be informed of how long direct work with their child will last which may increase their satisfaction.

Studies which included an examination of father's perceptions of the diagnostic process highlighted their feelings of exclusion and their differential responses to the diagnosis. Therefore, post-diagnostic support should be offered to mothers and fathers as a couple or individually (Towers, 2009), and should be tailored to their gender-specific needs. For example, it is possible that fathers may

respond better to a strengths-based approach which focuses on their ability to nurture their child rather than typical support programmes offered (Oren et al., 2010).

A range of emotional responses were reported by parents in relation to the diagnosis, but these could broadly be categorised as relief or distress. For those who react negatively, the process has been likened to bereavement (Hornby, 1995) and so it is possible that post-diagnostic support for these parents could be informed by literature concerning managing grief.

Parents in some studies cited their growing knowledge about ASD as being partly responsible for their increased acceptance and adaptation. It is possible that the information gained increased feelings of self-efficacy and competence (Jones & Prinz, 2005), and learning more about the causes of ASD allowed them to employ biological and social narratives in order to reframe their child's ASD in a positive light by recognising their differences, but also their value (Norwich, 2008).

NAS (2003) states that once a child's needs have been identified, they have a right to a coordinated Family Care Plan including potential involvement from health, therapy, and social services, the Local Education Authority and the voluntary sector, and that this information should be received within four weeks of diagnosis. For some parents in studies reviewed, this was clearly not the case. NAS (2003) also endorse parents' assertions of the utility of a keyworker to advocate on their behalf, access information, provide support and attend meetings as they have been found to be effective in coordinating care for families with complex needs (Mukherjee et al., 1999).

Several limitations of the review process and the studies included in the review must be noted. Firstly, the review may be criticised for only including qualitative research. However, the purpose of this review was to synthesise and research into the experiences and views of parents which would not be explored in the same level of depth by qualitative studies, although these also offer a valuable contribution to the evidence base.

The quality of studies included in this review was variable, and although some authors suggest that lower quality studies should be excluded (Campbell et al., 2003), others argue that all qualitative studies have their merits and should be included independent of their quality (Sandelowski et al., 1997). As the higher quality studies tended to have more clearly developed themes and stronger supporting data, this review drew more from them than the lower quality papers which offered supporting evidence rather than generating new themes. It is also

important to note the variability in the frequency of use of direct quotes from the different studies. Some papers may appear to be over-represented in the analysis, but this merely reflects the fact that these studies contained a higher number of lengthier quotes which illustrated the themes well. Conversely, some studies may seem to be under-represented, but this is because they included few, brief participant quotations. Future qualitative studies could benefit from providing more direct quotes to support themes presented.

The quality appraisal tool employed in this review highlighted areas of improvement for the reporting of future qualitative research. Although papers included in this review provided clear descriptions of their aims, methods of data collection and their findings, reporting of ethical standards was generally lacking and there was limited examination of the researcher's role and their potential for introducing bias.

Conclusion

Parents tended to recognise their child's difficulties before professionals and struggled to make sense of them. Opinions were mixed about the timing of the referral and assessment process, communication with clinicians and the content of the assessment and the provision of post-diagnostic support. Parent's reactions to diagnosis could be broadly categorised as distress or relief, and gender differences were highlighted. Gaining information and understanding, and time were found to be important in parents' acceptance and adaptation to the diagnosis.

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Thesis Abstract

The aim of this study was to explore the experiences of parents of sons or daughters diagnosed with Asperger's Syndrome (AS) in adulthood and their resulting support needs. Literature regarding individuals diagnosed suggest they experience complex emotional reactions, often experience 'biographical illumination', reflecting on past experiences in a process of sense-making resulting in increased self-acceptance and self-worth. The sole study which has explored the experiences of parents of adults used the concept of 'biographical continuity' to frame the continued search for understanding of their son or daughter's behaviour and 'biographical disruption' to encapsulate the frustration and disappointment relating to the lack of available post-diagnostic support. Models and theories of adjustment to diagnosis are discussed. Literature demonstrates a lack of post-diagnostic support which is of concern to parents of adults and children, and is recognised by researchers as an important gap to fill.

A critical realist epistemological position was adopted, and a qualitative approach was taken. A total of 11 parents were recruited and took part in semi-structured interviews, either individually or with their spouses. Interviews were transcribed verbatim and analysed using inductive-deductive thematic analysis.

Three overarching themes with related subthemes were identified: (1) Arriving at diagnosis in adulthood: *Trying to make sense of differences; Decisions about seeking assessment in childhood and adulthood;* (2) Reaching a new understanding of self and child*: Emotional reactions to diagnosis; "When you put it all together, it does come to autism"; New relationships and interactions; Carer identity* and *Sharing the diagnosis;* and (3) Parents' information and support needs: *Barriers to seeking support; Decisions to seek further support;* and *"…if somebody could just hold our hands whilst we hold his".*

The findings demonstrate that parents of adults experienced broadly similar emotional reactions to parents of children, but that guilt was more prominent. The majority experienced ‘biographical illumination’, using the diagnosis as a lens through which to make sense of their child, resulting in positive changes in relationships. However, some parents also experienced ‘biographical disruption’ reflecting on their past decisions and behaviour and leaving them feeling unsure how best to support their child. Parents expressed their desire for emotional and informational support and were frustrated and disappointed by the lack of post-diagnostic support. Similarities with extant literature are discussed as well as new insights gained. The thesis concludes with my personal reflections on the experiences which motivated me to undertake the study, and the conduct of the research including the power differential between researcher and participants and my difficulty in maintaining the boundary between researcher and therapist.

Statement of contribution

1. Project design:

    Hannah Legg (with supervision from Anna Tickle and Alinda Gillott)

2. Applying for ethical approval:

    Hannah Legg (with supervision from Anna Tickle)

3. Systematic literature review:

    Hannah Legg (with supervision from Anna Tickle)

4. Recruiting participants:

    Hannah Legg, Alinda Gillott and other members of staff at the Asperger's Service

5. Data collection:

    Hannah Legg

6. Transcription:

    Interviews with Jane, Barbara and Phil, Mary, George and Susan, Tracey – Hannah Legg

    Interviews with Karen, Kate, Linda and Rita - Helen Smith (transcription service)

7. Analysis:

    Hannah Legg (with supervision from Anna Tickle)

8. Write-up:

    Hannah Legg (with supervision from Anna Tickle, Sarah Wilde, and Alinda Gillott)

List of Figures and Tables

List of Appendices

Journal Paper

This paper is prepared in line with guidelines for submission to Autism: https://uk.sagepub.com/en-gb/eur/journal/autism#submission-guidelines

Exploring the experiences of parents whose son or daughter has received a diagnosis of Asperger's syndrome in adulthood

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Abstract

Asperger's syndrome (AS) is a lifelong neurodevelopmental condition which is typically diagnosed in childhood, but there is a growing trend of diagnosis in adulthood. Research concerning individuals themselves, parents of children and of adults has found a range of emotional responses to diagnosis, and that it can prompt a process of sense-making which may be disrupted by lack of post-diagnostic support. Given the continued significant involvement of many parents in supporting their adult son or daughter with AS in their daily lives, it is vital to understand their experiences to meet their needs in understanding and adapting to the diagnosis, allowing them to continue to support their child effectively. Eleven parents of adults recently diagnosed with AS (nine mothers and two fathers) participated in semi-structured interviews. Interviews were transcribed verbatim and analysed using thematic analysis. Findings demonstrate complex emotional reactions to diagnosis and the new knowledge of the diagnosis facilitates changes in attributions, interactions and

relationships, and can result in unmet needs for emotional and relational support. These findings are of particular relevance to those involved in adult diagnosis of AS and should be used to guide conversations about expectations and consequences of diagnosis, as well as the provision of post-diagnostic support.

Keywords

Asperger's syndrome, adult diagnosis, biographical illumination, unmet needs, thematic analysis

Introduction

Asperger's syndrome (AS)[1] is a lifelong neurodevelopmental condition characterised by impairments in social interaction and repetitive, restricted or stereotyped patterns of interests, activities and behaviours without significant delays in language or cognitive development. AS was previously considered a separate entity in commonly used diagnostic systems, but was recently subsumed into the category of Autism spectrum disorder (ASD) (American Psychiatric Association, 2013; World Health Organisation, 2018). However, many individuals still use the term AS to describe their condition (Giles, 2014).

Proponents of the neurodiversity movement argue against the conceptualisation of ASD in terms of impairments, considering ASD a natural neurological variation (Ortega, 2009). They contend that it is the lack of accommodation in the social environment rather than any impairment that is disabling (Oliver, 1996), and that the value of people with ASD should be recognised and accepted by society (den Houting, 2019).

[1] As the inception of this study was prior to the change in ICD-11 (2018) classification of ASD, the term AS will be used throughout to describe the diagnosis given to the sons and daughters of the participants.

Although ASD and AS are typically diagnosed in childhood, there is a trend of diagnosis-seeking in adulthood, possibly explained by growing public awareness (Hansen, Schendel, & Parner, 2015) and difficulties becoming apparent when faced with challenges of adult life (Young, Murphy, & Coghill, 2011). When AS is suspected in adults, the National Institute for Health and Care Excellence (NICE) guidelines (2016) recommend a comprehensive assessment. However, diagnosis of AS in adulthood is challenging for reasons including lack of valid and reliable assessment measures (Wigham et al., 2019), service availability (Wigham et al., 2019), and social barriers (Lewis, 2017).

Individuals diagnosed with AS in adulthood experience complex reactions. Themes such as feelings of relief, anger, sadness and disappointment are common (Jones, Goddard, Hill, Henry, & Crane, 2014; Lewis, 2016; Powell & Acker, 2016; Punshon, Skirrow, & Murphy, 2009) as are improved self-understanding leading to increased self-acceptance, and making sense of past experiences (Lewis, 2016; Powell & Acker, 2016; Punshon et al., 2009). The sense-making process individuals engage in post-diagnosis has been framed as 'biographical illumination' (Tan, 2018) whereby individuals review their life history, facilitating a transformation of self-concept.

A large body of research describes the experiences of parents of children diagnosed with AS or ASD. Common themes include a range of emotional reactions and appraisals (e.g., Lutz, Patterson, & Klein, 2012; Mansell & Morris, 2004; Midence & O'Neill, 1999; Mitchell & Holdt, 2014; Russell & Norwich, 2012). It is possible that parents of adults may experience similar emotional responses, changes to their identity, role and sense of self as parents of younger children. However, because of the large differences (in terms rights and autonomy) between parenting an adult and a younger child and the longer time period to receive a diagnosis, it cannot be assumed that the impact will be similar.

Thus far, only one study has explored the experiences of parents of sons or daughters diagnosed with AS in adulthood (Raymond-Barker, Griffith, & Hastings, 2016). The study used the concept of 'biographical continuity' (Williams, 2000) to frame the continued search for understanding of their son or daughter's behaviour and 'biographical disruption' (Bury, 1982) to encapsulate the frustration and disappointment that ensued relating to the lack of post-diagnostic support for themselves and their child.

Lazarus and Folkman's (1984) process model of stress and coping is suggested to account for individual differences in response to diagnosis of AS, considering the role of appraisal of socio-ecological and personal resources in directing coping attempts (Punshon et al., 2009). Attribution theory (Weiner, 1985) is also relevant to parents' process of making sense of their adult child's behaviour following diagnosis as this new knowledge and understanding may result in changed attributions about causes and controllability, and affective and behavioural responses (Williams, Dagnan, Rodgers, & McDowell, 2012).

Many individuals with AS continue to require support with numerous aspects of their daily lives (Griffith, Totsika, Nash, Jones & Hastings, 2012), which for the majority is provided by their parents (Piven & Rabins, 2011). Parent-carers of adults with AS experience numerous burdens (Marsack-Topolewski & Church, 2019), often resulting in lower quality of life and reduced psychological wellbeing (Herrema et al., 2017). Part of parents' adjustment to the AS diagnosis may entail developing understanding that their son or daughter is likely to require lifelong support. NICE guidelines (2016) and the 'Think Autism' (Department of Health, 2014) strategy document recognise the potential impact on those caring for individuals diagnosed with AS or ASD and advocate that carers should have an assessment of their own needs. However, in the reality of clinical practice, this is often not the case (Raymond-Barker et al., 2016).

Lack of post-diagnostic support is of similar concern to parents of adults (Raymond-Barker et al., 2016) as it is to parents of children (Crane, Chester, Goddard, Henry & Hill, 2016) and individuals diagnosed themselves (Jones et al., 2014), resulting in feelings of frustration, disappointment, confusion and abandonment. The importance of post-diagnostic support for parents is highlighted by Crane et al. (2018), who recognise the potentially detrimental impact on parents of the discussion of difficult past experiences during assessment, and Punshon et al. (2009) who suggest that individuals and their families should have the opportunity to process the meaning of diagnosis to them with a professional.

Given the potentially detrimental impact on the psychological and emotional wellbeing of parents in light of their son or daughter's diagnosis, it is important to understand their experiences and needs. Further understanding could inform the provision of support offered to parents regarding adapting to the diagnosis and effectively supporting their adult son or daughter. Therefore, the research questions the current study will qualitatively explore are:

1. What are the experiences of parents of sons or daughters diagnosed with AS in adulthood?
2. What are parent's views on any informational or emotional support needs they have resulting from the diagnosis?

Methods

This study was approached from a critical realist epistemological position, which assumes that knowledge of reality is mediated by beliefs and perceptions shaped by external factors, and stresses the importance of context in explanation and understanding (Maxwell & Mittapalli, 2007). This position was adopted as it acknowledges that the diagnosis of AS is influenced by social, cultural, and historical factors; and that the meanings and experiences of parents are shaped by external factors. The researchers' (HL, AT, and AG)

experiences of working with adults and children with AS and ASD and their families played a role in shaping the aims and interpretations of the study.

Participants

Eleven parents (two fathers, nine mothers) participated in nine interviews (four of the participants chose to be interviewed with their respective spouses rather than individually). To be eligible to take part, participants were required to be a parent of an adult (aged 18 or above) diagnosed with AS without intellectual disability within the three to six months prior to recruitment, be able to communicate verbally in English and provide informed consent.

All participants were biological parents. Most were female (82%) and the majority of their adult children were male (91%). Almost all participants identified as White British (82%) with two being from another ethnic group. Most were married (73%) whilst the others were divorced (18%) or widowed (9%). Most of the participants' sons or daughters lived independently (56%), whilst Jane, Mary, Rita and Karen's[2] sons or daughters lived with them. Five participants were working either full- or part-time, five were retired, and one participant was unemployed. One participant disclosed that they also had a diagnosis of AS themselves.

Procedure

Ethical approval was obtained from the University of Nottingham Research and Innovation department, the local NHS Research and Development department, and the Health Research Authority.

Participants were recruited from a specialist AS service which provides multidisciplinary diagnostic assessment for adults. An opportunity sample consisting of parents attending to participate in their son or daughter's

[2] Pseudonyms for both parents and their sons and daughters have been used throughout to protect their anonymity.

assessment in the study recruitment period was used. The intended sample size was based on recommendations in relevant literature (Clarke & Braun, 2016; Guest, Bunce, & Johnson, 2006) and the final sample was determined by the number of eligible participants who agreed and arranged to take part within the time limit for completing the research.

For the most part, the initial recruitment approach was made by the clinician involved in the diagnostic appointment. Posters providing brief details of the study and the researchers' contact details were also displayed in the waiting room of this Service and an advert was placed on the Service's social media site. During the diagnostic appointment, the purpose of the study was briefly introduced, potential participants were given an information sheet and were able to opt-in to be contacted. Those who opted in were contacted 10 weeks later to arrange an interview two weeks later. Participants were given the option of a face-to-face, telephone, or Skype interview to ensure equality of opportunity. All elected to be interviewed face-to-face.

An interview schedule was collaboratively produced with clinicians experienced in diagnosing adults with AS and with a parent with similar experience to that which this study was investigating, as well as the researchers' reading of relevant literature to ensure all relevant topics were covered and questions were easily understood and acceptable. Interview topics included the impact of the diagnosis on parents' understanding of themselves and their son or daughter, their relationships, and their support needs resulting from the diagnosis.

All participants provided signed informed consent prior to being interviewed. They also completed a brief verbal demographic questionnaire to gain understanding of their personal contexts. The audio-recorded interviews ranged in length between 36 to 128 minutes (M = 77.50; SD = 30.44) and were transcribed verbatim.

Analysis

An inductive-deductive, semantic level thematic analysis was conducted recursively following the guidelines provided by Braun and Clarke (2006; 2013). The method was chosen as it enabled the production of a rich, detailed analysis of the dataset as a whole, which is beneficial when exploring under-researched areas such as the topic concerned, and was consistent with the chosen epistemological position. The inductive-deductive approach allowed for the data to first be read inductively and coded without preconceptions, then to be read through a lens of extant research in similar areas to guide coding. A semantic approach to coding was taken looking at the explicit, surface meanings of what participants said to describe their experiences in detail (Braun & Clarke, 2006).

First, transcripts were read repeatedly, and initial ideas noted. Next, initial codes of interesting features were produced and organised into meaningful groups. It was then considered how these codes fitted together to form overarching themes and subthemes with all relevant data collated. Emergent themes were discussed within the research team until agreement was reached. Next, the coherence of each theme and the ability of the themes to reflect the dataset as a whole was considered. Themes were then refined and named, and illustrative extracts were chosen. A reflexive diary was kept by the first author (HL) to maintain awareness of assumptions and biases. Initial coding of the first transcript was checked by the second author (AT) and the analysis was discussed extensively in supervision. Quality of analysis was monitored by the first author using checklists by Braun and Clarke (2006) and Elliott, Fischer, & Rennie (1999).

Results

Overview of themes

Three overarching themes with related subthemes were identified (see Figure 1 below for thematic map). The central theme of 'Reaching a new understanding of self and child' will be described in depth as this is most important for understanding the psychological impact on parents with a briefer overview of the other themes.

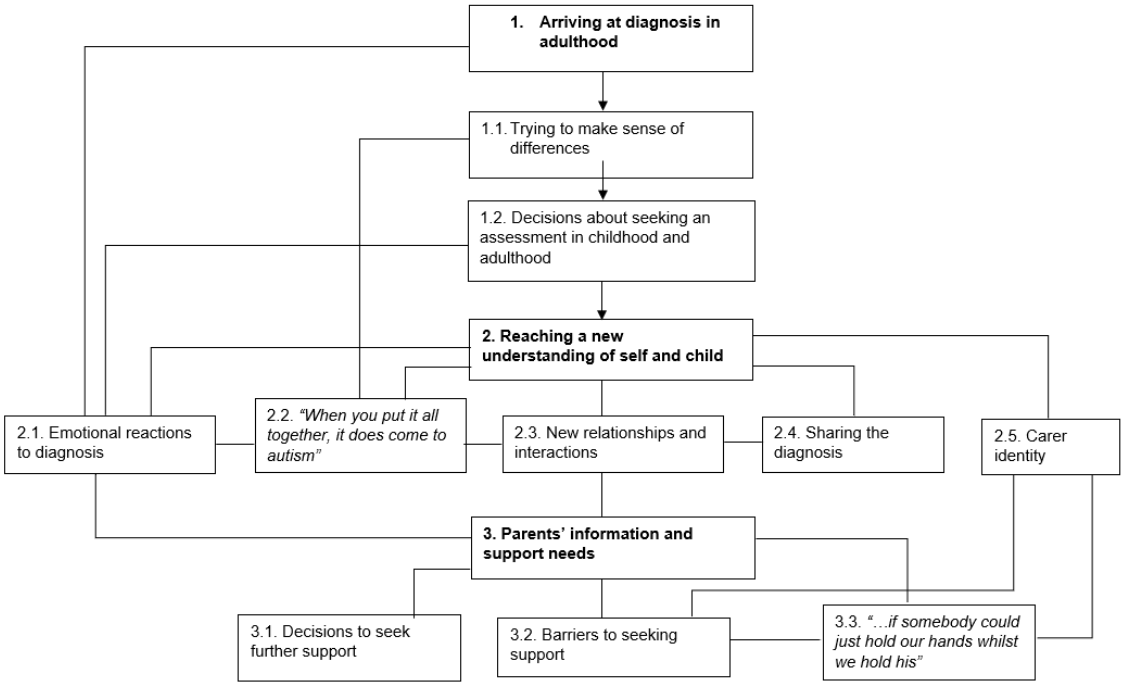

Figure 1: Thematic map.

1. Arriving at diagnosis in adulthood.

1.1. Trying to make sense of differences.

The majority of parents had recognised that their son or daughter had difficulties from school age but “didn’t know why”. This led parents to generate various attributions for their behaviour including being “a bit backward”, “fussy”, “shy”, “stubborn”, “awkward”, or “naughty”.

1.2. Decisions about seeking an assessment in childhood and adulthood.

Parents who considered their child’s differences to be pathological chose to pursue assessment. However, they were met with reluctance, blaming and dismissive responses from professionals:

> No matter who I went to see, the doctor always said it was me. It was me they decided to put on anti-depressants and I was going for help for Richard, but all the time it was “I’m spoiling him”, “I’m wrapping him in cotton-wool”. (Jane)

Some parents whose child’s differences were highlighted by professionals chose not to pursue assessment due to concerns about their child being “excluded” from mainstream education, subjected to “stigma” and the label damaging their self-esteem. Karen, having witnessed her son’s negative reaction to his dyslexia diagnosis previously believed he would have “fought” an ASD diagnosis and wanted to protect his sense of identity:

> When you’re an adolescent you don’t want to be different, you want to be the same…. So, you get a diagnosis, you’re not the same as your friends. (Karen)

Later in life, some parents’ son or daughter’s difficulties were highlighted by professionals involved in managing their mental health needs, whilst other parents were more instrumental in the referral process, raising the possibility of seeking assessment themselves in a continued attempt to make sense of their child:

> It was me that said to him last year… "why don't you go and get yourself sorted?...Go to your doctors and ask to be referred 'cos there's something wrong chemically, maybe an imbalance". (Susan)

For parents who had taken an anti-diagnosis position during childhood, re-appraisal of attributions for their child's behaviour and their own coping resources prompted the decision to seek assessment. Karen recognised that she was less able to meet her son's needs in adulthood and could benefit from support which could only be accessed via diagnosis:

> As an adult, I can't support him to socialise, I can't go out with him on dates. I can't go with him to the pub or the club. (Karen)

2. Reaching a new understanding of self and child.

2.1. Emotional reactions to diagnosis.

A range of emotional reactions to the diagnosis were expressed, reflecting the complexity of the experience. The expectation that a diagnosis would be made resulted in "relief" and "satisfaction" for some parents when the diagnosis was received. However, other parents described feeling incompetent for not having recognised the possibility of AS:

> I felt a bit useless, not realising that that (AS) was the matter. (Mary)

Some parents felt "big guilt" due to beliefs that they'd "let their child down" (George) or "failed" them by not pursuing childhood assessment further, or for their previous negative attributions for their child's behaviour and management strategies employed:

> …I did go away feeling very guilty that I hadn't tackled it over the years…it brought back lots of thinking about that and how we did deal with her and how we did cope, which made me think, yes, you know, perhaps there were lots of things I could have done differently. (Kate)

2.2. "When you put it all together, it does come to Autism".

The majority of parents could be considered to be experiencing 'biographical illumination' with the diagnosis being used as a lens through which to make sense of their child explaining sensory sensitivities, "obsessions", difficulties with relationships, differences in communication and "meltdowns", which had powerful emotional consequences for some. For example, Linda was able to attribute a different meaning to her son's response to her crying when leaving him at university for the first time, and to reflect on this humorously rather than with sadness:

> I ended up in floods of tears and he just looked, I don't know, he just looked really bewildered, you know, at why I was crying really. You know, "I've got to go now mum," and he disappeared up the road. And he looked round as if to, you know, "what the hell's the matter with you?" We laugh about that to this day, hilarious really, when you think about it. (Linda)

However, some parents could be seen as experiencing 'biographical disruption', ruminating on their past actions and decisions and having a significant and enduring impact on their self-perception:

> …it's made me feel more of a failure in the sense of, "maybe I should have done this". So yeah, it made me not be confident in myself. It's made me re-look at myself…it's made a difference to how I feel and I'm still trying to understand it. I'm not there yet". (Tracey)

2.3. New relationships and interactions.

Knowledge and understanding of the diagnosis allowed almost half of the parents to reconsider their attributions, changing their behaviour and emotional reactions. For example, Karen and Jane discussed how the diagnosis had allowed them to be more objective and not "get so frustrated and hold on to things":

> So, what I would do previously, he'd be rude and then I'd say "no, I can't talk to you, you've been too rude". And then, obviously, that just makes him anxious…. so, I don't do that now. I'll just say, OK, he's back to normal, that's fine. (Karen)

Some parents expressed how their child's diagnosis had allowed them to feel "definitely closer" to their son or daughter, enabling understanding of past ruptures in their relationship, new attributions, and forgiveness:

> **…**they've suddenly turned into a father and a son, which they've never been, not since Richard was about two or three, since he stopped reading stories at night. They had that close bond then, suddenly that close bond is back. (Jane)

Other parents seemed unsure whether to and how to change when considering their sons' diagnoses. Linda felt a greater need to protect and care for her son, possibly reflecting her concern about stigma, but felt she had to fight the urge not to "smother him", be "overly clingy" or "too clucky":

> I don't know, I just feel, now that he's got this, you know, label, I just feel maybe I should look out for him more than I would my other son, whether that's right or not. (Linda)

Tracey experienced conflict as she had some doubt about Kele's diagnosis believing him to be "capable" of learning and understanding that "there are certain things that aren't acceptable", but also wondered whether she was unfairly overestimating his abilities:

> Am I being harsh in my expectations and it's that he can't help it? Is it that I am misjudging things?...I don't want to enable him and excuse certain things. But am I right? Am I wrong? I don't know. (Tracey)

Several of the parents discussed how their son or daughter's diagnosis had led to positive changes in their relationships with their spouses. Barbara described how she used to "fall out" with Phil over his handling of situations with

Logan creating “great animosity” between them. Since the diagnosis, Phil’s changed attributions towards Logan have seemingly allowed him to forgive his past behaviour, enabling him to respond with more patience and empathy:

> We can say 100% now, it’s not Logan’s fault. There was always a slight doubt in the past, “is he just being awkward with me?” So, to have it confirmed that he’s got this condition and the way he’s behaved is not his fault made me feel a lot better, knowing he wasn’t just picking on me to be nasty. (Phil)

Jane and Kate’s husbands’ improved understanding of their children encouraged them to take a more active role in caring for and supporting them, allowing the mothers to discuss their concerns more openly, resulting in a sense that they were no longer “bearing all the burden”:

> It’s a relief! It takes something off of me. I’m not the only one looking out for Richard. I leave for work at 8 am and I know my husband will get Richard up and he will get to work…I know it’s not just me running around after him. (Jane)

The diagnosis had a limited impact on behaviour, communication and relationships for several parents. For George and Mary, it seemed that this response was determined by their son or daughter’s relatively minimal need for care and support from them, whilst for Rita and Barbara, it was their perception that they already had a good understanding of their sons’ needs and were supporting them adequately.

2.4. Sharing the diagnosis.

Parents had different motivations for sharing the diagnosis with family and friends, the most common being to correct or avoid negative attributions for their son or daughter’s behaviour. Several parents mentioned that the diagnosis had given them a more acceptable way of explaining their child’s behaviour in social situations where they may be perceived as being “awkward” or “rude”.

Some parents shared the diagnosis with family in the hope that it would encourage empathy for their child as well as garnering social support, but this did not always come to fruition, leading to disappointment and frustration:

> They look at him all if he's done something or said something and I get angry with them for not understanding. (Barbara)

Other parents appeared not to have shared the diagnosis as extensively, perhaps reflecting the more minimal impact it had had on their understanding of their child. Mary's son's diagnosis of AS may have been less significant to her than her own, possibly influencing her lack of desire to discuss it with friends and family:

> I suppose it's something you don't need to talk about all the time. Unless I'm asked a question about it, I'll answer it. I suppose if you need to talk about it, you will. (Mary)

2.5. Carer identity.

Given their continued high involvement in their children's lives, the diagnosis served to reaffirm their already established carer identity for the majority of the sample. Only Karen's perception of her role changed when a professional referred to her in this way:

> Well when he had to see a clinical nurse specialist the first time, and he said to me, "you are his carer". He said, "no, you are". (Karen)

Parents whose sons or daughters had less significant needs tended not to ascribe to the carer label with Linda describing what she did for her son as "sort of a support role, I suppose".

3. Parents' information and support needs.

3.1. Decisions to seek further support.

Parents' employment experiences, existing knowledge and access to social support, and their child's care and support requirements determined their

support needs. Some parents were disappointed and frustrated by the lack of post-diagnostic support and there was a sense of abandonment:

> It was a bit like, “Logan has got Asperger’s. Thank you very much. Goodbye.” and that’s the end of it…they were lovely people, but they can’t offer us what’s not there. (Phil)

The lack of support had significant psychological consequences for some, impacting on their sense of parental self-efficacy. Tracey described feeling “lost”, “blind” and “in the dark” following Kele’s diagnosis and de-skilled in her ability to support him:

> It’s just very difficult knowing what to do, what not to do. When he was younger, I thought I did the right thing, but now he’s older, I don’t know what to do. Will I reflect again and think, “I should have done this?” You don’t want to make the same mistake twice. (Tracey)

3.2. Barriers to seeking support.

Several parents described their difficulties in accessing relevant, easily digestible, good quality information about AS, leading some to feel overwhelmed.

> I mean obviously you can look online, but you know, if you look up online, you get ten different completely conflicting things about it, won’t you?... (Linda)

Others discussed the obstacles they had encountered in trying to secure support for themselves and their children including a lack of information about high-functioning individuals and an absence of support groups for parents of individuals diagnosed in adulthood.

3.3. “If somebody could just hold our hands whilst we hold his”.

The most significant need expressed by over half of the parents was for emotional and relational support. Some parents stated this could be best met through contact with other parents of late-diagnosed children to allow normalisation and sharing of coping strategies:

> If it was just a group where there was other mums and dads that have got high functional late diagnosis where you can sit and laugh about some of your situations, but you know you're not the only one that's got that…if you'd had that experience, you could talk through how you'd got through that. (Jane)

Conversely, other parents stated a preference for "expert" involvement to support them in understanding their child's diagnosis and needs, perhaps reflecting uncertainty about how to support their children and doubts about their parenting abilities:

> Someone to ask, "OK, he's got this diagnosis. What does that mean now? Do I need to do anything? How is it manifesting in him? How's it impacting?" There's nothing there and I'm trying to just figure it out. (Tracey)

Given their unmet support needs, some parents were concerned about their children's futures with those with most involvement having the greatest concerns. This "worry" was brought into sharp relief for Rita, whose husband had died suddenly:

> I mean I'm seventy-eight, I'm not going to last forever. Obviously, my husband was eighty. That was a shock, you know, he was always fit and healthy….It brings it home more now that he's died that, you know, it could happen to me any day sort of. And what will happen to Anthony? (Rita)

Several parents expressed a desire for more information than that provided by the service, such as "proper guidance" about where to access

reliable information about AS and signposting to services concerned with benefits and supported living accommodation.

Discussion

This was the second study to explore parents' experiences of their son or daughter receiving a diagnosis of AS in adulthood. The present study differed from the first by Raymond-Barker et al. (2016) exploring the wider ramifications for parents rather than just the assessment process.

As in Raymond-Barker et al.'s (2016) study, the majority of parents had recognised differences during childhood, and some who chose to pursue diagnosis experienced unhelpful or even negative responses from healthcare professionals. This has important implications about the development of knowledge of healthcare professionals working with both children and adults in recognising ASD symptomology and having an awareness of local referral pathways to allow for earlier diagnosis and access to support.

Some parents also described having rejected the possibility of seeking diagnosis due to their concerns about stigmatisation or exclusion of their children. Proponents of the neurodiversity movement purport that viewing ASD as a different but positive and equal way of being may reduce perceptions of stigma and encourage parents to seek diagnosis (Kapp, Gillespie-Lynch, Sherman, & Hutman, 2013).

Parents' accounts demonstrated that they experienced broadly similar emotional reactions as parents of children (e.g., Lutz et al., 2012; Mansell & Morris, 2004; Midence & O'Neill, 1999; Mitchell & Holdt, 2014; Russell & Norwich, 2012) and adults diagnosed themselves (Jones et al., 2014; Powell & Acker, 2016; Punshon et al., 2009; Tan, 2018). However, although research with parents of children suggests that some experience guilt (e.g,. Midence & O'Neill, 1999), this appeared to be a more prominent emotional experience in the present study related to not having recognised the possibility of AS, not having pursued childhood assessment more thoroughly, parents' previous

negative attributions for their child's behaviour and the ways they responded to this.

Extending Tan's (2018) suggestion that AS diagnosis can engender 'biographical illumination' for those receiving a diagnosis in adulthood, the majority of the parents in this study engaged in a review of their child's life history using their new knowledge of AS to make sense of their son or daughter's sensory sensitivities, "obsessions", difficulties with relationships and communication. It also encouraged them to re-evaluate their prior attributions about the cause and controllability of their child's behaviour allowing them to forgive and reconcile difficult past interactions with their child, develop patience, empathy and tolerance, respond more sensitively to their child's communication, and build closer relationships. For some couples, having developed a shared understanding of their child had a positive impact on their marital relationships and resulted in a reduced sense of burden for mothers. Some parents shared their son or daughter's diagnosis with their wider network in the hope that they would experience the same 'biographical illumination' that they had, becoming frustrated when it did not have the impact they had hoped. However, as in Raymond-Barker et al.'s (2016) study, some parents also experienced 'biographical disruption' when they considered that they had made poor decisions and not supported their child adequately, having a detrimental impact on their self-esteem. The diagnosis also left some parents feeling de-skilled and unsure how best to support their child, perhaps relating to their appraisal of the diagnosis as threatening and their resources for coping with it as lacking (Lazarus & Folkman, 1984).

Supporting existing literature, the majority of parents in this study had significant involvement in supporting their sons and daughters in their daily lives, even when they were not living with their children (Griffith et al., 2012; Piven & Rabins, 2011). The diagnosis therefore served to reaffirm their status as carers for the majority, although this depended on the needs of the child.

Corroborating previous findings (Crane et al., 2016; Raymond-Barker et al., 2016), parents in the present study expressed their desire for emotional and relational support either through contact with professionals or peers, and guidance about where to access reliable information and relevant support services. They also expressed frustration, disappointment and abandonment regarding the lack of post-diagnostic support. Crane et al. (2018) and Punshon et al. (2009) advocate that parents should be given the opportunity to talk with a knowledgeable professional about what the diagnosis means for their family. Also, NICE (2016) guidelines state that families and carers of adults with AS should be offered an assessment of their own support needs, be given advice on obtaining practical support and in planning the future care of the diagnosed individual. However, the current findings would suggest that this is not happening in routine clinical practice, possibly due to demand exceeding available resources. Given the reported unmet needs of parents and the potential impact this may have on their ability to support their son or daughter, this is an important area to be addressed. Potential targets for post-diagnostic support suggested by the findings would be around boosting parental self-efficacy through developing understanding of how AS affects their son or daughter and building coping resources.

The findings should be considered by clinicians involved in the diagnosis of ASD in adults to allow them to prepare parents for their possible emotional reactions, the potential changes, both positive and negative, that they and their families may experience in terms of self-perception and relationships, and to encourage them to consider how they may cope with these issues. Acknowledging financial pressures on services, it is necessary that clinicians are open from the outset about the lack of support for adults with AS and their carers to encourage realistic expectations about the outcome of diagnosis. However, given the continual high levels of support a lot of the parents provided to their children and their expressed unmet needs, it is paramount that services provide good quality information about AS including useful websites to access,

and signposting to relevant local support groups and agencies who can advise on issues such as accommodation and benefits. It is also important to recognise the complexity and diversity of the experience and to tailor post-diagnostic support according to the level of need of the parent and child. The findings may also be useful to parents whose son or daughter has recently been diagnosed to allow normalisation of feelings and possibly provide hope and encouragement.

Limitations.

It is of course important to acknowledge the limitations of the study. As the sample was self-selected, it likely reflects the fact that these parents continued to have significant involvement in their son or daughters' lives, and so the findings perhaps would not reflect the experiences of parents who are less involved. The sample lacked diversity as there were only two fathers, one parent of a daughter, and two participants from ethnic backgrounds other than White British. It is important that future research attempts to recruit more diverse samples to understand any differences in experiences and needs of these groups. As most parents were interviewed individually and diagnosed sons and daughters were not interviewed at all, there is no verification of the spouses' responses or the children's perceptions of the changes in their parents. Future research could interview dyads composed of parent and child or mother and father to seek this additional understanding.

Implications for future research.

Although self-efficacy was not measured in this study, it appears that for at least some parents their son or daughter's AS diagnosis led to a decrease in parenting self-efficacy. Future research could use formal assessments to establish whether the diagnosis does in fact impact on parenting self-efficacy, then whether interventions designed to bolster self-efficacy can achieve positive outcomes.

Given that parents highlighted the need for online support forums, informational resources, and post-diagnostic support groups, future research could concentrate on the development of these through focus groups with parents of adults with AS to promote co-production and co-design of materials. These would then need to be piloted and evaluated to see whether they have any effect on parenting-related outcomes such as self-efficacy and stress, as well as seeking qualitative feedback.

Conclusion

Findings demonstrate that parents experience complex emotional reactions to diagnosis, with guilt being predominant for many, but that the new knowledge of diagnosis can facilitate changes in understanding, attributions, interactions and relationships. However, the lack of post-diagnostic support can result in unmet support needs. These findings should be considered by clinicians involved in adult diagnosis of AS to guide conversations about expectations and potential consequences of diagnosis, as well as informing the provision of post-diagnostic support.

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Extended Paper

1. Extended Background

1.1. A brief history of the diagnosis of Asperger's syndrome.

The term Asperger's syndrome (AS) was first used by the Austrian physician, Hans Asperger in 1944 to describe a sub-group of children who demonstrated social isolation or lack of social reciprocity; normal or advanced acquisition of language; a narrow and restricted focus of interest; specific cognitive strengths; and physical clumsiness. Following the translation of Asperger's work (Frith, 1991), the publication of studies by

Wing (1981; 1994), and a series of clinical studies establishing the reliability of the diagnosis (Volkmar et al., 1994), AS was included in the fourth edition of the Diagnostic and Statistical Manual (DSM-IV; American Psychiatric Association [APA]) in 1994, and similar criteria were also suggested in the International Classification of Diseases and Disorders (ICD-10, World Health Organisation, [WHO], 1992). In these diagnostic systems, the criteria for a diagnosis of AS were a triad of impairments in social interaction, communication skills and repetitive or restricted behaviour or interests with adequate functioning in other areas relative to age, and normal language and cognitive development before the age of three years.

However, the most recent editions of both diagnostic systems (DSM-5 and ICD-11) have subsumed AS and other previously separate disorders (Autistic Disorder [autism], Pervasive Developmental Disorder Not Otherwise Specified, Rett's Syndrome and Childhood Disintegrative Disorder) into the sole category of Autism spectrum disorder (ASD). Several lines of argument were provided to justify this decision. Firstly, although some studies demonstrate quantitative and qualitative differences between AS and high-functioning autism (those with intellectual abilities in the average range; Tsai & Ghaziuddin, 2014), it was concluded that there is not enough evidence to support the distinction between these groups as they have been found to demonstrate similar outcomes in adolescence and adulthood, do not show differential response to intervention, and there is limited evidence to suggest differential neurocognitive profiles (Witwer & Lecavalier, 2008). Secondly, the criteria for AS are argued to be flawed and difficult to implement in clinical practice (Mayes, Calhoun, & Crites, 2001) as they are dependent on parent memory of the child's (or adult's) language use before 3 years of age and also, as language and cognitive delay are not required for a diagnosis of ASD, most people with AS also meet these criteria. These issues have resulted in wide variation in how the diagnosis of AS is applied by clinicians (Lord et al., 2012). Thirdly, the new diagnostic

category is claimed to better reflect the consensus that ASD is best represented as a spectrum with large heterogeneity, and the categorical nature with the inclusion of dimensional descriptors means that individuals will not be forced into narrow categories which do not fit them (Happé , 2011).

Currently, ASD falls under the category of Neurodevelopmental Disorders in both the DSM-5 (APA, 2013) and the ICD-11 (WHO, 2019), characterising ASD by persistent deficits in social communication and interaction and repetitive, rigid and restricted patterns of interests and behaviour with deficits causing impairment across all areas of functioning and contexts. DSM-5 (APA, 2013) criteria have however been criticised for their poor sensitivity with a recent meta-analysis demonstrating that between 45 - 81% of people with an AS diagnosis from the DSM-IV (1994) or DSM-IV-TR (2000) would not receive an ASD diagnosis using the new criteria (Bennett & Goodall, 2016).

As the inception of this study was prior to the change in ICD-11 (WHO, 2019) classification of ASD, the term AS will be used throughout to describe the diagnosis given to the sons and daughters of the participants.

1.2. The Neurodiversity Movement.

Neurodiversity is a social justice movement which was created in response to the perceived marginalisation of people with ASD (Chamak, 2008; Ortega, 2009). Proponents of neurodiversity usually consider ASD to be both a natural variation related to neurological differences *and* a disability for which individuals require support. They adopt the social model of disability which views disability as being caused by a poor fit between the cognitive, emotional, or physical characteristics of a person and their social environment, so it is not the impairment that is disabling per se, but the lack of accommodation in the

environment to meet the person's needs (Oliver, 1996). Therefore, advocates campaign for the recognition and acceptance of the value of autistic people in society as well as services and support to meet the needs of the community (den Houting, 2019). Neurodiversity advocates are critical of interventions based on the medical model which aim to normalise, reduce or eliminate unusual but harmless behaviours (e.g., avoidance of eye contact), instead calling for services that respect autistic ways of being and improving the quality of life of people with ASD (den Houting, 2019).

1.3. The prevalence of AS and ASD.

The lifetime prevalence of AS is estimated to be one percent (Brugha et al., 2009) and remains stable across the lifespan from childhood (Baron-Cohen et al., 2009) to adulthood (Brugha et al., 2011). Large-scale studies of children generally report a gender ratio of 3–4 males:1 female (Shattuck et al., 2009), although there is variability depending on whether individuals with intellectual disability are included or not (Rutherford et al., 2016). There is wide variation in the gender ratios of adults, ranging between 2–2.4 males:1 female (Hofvander et al., 2009) and 9 males:1 female (Brugha et al., 2009) which may be explained by whether the sample was drawn from a community or clinical setting. When specifically focusing on adult diagnosis, the male to female ratio has been found to be 1.8:1 (Rutherford et al., 2016).

Over the last few decades, there has been a significant increase in the number of people being diagnosed with AS or ASD, with some estimates suggesting up to 1000% increases (Fombonne 2005). However, Fombonne (2005) cautions that rather than reflecting a true increase, the broadening of the concept of ASD may be partly responsible. Moloney (2010) also suggests that greater awareness of ASD amongst the general public and professionals, more positive perceptions of ASD particularly at the higher functioning end of the spectrum, as well as greater availability of services may also have impacted on diagnostic figures.

1.4. Assessment and Diagnosis of AS in Adults.

Although ASD and AS are most typically diagnosed in childhood, there is a growing trend of diagnosis-seeking and diagnosis of these conditions in adulthood which is thought to be linked to a growing public awareness and changes in diagnosis reporting practices (Hansen, Schendel, & Parner, 2015). It is possible that for individuals with AS in particular, their difficulties may only become apparent when faced with the increasing challenges and complexities of adult life (Young, Murphy, & Coghill, 2011), which lead to seeking a diagnosis. The average age of diagnosis of AS in adult samples has been found to be approximately 34 years old, although the range is much greater (Jones, Goddard, Hill, Henry & Crane, 2014).

Prompted by reports of significant increases in incidence and prevalence rates of ASD from the 1990's onwards (Taylor, Jick, & MacLaughlin, 2013), in the past decade the UK Government has produced The Autism Act (UK Parliament, 2009) and 'Fulfilling and rewarding lives: The strategy for adults with autism in England' (Department of Health, 2010); legislation which has acknowledged the need for improvement in the provision of assessment and support for adults with undiagnosed ASD and has led to the development of diagnostic services within public services.

In the UK when AS is suspected in adults, National Institute for Health and Care Excellence (NICE) guidelines (2016) recommend that they should be referred for a comprehensive, multidisciplinary assessment which includes exploration of core signs and symptoms of ASD, early developmental history, physical and mental health, behaviour and functioning, and assessment of their needs and any risks, followed by feedback about the outcome. However, the diagnosis of AS in adulthood is challenging for a number of reasons. As individuals grow, they may learn compensatory skills to modify or "mask" behaviour meaning that indicators of autism become more subtle over time (Farley et al., 2009; Seltzer et al., 2003). This may be particularly true of

women, as girls are argued to be more effective than boys in developing these coping strategies (Gould & Ashton-Smith, 2011).

As many individuals with undiagnosed ASD also experience mental health problems, this can make it more difficult for clinicians to distinguish the core symptoms of ASD (Underwood, McCarthy, Chaplin & Bertelli, 2015). Therefore, individuals often experience misdiagnosis (Punshon, Skirrow & Murphy, 2009) and consequently may see a large number of professionals and experience long delays in their journey to diagnosis (Jones et al., 2014).

There is little consensus about the most appropriate measures to use to diagnose ASD in adulthood. Although NICE guidelines (2016) recommend the use of a range of structured questionnaires, diagnostic measures and observational assessments for screening and diagnosis (e.g., the Autism Diagnostic Observation Schedule-Generic [ADOS], Lord et al., 2000; Autism Diagnostic Interview Revised [ADI-R], Lord, Rutter & Le Couteur, 1994), these are not always followed in clinical practice (Rogers, Goddard, Hill, Henry & Crane, 2016; Rutherford et al., 2016), potentially resulting in different diagnostic outcomes.

The reliability and validity of the available tools has been found to be questionable. In their recent systematic review of the psychometric properties of tools used to diagnose ASD in adults, Wigham et al. (2019) found that there is little evidence to support the use of self-report or informant screening questionnaires due to their poor specificity (Ashwood et al., 2016). They also suggest that although the more in-depth measures such as semi-structured interviews and interactive tasks demonstrated some utility in the identification of ASD, these also had low specificity. There are also difficulties with gaining collateral accounts of an individual's developmental history as this is dependent on the availability and recall abilities of informants (Brugha et al., 2012; 2015).

Access to diagnosis may be limited by the availability of diagnostic services in an individual's local area (Wigham et al., 2019). Social barriers may also play a role with individuals who have a diagnosis of ASD reporting that anxiety, fear of not being believed, mistrust of healthcare professionals, difficulties describing symptoms, and stigma made it difficult for them to access assessment and diagnosis (Lewis, 2017).

It is also important to acknowledge that some adults may choose not to pursue assessment as they are concerned that others would pity them or view them as less capable (Davidson & Henderson, 2010), and others report being satisfied with their own self-diagnosis so do not see the need for formal diagnosis (Lewis, 2016).

1.5. Parents' Experience of their Children's AS Diagnosis.

A recent qualitative systematic literature review exploring UK parents' experiences of their child receiving a diagnosis of ASD (Legg & Tickle, 2019) found that parents have emotional, informational and relational needs which are evident throughout the process of seeking, receiving and adjusting to their child's diagnosis of ASD. They found that NICE (2017) guidelines which assert the importance of taking all parental concerns seriously were not being followed as professionals were often dismissive of concerns. Differential response to diagnosis by fathers was also highlighted suggesting that post-diagnostic support may need to be tailored differently for men and women. Finally, growing knowledge of ASD was recognised as significant in the process of parental acceptance and adaptation to diagnosis, possibly resulting in increased self-efficacy and confidence. The authors therefore emphasise the need for parents' emotional needs to be considered, information to be provided to aid understanding, and strong professional relationships between parents and clinicians.

Russell and Norwich (2012) explored the dilemma between pursuing or avoiding a diagnosis of ASD parents face when their children are recognised as displaying autistic behaviours, and the arguments they invoke to defend their

decisions. Parents who were not pursuing diagnosis for their children used pejorative language to refer to diagnostic labels, which the authors suggest reflects their perceived sense of threat to their child's "normal" status. They also discussed their concerns about preconceptions and rejection by others, self-fulfilling prophecies, and lifelong stigma to justify their position. Parents who chose to pursue diagnosis listed the benefits of this decision such as allowing them to name, understand and better manage their child's behaviour, as well as using it to deflect allegations of bad parenting and naughtiness and access a range of support services.

The theory of ambiguous loss (Boss, 1999; 2006) which developed from family stress theory has most often been applied to families where an adult member is either physically or psychologically missing (Boss, 1977; 1980). Several aspects of ambiguity that contribute to the distress experienced have been identified (Boss & Couden, 2002): lack of clarity provided by diagnosis; lack of information regarding potential prognosis; day-to-day fluctuations in the functioning of the ill person impacting on relationships; the ill person may appear healthy leading to increased expectations for their functioning; and concern that the illness will affect emotional relationships. O'Brien (2007) posits that these ideas are also relevant to the experiences of parents of children with ASD, especially around the time of diagnosis, as although their child is not physically absent, they are psychologically different from the child they expected, and they must learn to adapt to those differences in the face of the ambiguities described above.

Also stemming from family stress theory, boundary or identity ambiguity is used to describe occasions where there is confusion or enmeshment of the identities of family members (Carroll, Olson, & Buckmiller, 2007). O'Brien (2007) suggests this is also relevant for parents of children with ASD in situations where they become so preoccupied with their child's diagnosis, they take on responsibility for all areas of their life. It is possible that ambiguous loss and identity ambiguity are less relevant to the situation of parents whose adult son

or daughter is diagnosed with AS, as they have had much longer than parents of children to reconcile the differences between their expectations and their actual child, to somewhat adapt to these and negotiate some degree of separation.

1.6. Individuals' Experience of Diagnosis in Adulthood.

The trend in the pattern of adult diagnosis-seeking is reflected in the growing body of literature exploring the perspectives of the individuals themselves. Punshon et al.'s (2009) qualitative study of 10 adults diagnosed with AS reported seven themes: Negative life experiences (not feeling accepted, bullying and social withdrawal); Pre-diagnosis experiences of services (being misdiagnosed, contact with mental health services and feeling misunderstood); Beliefs about symptoms of AS (feeling different, other people being aware of their differences, wanting to be "normal"); Identity formation (internalisation of other's ideas about them, putting difficulties down to mental health problems); Effects of diagnosis on beliefs (emotional reactions, AS as framework of explanation); and Effect of societal views of AS (positive and negative reactions of family and friends and lack of understanding of AS). The authors emphasise that an individual's prior beliefs, the beliefs of those close to them and societal beliefs influenced their responses to diagnosis and subsequently changed their belief systems and self-identity. Given the negative reactions some individuals received from family members, and the lack of understanding of AS and how it affected them by the individuals' family and friends, Punshon et al. (2009) suggest that individuals and their families should have the opportunity to process what the diagnosis means for them with an appropriate professional.

AS diagnosis in adulthood can result in a range of emotional responses with Powell and Acker's (2016) study highlighting the complexity of initial emotional responses to diagnosis including relief, validation, sadness, frustration, shock and confusion, sometimes experienced in combination.

Similarly to Punshon et al. (2009), the findings also describe a process of self-reflection, sense-making and understanding, improved self-worth and both positive and negative changes in how others related to them.

Specifically looking at the experiences of an older cohort, Hickey, Crabtree and Stott's (2018) qualitative study of individuals aged over 50 suggests that some people in this age group externalise ASD, considering it as separate from themselves rather than integrating it into their self-identity allowing past difficulties to be attributed to ASD. The authors suggest this may be because by this stage of adulthood, individuals have already developed a stable sense of self-identity which is less malleable and propose that future generations may respond differently with the growing influence of the neurodiversity movement. It is possible that parents of individuals diagnosed in adulthood may also attempt to separate AS from the "true selves" of their sons or daughters for similar reasons.

Parents and professionals often play a significant role in advocating for ASD assessment, with Jones et al.'s (2014) quantitative survey finding that just under half of the respondents were the first to recognise they might have ASD themselves, whilst for 18% of others it was initially recognised by parents or health care professionals (14%). This study also showed that those who were expecting the diagnosis were more satisfied with the manner in which it was disclosed than those whom were not. Supporting qualitative findings, the majority of the sample (86%) were glad to have received the diagnosis and the most commonly reported emotion was relief (72%), but a significant proportion of the respondents also endorsed negative emotions.

1.7. Biographical Disruption, Biographical Continuity and Biographical Illumination.

Originally focusing on the experiences of individuals with rheumatoid arthritis, Bury (1982) coined the term 'biographical disruption' to describe the changes in life situation and relationships associated with the recognition and progression of the illness. He suggests that chronic illness is a 'critical situation'

which disrupts the structures of everyday life and the knowledge that underpins them. Three aspects of disruption are described. Firstly, there is disruption to taken-for-granted assumptions and behaviours when difficulties are beginning to be recognised. Secondly, there is profound disruption to explanatory systems involving the re-examination of the individual's self-concept and biography in a search for explanation and meaning. Thirdly, individuals attempt to mobilise their resources to adapt to the disrupted situation.

The theory of biographical disruption is criticised by some for its lack of generalisability to all experiences of chronic illness and its failure to recognise potential mediating factors such as age, expectations, timing, history of illness, and illness trajectory (Williams, 2000). Largely contrasting with Bury's (1982) perspective, Tan (2018) introduced the concept of 'biographical illumination' to describe how receiving a diagnosis of ASD as an adult can provide a new lens through which to review one's life history and identity, facilitating a transformation of self-concept. She suggests that individuals can use the diagnosis to legitimise their experiences, construct more valued and positive understandings of themselves and recalibrate their personal expectations.

'Biographical continuity' (Williams, 2000) is used to describe occasions when illness is expected or perpetuates an existing narrative, creating limited disruption (Llewellyn et al., 2014). It is also possible that previous experience of non-health related hardships minimises disruption experienced from chronic illness (Hubbard, Kidd & Kearney, 2010).

1.8. Parents' Experiences of Their Adult Son or Daughter's AS Diagnosis.

Very little research attention has been given to parents' experiences of their adult son or daughter being diagnosed with AS or ASD. It is suggested that although there may be some areas of overlap, the experiences of parents of children diagnosed with ASD are likely to be discrepant from parents of adults possibly due to differences in ASD symptoms in these groups, with those

diagnosed in adulthood hypothesised to display subtler traits (Raymond-Barker et al., 2016).

Raymond-Barker et al.'s (2016) study explores the experiences of six mothers of adults diagnosed with ASD of the diagnostic assessment process using semi-structured telephone interviews. Two over-arching themes and five sub-themes were developed. The first superordinate theme was biographical continuity which refers to the early stages of assessment being viewed as a continuation of the lifelong search for understanding of their son or daughter's behaviour. The sub-themes concerned securing a referral (early suspicions of ASD, misdiagnosis and inappropriate referrals, regret at late diagnosis earlier) and perceptions of their son or daughter's assessment (satisfaction with the professional approach of clinicians, thoroughness of the assessment, time taken to receive a diagnosis and the method of delivery).

The second superordinate theme was biographical disruption. This explored parents' experiences of seeking support for themselves and their sons or daughters post-diagnosis, and the stress, frustration and disappointment that ensued when they came to the realisation that no support was available. The sub-themes were the parents' fight for post-diagnostic support for their son or daughter (feeling abandoned, "begging" or "fighting" for support); the mothers' support needs (positive experiences of support groups for carers; desire for contact with a professional to support them to understand and respond to the needs of their sons or daughters); and parents' fears for the future (concerns about their son or daughter's continuing care needs, quality of services for adults with ASD generally).

Although this study as the first published peer-reviewed article concerning the experiences of parents of adults is useful for understanding parents' perceptions of the assessment and diagnostic process and goes some

way to understanding their post-diagnostic support needs, it is hoped that the current study will extend these findings by explicitly exploring the impact on identity, family relationships and interactions and unmet needs.

1.9. Attribution theory.

As humans, one of the ways in which we try to make sense of events is by making attributions about the cause of these events. Weiner (1985) suggested that there are three elements of attribution. These are the locus of cause (whether the event is perceived to be caused by internal (personal) or external processes); stability (chronic vs. possibly changeable); and controllability (whether the event can be changed by external or internal forces). Attributions made influence emotional and behavioural responses as well as expectations. When negatively perceived behaviour is considered to be under an individual's control, responsibility is inferred potentially resulting in blame, criticism and punishment. Supporting this, Ling, Mak and Cheng (2010) found that when education staff attributed greater controllability to children with ASD for their behaviour, they were more likely to experience negative emotions such as anger and hold greater intentions to punish them. Conversely, when staff attributed lower controllability, they were more likely to experience positive emotions such as sympathy, leading to greater intentions to help.

Evidence suggests that attributions can be changed when individuals gain more knowledge about an individual's behaviour, allowing them to view it from a different perspective. Williams, Dagnan, Rodgers and McDowell's (2012) systematic review demonstrated that through training, carers of people with intellectual disabilities were able to change their causal and controllability attributions about behaviour that challenges displayed by those they cared for.

Applying attribution theory to the current study, it's possible that the new knowledge and understanding gained from diagnosis of the causes and

controllability of their son or daughter's behaviour may result in changed attributions, affective and behavioural responses in parents.

1.10. Models of adjustment to diagnosis.

Most research concerning individual reactions to diagnosis considers physical illnesses which are often progressive and usually diagnosed after a short time of recognising symptoms. Receiving a diagnosis of AS in adulthood differs in several important ways: Parents have often lifelong recognition of their son or daughter's differences and difficulties with little understanding of what might be causing them; there is no treatment or "cure" for AS which can leave parents with unanswered questions about how best to support their adult child; and as AS is not progressive, there is no "prognosis" about likely trajectories often leaving parents with queries and concerns about the future. Therefore, it is not appropriate to apply models of response to physical illness to the situation of adult diagnosis of AS.

Previously, models based on the "stage" theories of bereavement were proposed to describe the experiences of individuals of receiving a medical diagnosis. It was purported that all individuals went through stages of denial, anger, bargaining, depression and acceptance (Kubler-Ross, 1970), and this was later extended to include shock, pain and hope (Punshon et al., 2009). However, these models have been criticised for being too prescriptive as they do not recognise differences in individual's trajectories (Wortman & Silver, 1989) and do not stand up to empirical testing (Bonanno et al., 2002). Also, as "stage" theories focus on responses to unwanted events, they do not necessarily reflect the experiences of individuals who actively seek diagnoses. Therefore, more recent models (Lazarus & Folkman, 1984) have suggested the role of cognitive mediation in response to diagnosis, which allows more for individual differences.

Lazarus and Folkman's (1984) process model of stress and coping defines 'stress' as occurring when an individual appraises a situation as outstripping their resources and threatening their wellbeing. Coping is defined

as attempts by the individual to manage the demands they have appraised as outstripping their resources. Coping resources are categorised as either socio-ecological (social networks, money, training programmes) or personal (problem-solving skills, self-efficacy, locus of control, physical health). Coping attempts are either problem-focused with the intention being to manage the problem that is causing distress or emotion-focused whereby the aim is regulation of the emotions related to the stressor.

It is important to provide further definition of both locus of control and self-efficacy as they have been found to play a significant role in the process of adjustment (Beresford, 1994). Locus of control concerns the explanations individuals ascribe to situations and has two dimensions: internal and external (Rotter, 1975). Those who have an internal locus of control consider events to result from their own behaviour and actions. When coping with stressors, they are more likely to actively seek information, take responsibility and believe their attempts will be successful. Those who have an external locus of control consider events to be outside of their control and caused by powerful others. Therefore, they tend to be less active in their information-seeking and coping attempts. Parental self-efficacy describes how confident parents feel in their abilities to manage their child's behaviour effectively. Parents who have low self-efficacy are more sensitive to their child's behaviour and cope poorly, often demonstrating poor persistence, low parenting satisfaction and self-blame (Johnston & Mash, 1989).

1.11. The carer role, carer burden and unmet needs.

As AS is a lifelong condition it means that some individuals will have difficulty finding and keeping employment, experience social isolation, struggle to access higher education and will continue to require support with many aspects of their daily lives (Chamak & Bonniau, 2016; Griffith, Totsika, Nash, Jones & Hastings, 2012). External support tends to reduce however during adulthood for individuals diagnosed during childhood (Howlin & Moss, 2012), so for the majority of individuals, this care and support is provided by their parents

(Piven & Rabins, 2011). This is also true for parents of adult children who are living independently as they often maintain a high degree of involvement in their son or daughter's lives (Krauss, Seltzer, & Jacobson, 2005). This dependency may have a negative impact on some parents, particularly in the context of their own and their co-parent's advancing age, and potentially deteriorating physical health (Marsack & Perry, 2017).

Caregiver burden has been defined as: "The extent to which caregivers perceive that caregiving has had an adverse effect on their emotional, social, financial, physical, and spiritual functioning." (Zarit, Todd, & Zarit, 1986). This definition highlights the multi-dimensional impacts that caring can have on carers' lives and the role that an individual's perception can play in this.

There is a paucity of research concerning the caring experiences of parents of adults who have AS or ASD (Hines, Balandin, & Togher, 2014; Herrema et al., 2017; Raymond-Barker et al., 2016), and no studies exploring the care and support needs of parents whose son or daughter received a diagnosis in adulthood could be located. Due to the dearth of literature, it has been necessary to draw on studies which do not separate AS and ASD, which has some obvious draw-backs in terms of comparability. Developing an understanding of the various ways in which caregiving impacts on parent-carers of adults with AS is vital to determine how best to support them and their sons or daughters effectively.

Time dependence burden is defined as the constraints on time imposed by the demands of the caring role and which make it difficult to participate in personal interests and/or complete activities of daily living (Novak & Guest, 1989). Studies specifically of parents of adults found that many parents spent a great deal of time advocating for their adult children and providing daily care in various ways, impacting on the amount of time they had available to spend with friends, spouses and family (Marsack & Perry, 2017), and their ability to work and practice self-care (Marsack-Topolewski & Church, 2019).

Developmental burden is defined as the perceptions of caregivers that their life course is incongruent with others who are not carers (Novak & Guest, 1989). Parents of both children and adults with ASD have described feeling isolated from their peers who do not care for adult sons or daughters with ASD (Marsack & Perry, 2017; Woodgate, Ateah, & Secco, 2008). Marsack-Topolewski and Church (2019) found that parents perceiving more developmental burden had lower quality of life, expressed a desire for an "empty nest" and a life more similar to their peers.

Emotional burden is defined as the impact on psychological and emotional wellbeing experienced by caregivers (Novak & Guest, 1989). There is a general consensus in the literature that adults with ASD have high rates of comorbid mental health problems such as anxiety and depression (Hutton, Goode, Murphy, Le Couteur & Rutter, 2008; Joshi et al., 2013) and they are also often prominent in carers of adults with ASD (Hare, Pratt, Burton, Bromley & Emerson, 2004). Quality of life and psychological wellbeing are often significantly poorer in parents of individuals with comorbid mental health problems than those without (Herrema et al., 2017). The psychological wellbeing of parents of adults has been demonstrated to be affected by contextual factors. In a large-scale longitudinal study, parents' depressive symptoms were stable across time whilst there were fluctuations in anxiety with increases related to stressful life events and reductions in social support networks, and a decrease associated with the adult child moving out of the family home (Barker et al., 2011). However, this decrease in anxiety when an adult child leaves home is not reflective of all parents' experiences, with some reporting continued worry about the quality of care (for those in residential living), the possibility of exploitation and not knowing what their son or daughter is doing everyday (Krauss et al., 2005).

Social burden describes a caregiver's conflictual feelings about their role and the limits it places on the time and energy they can invest in work or

relationships (Novak & Guest, 1989). A recent study of caregivers of adults found that informal social support mediated the relationship between quality of life and burden with parents with low levels of informal social support (emotional and physical assistance provided by friends and family) demonstrating lower levels of quality of life and higher levels of caregiver burden (Marsack & Samuel, 2017). Hare et al. (2004) found that some parents believed their caring role had had a detrimental impact on their relationship with their partner and described major restrictions on their social lives ("like being grounded for 20 years"). Hartley, Barker, Seltzer, Greenberg, and Floyd (2011) found that parent-carers of adults with ASD with above average levels of marital satisfaction, experienced less burden than those with lower marital satisfaction, and lower marital satisfaction reduced fathers' feelings of emotional closeness to their son or daughter. The authors stress the likely bi-directionality of the relationship between marital satisfaction and these factors. Parents of adults with ASD have also been reported to experience financial burdens associated with their caregiving role related to the challenges of balancing paid employment and caring (Marsack-Topolewski & Church, 2019).

Parents' perception and appraisal of unmet need can also contribute to their experience of burden. Cadman et al. (2012) found that level of unmet need continued to be a significant predictor of burden even when other possible contributory factors were taken into consideration. There were significant associations between unmet need and burden regarding social relationships, daytime activities, mental health problems, self-safety and communication. Similarly, Hare et al. (2004) found that the main unmet needs were for breaks from caring, information on services available and preparing for the future. There were significant associations between unmet needs and lack of formal support and unmet needs and psychological distress.

As well as burdens and strains associated with caring for adults with AS or ASD, some parents highlighted the positives of this experience such as the development of qualities in themselves such as empathy, patience and

tolerance (Hare et al., 2004) and experiencing personal growth from overcoming the challenges associated with parenting an individual with additional needs (Griffith et al., 2012).

1.12. Post-diagnostic support.

When adults are diagnosed with ASD, NICE guidelines (2016) state that they should be offered a follow-up appointment to discuss the implications of the diagnosis and any care or support needs. However, this often does not occur in clinical practice. Rogers et al.'s (2016) research with 116 professionals involved in the diagnosis of ASD in children and adults found that only 44% were compliant with this guidance. Wider systemic factors such as limited funding and resources and growing caseloads are often cited as obstacles to providing post-diagnostic support. When post-diagnostic support is available, the most commonly offered types were information leaflets, information about support groups, and liaison with other services such as schools. Only 26% of professionals reported that they "always" offered education or support groups for parents. As well as exploring the types of support offered, this study also explored the professionals' perceptions of the service they were providing. The majority (47%) reported they were satisfied with the post-diagnostic support their service provided, whilst 31% reported they were dissatisfied (the remaining respondents were neither satisfied or dissatisfied), and 40% reported being dissatisfied with the provision of onward referral services (compared to 27% satisfied and 32% neither satisfied or dissatisfied).

Strong post-diagnostic support has been demonstrated to reduce depression and anxiety (National Autistic Society, 2008), improve quality of life (Renty & Roeyers 2006), and reduce high-cost acute hospital stays (National Audit Office, 2009) for adults diagnosed with ASD. However, adults' perceptions of post-diagnostic support are often poor. Jones et al. (2014) in their quantitative survey of 128 adults with ASD found that almost 54% of the sample were dissatisfied with the post-diagnostic support they were offered; almost 42% were offered no post-diagnostic support whatsoever; and only 3% were

offered a needs assessment. Crane et al. (2018) also recognise the potentially detrimental impact on relationships between parents and adult children resulting from the discussion of difficult past experiences in the diagnostic assessment, and suggest that ways of managing this consequence should be given consideration.

Hickey et al. (2018), based on the findings of their study exploring the experiences of individuals diagnosed with ASD in older adulthood, suggest that externalisation of ASD may be a useful therapeutic intervention in this population as it disrupts the problem-saturated narrative and allows separation of the individual from their difficulties (White & Epston, 1990). They also propose that compassion-focused (Gilbert, 2009) or acceptance-based (Hayes, Strosahl & Wilson, 1999) therapies may be useful in supporting self-acceptance after diagnosis, but as yet, this remains untested. These interventions may prove beneficial to parents in accepting and adapting to their child's diagnosis too, although this would need to be empirically demonstrated.

Research with parents of children with ASD suggests that they find informal support from other parents, both face-to-face and online, to be highly beneficial (Mandell & Salzer, 2007; Wynter, Hammarberg, Sartore, Cann, & Fisher 2015). Supporting this finding, Galpin et al.'s (2018) qualitative research demonstrates that for parents of children with ASD, contact with other parents reduced feelings of isolation and loneliness, created a sense of community and was seen as useful for gaining emotional support and practical advice. Parents in this study also raised the importance of considering the timing of support as in the initial post-diagnostic period, they said they struggled to take in information. Specifically focusing on the experiences of online support forums, mothers identified many positive aspects of participation such as feelings of acceptance and being cared for, the opportunity to connect with others who shared their reality and instant access to information to help them problem-solve difficult situations (Reinke & Solheim, 2015).

There is evidence to suggest that educational and skills courses are considered beneficial by parents. For example, the National Autistic Society's Early Bird programme (Shields, 2001) which is available to parents of children with ASD in the UK was found to be helpful for developing parents' understanding of ASD and building their confidence in supporting their child (Galpin et al., 2018). Findings by Breen and Buckley (2016) also suggest that parents of children with ASD find it useful when knowledgeable professionals summarise up-to-date, evidence-based information for them as it saves them from sifting through the vast amount of unreliable information available online.

As previously discussed (see Section 1.8), parents of sons or daughters diagnosed in adulthood describe a similar desire for support as parents of children and the individuals themselves, and report a sense of abandonment stemming from the realisation that post-diagnostic support for them and their offspring is largely absent (Raymond-Barker et al., 2016).

2. Extended Methodology

2.1. Qualitative methodology.

In basic terms, qualitative research involves the collection and analysis of non-numerical data with the aim of understanding how people make sense of the world and their experiences (Coyle, 2016) rather than aiming to identify cause and effect relationships and make predictions as in quantitative research. However, qualitative research is not a homogenous domain as it covers a wide variety of methods such as in-depth interviews, focus groups and observation, and methodologies with differing epistemological positions (see below). The status of qualitative methodology as a legitimate means of research enquiry has a long history of debate centred around the relative merits of nomothetic approaches over idiographic approaches. However, now it is widely accepted in the research community (Lincoln & Guba, 2000).

Unlike in quantitative research where the researcher's role in collecting data and conducting analyses is considered a source of bias and

contamination, qualitative methods place high importance on reflexivity: the acknowledgement of the researcher's influence including how their values, beliefs, experiences, identity and theoretical commitments may have shaped their interactions with participants and the research.

Quantitative research is often criticised for "context-stripping" (isolating phenomenon under investigation from its context), undermining the meaning of data generated (Mishler, 1979). Qualitative research aims to avoid this critique by focusing on exploring the meanings and behaviour of individuals in their own systems (Guba & Lincoln, 1985).

The aim of the study was to explore parents' experiences of their adult son or daughter receiving a diagnosis of AS, an area which currently has received very little research attention. Qualitative methods are suggested to be suitable for this kind of exploratory research as they allow for the development of theory where existing knowledge is limited (Barker, Pistrang, & Elliott, 2002). They also allow for "top-down" and "bottom-up" approaches to be used complementarily, allowing data and extant theory to shape the research. Finally, they enable participants to talk about what they consider to be relevant to the topic under investigation, rather than being constrained by pre-determined response options and so are better able to capture individual experiences and attribution of meaning than quantitative methods (Strauss & Corbin, 1998; McEvoy & Richards, 2006). For these reasons, a qualitative approach to data collection and analysis was deemed to be most suitable.

2.2. Epistemology.

Epistemology is a branch of philosophy concerned with answering questions about what comprises valid knowledge and how we can access it (*how* we can know and *what* we can know). Epistemological assumptions govern what types of things can be found by research, and different research methodologies are associated with different epistemological positions. Epistemology is often considered alongside ontology, another branch of philosophy with a focus on how reality and existence are defined and

understood (*what* there *is* to know), and influences the epistemology (Harper, 2012).

There are many different ways of conceptualising the underlying assumptions of different qualitative data analysis approaches (Madill & Gough, 2008). These can be placed on a continuum of knowledge from positivism to constructivism and a spectrum of reality from realism to relativism with positions in between (Harper, 2012). Positivism (also known as direct realism) is most frequently linked with quantitative methodology and purports that there is direct relationship between objects, events and other phenomena in the world and our perception of them. Reliable knowledge of these things can be acquired through hypothesis testing, so long as accurate methods of measurement are adopted (Lincoln & Guba, 2000). Therefore, they can be considered epistemologically and ontologically realist. The researcher and participants are seen as existing separately and attempts are made by the researcher to reduce bias and maintain objectivity.

Post-positivism is aligned with an objectivist epistemological position as is positivism, with the reliability of findings judged by whether they "fit" with the extant evidence base and the opinions of the critical community such as peers and editors (Guba & Lincoln, 1994). The ontological position associated with post-positivism is that of critical realism (Cook & Campbell, 1979) as although reality is assumed to exist, it can only be imperfectly comprehended because of flawed mechanisms of human understanding (Guba & Lincoln, 1994). Proponents of critical realism state that assertions made about reality must be subjected to rigorous critical inspection to potentially allow falsification of hypotheses.

Critical Theory is aligned with the position of historical realism and assumes that reality has been shaped by political, cultural, social and economic factors over time then crystallised into structures which are seen as "real" (Guba & Lincoln, 1994). The related epistemological positions are subjectivist and

transactional, meaning that the researcher and participants are considered to be interactively linked with what can be known inseparably connected to the interaction between the two.

Constructivism and social constructionism are associated with the ontological position of relativism and view reality as being socially constructed, allowing for the possibility of multiple realities. Like Critical Theory, the related epistemological positions are transactional and subjectivist and so the researcher is viewed as both a facilitator and a participant, playing an active role in the production of knowledge. Research in this paradigm aims to gain more informed and sophisticated understanding of social constructions through continual interpretation and refinement to develop a consensus construction (Guba & Lincoln,1994).

It is important for researchers to make their epistemological position and ontological assertions clear as they are necessary to allow the reader to understand the methods of inquiry utilised, the role of the researcher in the process and the claims made about the knowledge generated by the research (Braun & Clarke, 2006, Carter & Little, 2007).

Chosen epistemological position: Epistemology and ontology informed the aims of the research and selection of the appropriate methodology for meeting these. The epistemological position of critical realism was adopted by the researcher in the current study as it acknowledges that the diagnosis of AS is influenced by social, cultural and historical factors and the event of diagnosis exists in reality, but that there are differing views about the construction of AS and the experiences of individuals in making sense of their son or daughter receiving this diagnosis. The meanings and experiences of parents of their son or daughter's AS diagnosis and their perceptions of their own care and support needs are shaped by external factors such as the media, social support, family and societal narratives, and access to services. Critical realism aims to

generate rich, thick data to allow deeper understanding rather than producing generalisable findings and therefore fits with the aims of this research.

Given that researcher reflexivity is central to the critical realist position, the researcher acknowledged the role that their experience of working with adults and children with AS and ASD and their carers and families has played in the development of the study, its aims and the interpretations made. Based on these experiences and reading of the literature, the researcher held assumptions about parents' potential emotional reactions to the diagnosis broadly categorised as guilt about not having recognised any differences or difficulties or not having pursued assessment at an earlier age, or relief about having an explanation for the differences or difficulties, that they aren't due to their parenting and that their son or daughter will receive the help and support they require; the frustration, confusion and disappointment that parents might feel post-diagnosis when they realise that there is little support for their sons or daughters and even less for them; and what parents may find helpful to accept and adapt to their son or daughter's diagnosis.

Given these experiences and assumptions, it was imperative to remain reflexive when reading and interpreting data to remain open to findings which did not fit with these pre-existing ideas. A reflexive diary was therefore used throughout the research process to maintain awareness of these processes. It was also recognised that the accounts parents gave of their experiences of their son or daughter's diagnosis were inextricably intertwined in the interaction between them and the researcher. Therefore, descriptive information about participants and their sons or daughters is provided to allow the situation of the sample within a context from which the findings can be interpreted.

2.3. Qualitative approaches considered.

Thematic Analysis.

Thematic Analysis (TA) is a method for identifying and analysing patterns of meaning across a data set (Braun & Clarke, 2006). The term TA was formerly used synonymously with Content Analysis to describe a method of quantifying the content of qualitative data sets (Christ, 1970), as well as more interpretive forms of analysis (Baxter, 1991). This previous form of Content Analysis was criticised for being “trite” (Silverman, 2011, p.85) and for stripping data of their context. TA was therefore developed to go beyond surface level analysis to discover the more implicit themes and structures in the data (Merton, 1975).

Whilst other approaches to qualitative analysis such as Grounded Theory could be characterised as methodologies as they determine the epistemological and ontological assumptions made, the types of questions that can be asked, the size and composition of the sample, acceptable methods of data collection and analysis, TA is a method which means that it is not tied to any particular theoretical framework so can be applied flexibly from any epistemological or ontological standpoints (Braun & Clarke, 2013).

The aim of TA is to describe and summarise, but also to interrogate and interpret. This is achieved by looking at surface-level, overt meanings (semantic or manifest) and from this deducing the implicit, covert meanings (latent). TA can be used deductively where extant theories and concepts are used as a lens through which to interpret the data but can also be grounded in the raw data itself. These approaches can be combined by using pre-existing categories to guide the analysis whilst remaining open to new possibilities (Joffe, 2012). TA acknowledges the impact of researcher subjectivity and recognises that differences in skills, knowledge, training, and personal and professional experiences will shape the analysis (Braun & Clarke, 2013). Although TA has been criticised for lacking distinctiveness from the processes used by many qualitative methodologies (Holloway & Todres, 2003), the development of systematic procedures for doing TA has encouraged its acceptance as a stand-alone method.

Interpretative Phenomenological Analysis.

Interpretative Phenomenological Analysis (IPA) is theoretically rooted in phenomenology (a philosophical approach concerned with subjective experience; Moran, 2000), hermeneutics (related to the process of interpretation; Palmer, 1969) and idiography (understanding individuals in their own terms (Smith, Harrè & Van Langenhove, 1995). The aim of IPA is to explore individual personal experience in depth with emphasis on meaning making and the individual's understanding of their personal and social world, and the events which happen to them (Lyons & Coyle, 2016). This meaning making occurs at the level of person-in-context, so the focus is on the particular rather than the general. IPA emphasises the active role of the researcher in interpreting participants' experiences, using the term double-hermeneutic to describe the process of the participant attempting to make sense of their world whilst the researcher tries to make sense of the participant's sense-making process (Smith & Osborn, 2015).

There are similarities between TA and IPA in that both consider semi-structured interviews a suitable method of data collection, and both analysis processes result in the generation of initial codes followed by the development of themes. Both also strive to produce patterns of meaning across the data-set. However, IPA is more focused on the in-depth meaning-making processes of individual participants, analysing each individual's data in detail before considering the next as attentively. Some IPA researchers even advocate for the value of analysis based on a sample size of one (Smith, 2004).

Although this research is exploring an experience of which the participants have experience consistent with IPA, the focus of the study was broader than just the meaning-making process of parents following diagnosis and IPA's idiographic emphasis was not considered suitable for meeting the aims of the current study.

Grounded Theory.

The aim of Grounded Theory (GT) is to inductively develop a theory of social or psychological processes grounded closely in the data from which it was derived. This involves simultaneously collecting and analysing data and constant comparison between developed concepts, codes and categories (Glaser & Strauss, 1967). Early incarnations of GT were based on a positivist perspective and were concerned with empirical testing and objective verification in an attempt to evidence the explanatory power of qualitative analysis (Glaser & Strauss, 1967). However, later developments have taken a more interpretative stance with the recognition of the role of the researcher in the creation and interpretation of data (Corbin & Strauss, 2015).

Although GT can be used to explore under-researched areas and to elicit individual personal perceptions, understanding and experiences of the world (Charmaz, 2006), it was not considered an appropriate method for the current study as the aim was to demonstrate shared experiences across participants rather than to develop a new theory. Also, given that there is some extant literature in areas similar to that under investigation, it was considered prudent to consult this to deductively guide analysis rather than analysing solely inductively as is advocated by GT.

Discourse Analysis.

Discourse Analysis (DA) is a social constructionist approach to research which is concerned with how language is used to construct reality through verbal interactions and written text, and the social actions it performs such as justifying or questioning (Potter & Wetherell, 1987). In DA, the language individuals use is not treated as a means of accessing their private social and psychological worlds, but instead focuses on how their reality is constructed through social practices and interpersonal processes to achieve interpersonal goals (Georgaca & Avdi, 2012).

DA was not deemed to be an appropriate analysis method for the current study as the focus was on describing experiential aspects following diagnosis

rather than critically examining the language parents used to construct this account.

Approach adopted in the current study.

The TA approach allows for an in-depth account of parents' experiences of their son or daughter receiving a diagnosis of AS to be developed through both inductive and deductive analysis so that interpretations can be guided by existing theory and grounded in the data but also open to new understandings.

As TA is theoretically flexible, it can be used consistently with the critical realist epistemological position, enabling recognition that responses to this event will be individual and shaped by external factors. TA allowed exploration of the impact of the diagnosis broader than just sense making, and for patterned rather than idiosyncratic meanings to be found. As there is a body of literature concerning parents' experiences of child diagnosis and experiences of individuals themselves, the study aimed to use extant theory as a lens through which to interpret the data rather than generating a new theory. The purpose was not to critically deconstruct the language participants used to produce their accounts as in DA. Braun and Clarke's (2006) approach to TA was followed as it provides a transparent and systematic method of analysis.

2.4. Participants and Recruitment Strategy.

In keeping with assumptions associated with the qualitative research paradigm, purposive sampling was used to recruit participants whose sons or daughters had received a diagnosis of AS in adulthood, rather than attempting to recruit a statistically representative sample of the population (Carter & Little, 2007).

Inclusion and exclusion criteria.

Although the inclusion and exclusion criteria are outlined in the journal paper, it is necessary to provide further detail of some of the decision-making processes here. "Parent" was defined as any person who had primary care-taking responsibility for the adult with the diagnosis of AS from when they were 4 to 5 years old or younger as this is the period that the ADI-R (Lord et al.,

1994) is concerned with and means they will probably have knowledge of their development. They may be a biological, adoptive, foster or step-parent, or another relation with care-taking responsibility. The thinking behind the criterion concerning the diagnosis being received in the last 3 to 6 months was so that participants could relatively easily recall their feelings and reactions as the event was fairly recent, but also have had some time to accept and adapt to the diagnosis. The reasoning behind excluding parents of adults who had received any other ASD diagnosis than AS was that it was assumed that individuals with these other diagnoses may present very differently and have dissimilar care and support needs, and therefore parents' experiences would not be comparable.

Sample size.

Unlike quantitative research where power calculations are used to decide on an appropriate sample size, qualitative research does not have equivalent guidelines for establishing how many participants to recruit (Malterud, Siersma, & Guassora, 2016). A review by Carlsen and Glenton (2011) highlights that qualitative researchers often demonstrate little transparency with regards to the justification of their sample sizes. Saturation or the concept of diminishing returns (increasing the sample size until this no longer leads to the emergence of new examples of the categories identified through the analysis; Glaser & Strauss, 1967), originally developed as part of GT but since extended to other analytic approaches, has been used by qualitative researchers to justify sample sizes. Guest, Bunce, and Johnson (2006) for example found that data saturation is possible with 12 interviews and beyond this number, new data was less likely to emerge. However, the concept of saturation has been criticised for being poorly defined and impossible to operationalise (Charmaz, 2006), and it is argued that researchers limited by time and funding are unlikely to achieve true saturation as they do not have the luxury of undertaking the ongoing, open-ended research needed for this (Green & Thorogood, 2018). Recent revisions to the definition of saturation have acknowledged that data collection is rarely an exhaustive process, and instead researchers should focus on how able their

data is to produce a sufficient theoretical account ('theoretical sufficiency'; Dey, 1999).

TA does not have any particular sampling requirements, but it suggested that some homogeneity in the sample can be helpful for identifying patterns across the data (Clarke & Braun, 2015). The sample were recruited from one assessment and diagnostic service in a city in the UK. In terms of number, Clarke and Braun (2013) suggest that if the interview method is to be used then a sample size of at least six is recommended to capture patterned meaning. However, others recommend much larger numbers (e.g., Joffe [2012] suggests 32-60 participants), although these studies tend to be conducted by a group of researchers, which was not possible for the current research. Braun and Clarke (2015) caution that there is greater risk with bigger samples of not doing justice to the nuances and complexity of the data set.

Based on the arguments above, the study aimed to recruit between 12 and 15 participants to achieve sufficiency rather than saturation. This number is reflective of the aims of the study, the chosen methodology and epistemological position, and was also pragmatically decided by the number of potentially eligible participants and the time limits imposed for completing the research.

Recruitment.

Parents of individuals seeking a diagnosis of AS are often involved in the assessment process (if the client wishes and the parent agrees), completing measures such as the ADI-R (Lord et al., 1994) with a clinician to provide a detailed overview of the client's developmental history and current behaviour and functioning.

Participants were recruited from a specialist adult AS service located in the East Midlands which provides multidisciplinary diagnostic assessment, treatment and support for adults seeking a diagnosis of AS who do not have a diagnosis of intellectual disability. In this service, parents involved in assessments are also invited to attend the diagnostic appointment (with the

client's consent). Therefore, for the most part, the initial approach for recruitment to the study was made by the clinician involved in the diagnostic appointment.

Given that it could be difficult for parents to take in detailed information following the news of the diagnosis, the study was only briefly introduced at this point. It was explained that entry into the study was entirely voluntary and that their son or daughter's care would not be affected by their decision. Potential participants were able to opt-in in to be contacted about the study by providing their contact details and were given a Participant Information Sheet[3] (PIS) to take away with them. Potential participants were then contacted 10 weeks after the diagnostic appointment by telephone to arrange an interview two weeks later.

Posters[4] providing brief details of the study and the researcher's contact details were also displayed in the waiting room of this Service, and an advert was also placed on the social media site associated with this Service.

In total, 15 potential participants were approached to take part in the study; two declined to participate for personal reasons, one was unable to arrange an interview, and one completed the interview then chose to withdraw their data leaving a total of 11.

2.5. Data collection

Demographic Information.

Some demographic details were collected from participants to aid interpretation and analysis, and to provide context for the sample to allow the reader to interpret the findings. The information below was collected via a verbally administered questionnaire (see Appendix J) prior to the interview taking place:

[3] Appendix G
[4] Appendix H

Table 1: Demographic information collected

Characteristic	Rationale
Gender of parent	To indicate the gender composition of the sample and highlight any

	differences in response to diagnosis and support needs between mothers and fathers.
Parent's relationship to their adult son or daughter diagnosed with AS (biological-, step-, adopted-, foster-parent etc.)	To situate the sample within its context and to aid interpretation about any interaction of this with response to diagnosis.
Gender of the adult son or daughter diagnosed with AS	To highlight any differences in response to diagnosis between parents of sons or daughters.
Living situation	To highlight any differences in response to diagnosis and support needs between parents whose son or daughter was living with them as opposed to living independently.
Ethnicity of the parent	To highlight any differences in response to diagnosis and support needs between parents from different ethnic groups.
Parent's marital status	To highlight any differences in support needs between parents according to their marital status.

Semi-structured interviews.

Participants were given the option of a face-to-face, telephone, or Skype interview to ensure all those who wished to take part were not restricted by lack of ability to travel. All chose the option of a face-to-face interview which is

considered the “gold standard” of interview data collection (Novick, 2008). Interviews took place between October 2018 and February 2019. Interviews ranged in length between 36 and 132 minutes.

Participants were also given the option of being interviewed individually or with their spouse. Given that it has been found that joint interviews might uncover conflict or tensions within a couple’s relationship (Valentine, 1999), the researcher remained sensitive to this possibility throughout, observing each member of the couple carefully for body language or facial expressions that suggested discomfort or disagreement. If this did occur, it was decided that the researcher would ask in a neutral way whether the individual would like to add anything and if not, would not probe further. Although the researcher is a Trainee Clinical Psychologist, it is not appropriate for research interviews to be used to provide therapeutic intervention (Hewitt, 2007), and so if a couple were to start arguing, the researcher would remain as neutral as possible and try to defuse the tension by moving on to a different topic. No tension was observed in the couple interviews and no arguments occurred.

Some researchers have expressed concern that in a joint interview, one partner might dominate (Morris, 2001), overtly or covertly, intentionally or unintentionally. To try to limit the impact of this, the researcher remained aware of how much each partner was contributing and ensured that each partner was either asked the same question, or whether they had anything to add to their partner’s response to allow them the opportunity to express their perspective.

Another potential disadvantage of joint interviews is that individuals may not feel able to speak honestly and openly in the presence of their partner (for example, avoiding raising issues that they fear may hurt their partners), adjusting their responses according to their partner’s expectations. Despite the possible impact of couple desirability, it is argued to be difficult to recognise in reality (Taylor & de Vocht, 2011). The couples interviewed appeared able to speak frankly in front of each other about some difficult experiences and

feelings, and so couple desirability was unlikely to have had a significant impact on the data.

Despite the potential risks and difficulties associated with conducting joint interviews, some researchers argue that joint interviews can encourage spontaneous further discussion and provide more detailed, richer accounts than those produced from individual interviews. Also, given the current underrepresentation of the experiences of fathers in ASD research (Burrell, Ives & Unwin, 2017), it was deemed that allowing men the opportunity to be interviewed with their partners might encourage their participation and allow their views to be expressed. Therefore, joint as well as individual interviews were deemed to be appropriate for collecting data.

Semi-structured interviews are deemed to be an acceptable method by which to collect data for TA (Braun & Clark, 2006; Joffe, 2012). They allow for consistency in the topic areas discussed across the sample, but also have the flexibility to enable the interviewer to follow the lead of the participant (Braun & Clarke, 2013).

An interview schedule (see Appendix K) was developed in order to facilitate the semi-structured interviews. The questions were initially formulated in collaboration with clinicians with experience of diagnosing adults with AS, and from the literature examining how parents of children and adolescents and individuals themselves have made sense of receiving an AS diagnosis. The interview schedule was also amended to include the perspective of a parent of an adult diagnosed with AS, and the feedback received from the Research Ethics Committee. Consideration was given to the sequencing of questions (moving from less to potentially more sensitive questions to allow rapport to be built and encourage openness); the wording and construction of questions (ensuring questions were open-ended and free from technical terminology so they could be understood by those without expert knowledge); possible probes and prompts to encourage participants to elaborate on responses; and the

inclusion of an ending clean-up question allowing participants to raise any further issues they felt to be relevant which had not been explored.

The final interview schedule was comprised of 11 questions designed to explore participants' experiences in detail, and was employed flexibly to allow for the natural flow of the conversation (Smith, 2003).

2.6. Ethical Approval

This research was conducted in accordance with the ethical codes produced by the British Psychological Society (BPS, 2014; 2018). Ethical approval for this study was gained from the ethics committee at the University of Nottingham and from the Health Research Authority through the Leicester South Research Ethics Committee (see Appendices A to F).

2.7. Ethical considerations

Informed consent.

Participants were provided with a PIS which included a brief overview of the rationale and aims of the study, what participation would involve, the potential risks and benefits of participation, data protection and confidentiality issues. All participants were given the opportunity to ask any questions before they signed the consent form[5] and were made aware that their participation was voluntary. Participants were assured that their decision to participate or not would not affect their son or daughter's care. They were also informed of their right to withdraw, but that their audio data would still be used in the final analysis if their withdrawal was more than one week after the interview. The consent form was signed and dated by the participant and the researcher and each kept a copy.

Concerning the couples who chose to be interviewed together, both partners were present when the study was introduced to avoid the issue of one partner being a gatekeeper to the study information. Gatekeeping by one partner has been found to problematic in terms of coercion in some studies

[5] Appendix I

involving couples (Forbat & Henderson, 2003). As the study was aiming to interview individuals, the participation of one member of a couple was not contingent on the other's participation which hopefully limited the effect of coercion. However, it is possible that one partner may have pressured the other to participate, and the coerced partner may have felt unable to refuse for fear of causing conflict in the relationship. Each member of the couples interviewed signed an individual consent form.

Interviewing.

All participants were given a choice about when, where and how the interview was conducted to ensure it was as convenient as possible to them. All participants consented to the interviews being audio-recorded and to an external service being used to transcribe data (once a confidentiality agreement had been signed; see Appendix L).

Confidentiality and anonymity.

Participants were made aware of the limits of confidentiality regarding criminal activity and safeguarding concerns before the start of the interview. In order to maintain the anonymity of participants, pseudonyms were used, and any references to third parties, services and locations were omitted. Participants were aware of and consented to anonymised direct quotes being used in the study reports.

Data storage.

Before transcription, audio recordings were stored on a password protected, encrypted memory stick and once transcribed and checked, they were deleted. Anonymised transcriptions were stored on the University of Nottingham secure system and also on the password protected, encrypted memory stick.

Adhering to the Data Protection Act (1998), all documents and data were stored securely at the University of Nottingham, access to which was limited to the researcher, academic research supervisors and administration staff affiliated to the Doctorate programme. Anonymised data were stored in one locked filing

cabinet and participant identifiable data were stored in a separate locked filing cabinet. This information will be retained in secure storage at the University of Nottingham for at least 5 years, after which it will be securely destroyed in adherence to University protocol.

Participant distress.

Participants were informed that they did not have to answer any questions that they did not want to and could stop for a break or terminate the interview at any time. The interviewer (HL) has experience of working therapeutically with adults with mental health problems and remained alert to any signs of distress throughout the interview. On the occasions when participants became distressed, the interviewer used their clinical skills to manage this and offered a break or to end the interview. Participants declined this offer and expressed that they wished to continue. After the interviews, participants were asked about their distress levels. No participants reported feeling distressed at the end of the interview and all shared that they had partners, friends and broader networks that they could seek support from.

2.8. Analysis.

Braun and Clarke's (2006) six-stage guidelines were followed to conduct a Thematic Analysis (see Table 2 for a summary). Although these stages are presented sequentially, it is important to note that analysis is a recursive rather than linear process, moving back and forth between the stages as necessary (Braun & Clarke, 2006).

There is some debate as to when to read literature pertinent to the analysis. It is argued by some that reading early in the process can restrict the analytic focus meaning that crucial aspects may be overlooked, whilst others suggest that this can actually be productive by sensitising the reader to more subtle aspects (Tuckett, 2005). In this case, literature regarding the experiences of parents of children and adolescents and adults themselves of receiving a

diagnosis of AS was studied to prior to the start of analysis to gain an idea of themes which may be likely to occur, whilst also maintaining openness to the possibility of alternative themes.

An inductive-deductive approach was taken to analyse the data as this was deemed to be the most appropriate way to answer the research question. Inductive analysis means that coding of data is not governed by the use of pre-existing coding frames or directed by the researcher's interests or preconceptions, and so themes are strongly linked to the data (Boyatzis, 1998). However, it is impossible for researchers to be completely free of these potential biases and so they should be acknowledged. Conversely, deductive analysis is driven by the researcher's theoretical interest in an area and may use themes from extant research to guide coding (e.g., Crabtree & Miller, 1999).

The decision was made prior to starting the analysis that given the growing body of research exploring similar topics to that of the current study, inductive coding would be followed by deductive coding to see if, and how, existing theory might apply to the data. The inductive phase involved coding anything which was considered relevant to the research question, whilst the deductive phase was specifically searching for instances which could be considered examples of biographical illumination (Tan, 2018), biographical disruption (Bury, 1982) and biographical continuity (Williams, 2000) as these are prevalent in the existing literature, as well as desired informational, relational and emotional post-diagnostic support. The appearance of these aspects in the data formed part of the analytic narrative, rather than requiring themes to be developed from these. Themes can either be identified at a semantic (explicit) or latent (interpretative) level (Boyatzis, 1998). A thematic analysis usually focuses entirely or predominantly on one level (Braun & Clarke, 2006). When a semantic approach is taken, the analyst is not looking beyond what a participant has said, focusing solely on the surface meanings. The analysis then progresses from description to interpretation with the aim of theorising the significance of patterns and their broader meanings, often relating

this to extant literature. Latent level analysis goes beyond the semantic content to examine the underlying assumptions, ideas and conceptualisations which shape what is said, and can be quite abstracted from the explicit content of the data (Braun, Clarke, Hayfield, & Terry, 2018). At the more latent end of thematic analysis, there is overlap with some forms of Discourse Analysis (Braun & Clarke, 2006). Braun et al. (2018) suggest that the boundaries between semantic and latent codes are not always discrete and they consider them as being on a continuum rather than being mutually exclusive. A semantic approach was taken to analysis using the language and understanding of the participants in order to describe their experiences in depth.

The aim of the analysis was to provide a rich, detailed description of the data set as a whole to reflect the important or predominant themes, rather than producing a more detailed account of one theme in particular. It is suggested by Braun and Clarke (2006) that this is a beneficial method when exploring an under-researched area such as the topic concerned. However, it is acknowledged that by taking this approach some complexity and depth is lost.

Interactions between participants during the couple interviews were not the focus of the analysis as this was not the research goal (Morgan, 2010). On the couple transcripts, each individual was assigned their own text colour to separate their speech, and their contributions were analysed individually.

Table 2. Braun and Clarke's (2006, p. 87) stages of Thematic Analysis

Stage	Description
1. Familiarising yourself with the data	Transcribing the data, reading and re-reading transcripts, noting initial ideas.
2. Generating initial codes	Coding interesting features, organising codes into meaningful groups.
3. Searching for themes	Considering how codes fit together to form overarching themes and sub-themes, collating all relevant data into each theme.
4. Reviewing themes	Considering whether collated extracts for each theme form a coherent whole (level 1); considering whether the potential themes reflect the data set as a whole

	(level 2). Producing a provisional thematic map.
5. Defining and naming themes	Determining the “essence” of each theme, identifying sub-themes, naming themes.
6. Producing the report	Producing a concise, coherent, and interesting account of the data, using extracts to illustrate points made.

Stages of analysis.

Phase 1: Familiarisation began with the process of transcription and with accuracy checking of the transcripts produced by the researcher and external transcriber. Following this, each transcript was repeatedly re-read to encourage immersion in the data. Initial notes on aspects of interest relating to the research question were made on the transcripts.

Phase 2: Coding is the process of identification of features of the data salient to the research question with the aim of organising data before themes are developed. Each transcript was coded line-by-line in order to capture everything of interest across the dataset except for when a section of transcript did not have any relevance for answering the research question. The researcher ensured that codes had enough contextual information so that they could be understood when separated from the data.

Phase 3: Each transcript was colour coded to allow easy identification of the transcript from which the code was originally taken. Using a Word document, codes which related to a particular issue were clustered together into groups of candidate themes which had become apparent during the previous phases. Codes which did not fit into these candidate themes were discarded. The aim of

this phase was to bring groups of codes together under a “central organising concept” (a core idea underpinning a theme) which was coherent and distinctive, but that also related to other themes. The research questions were continually referred to throughout this process to ensure that candidate themes developed were relevant to answering these. A thematic map was produced to visually represent the locations of candidate themes and the codes attached to these in relation to each other. This provisional thematic map was reviewed in research supervision allowing some themes to be collapsed into each other and refined, and codes to be redistributed accordingly.

Phase 4: In this phase, candidate themes were checked against the codes and associated data extracts, and then against the entire data set to ensure the final themes captured all crucial aspects of the data, provided a true reflection of the meanings expressed within and gave a thorough but nuanced account. A final thematic map was produced to show how the themes fitted together. Subthemes which highlighted information pertinent to answering the research question were identified.

Phase 5: Themes were further reviewed and refined and then analytic narratives for each were developed to tell the “story” of each theme. Data extracts drawn from across the dataset were selected to illustrate the idea each theme was conveying. The names of the themes and subthemes (some of which were direct quotes from participants) were chosen to reflect the focus of that theme.

Phase 6: The final stage of analysis involved writing the findings section in a way which combined analytic interpretation of the data with compelling extracts to construct an argument which addressed the research question. Extant literature was used to contextualise the analysis, highlight continuities and differences and extend the insights gained from the current dataset.

2.9. Quality Assurance.

Although there are widely approved criteria for evaluating the quality of quantitative research (reliability, validity and generalisability), these are largely not applicable to qualitative research (Braun & Clarke, 2013). As yet there is no standardised guidance for quality assurance in qualitative research, which is suggested may be due to the lack of consensus in the field about how quality should be defined (Reynolds et al., 2011). Qualitative researchers have however developed a range of specific techniques and criteria to guide the evaluation of quality in qualitative research. For example, Braun and Clarke (2006) developed a 15-point checklist specifically for TA which is mostly applicable to qualitative research generally, and more general criteria have been provided by Elliott, Fischer, and Rennie (1999), who synthesised a range of validity criteria to produce guidelines for the publication of qualitative research.

Braun and Clarke's (2006) checklist and Elliott et al.'s (1999) guidelines were adhered to, to promote the quality of the analysis and the study as a whole:

Owning one's perspective – Madill, Jordan, and Shirley (2000) state the importance for qualitative researchers making their epistemological assumptions and theoretical position clear to allow appropriate evaluation by the academic community. Therefore, care has been taken to outline how the critical realist epistemological position impacted on: the understanding of the autism spectrum; the differing views and experiences of individuals in making sense of their son or daughter's diagnosis and their perceptions of their own care and support needs; and the researcher's active influence over the collection, analysis and interpretation of data. Consideration has also been given to how the researcher's own experiences of working with individuals and their families affected by ASD has shaped the development of the study, its aims and the interpretations made.

Situating the sample – The participants and their life circumstances have been described to aid the reader's judgement of the potential applicability of the findings to other groups and situations. The gender, ethnicity and marital status of parents as well as the nature of the parental relationship (biological, adopted etc.) has been included, as have the gender, age and living situation of the sons or daughters to provide context.

Grounding in examples – The researcher has attempted to include sufficient data extracts to illustrate the analytic procedures used and allow independent appraisal of the fit between the author's interpretation and the data.

Providing credibility checks – Elliott et al. (1999) suggest the use of any of the following methods for credibility checking: member checking (checking the analysis with the original participants or others similar to them); using an analytic auditor, multiple analysts or the original analyst for verification; or triangulation (employing two or more data collection methods to gain a fuller understanding).

Difficulties with member checking include the extra time the process requires from both participants and researchers making it prohibitive, and the possibility that participants may find it difficult to express doubts and criticism due to the perceived power of the researcher (Braun & Clarke, 2013). Also, as member checking is situated within a realist framework which assumes that participants are the authority on their experiences, it is argued that when a more critical and interpretative approach is taken, participants are not best placed to validate the analysis as it is not intended to be a direct reflection (Taylor, 2001). Therefore, member checking was not employed in the current study.

The research supervisor (AT) checked the initial coding of the first transcript and the analysis was discussed in a number of supervision sessions.

3. Extended Findings

3.1. Summary of themes.

Participants looked back on their son or daughter's childhood, describing early recognitions of difference or difficulty, the ways they tried to make sense of these, the arguments against and obstacles encountered in pursuing assessment, and the continual search for meaning or changes in thinking that culminated in their child being assessed as an adult.

The diagnosis prompted reflection on their child's and their own past behaviour and explanations resulting in a range of emotional responses, changes in relationships with their son or daughter, and in some cases with spouses and the wider family network and encouraged some to adapt their day-to-day interactions. It also triggered the recognition of their identity as a carer for some parents, serving to reaffirm this for others.

The diagnosis led some parents to feel de-skilled and unsure how best to support their child, desiring more easily accessible, good quality information and contact with knowledgeable professionals or other parents in similar situations, and left them with concerns about their child's future care.

3.2. Arriving at diagnosis in adulthood.

Arriving at diagnosis explores the process parents went through from recognition of their son or daughter's differences or difficulties in early childhood to them receiving a diagnosis in adulthood. There are two subthemes within this theme: Trying to make sense of differences; and Decisions about seeking assessment in childhood andadulthood.

3.2.1. Trying to make sense of differences.

The majority of parents had recognised that their son or daughter had a range of difficulties such as fitting in with peers, being bullied, losing things, having "tantrums", following instructions, poor attention and "silliness" from school age or below. However, these parents were at a loss to explain their child's behaviour:

> We knew at an early age…we used to say he was different from the other children, but we didn't know why. (Jane)

For other parents, their child's differences were highlighted by professionals, and some were more accepting of this information than others. Mary described how her son Andrew attended a children's centre in his early years "because they said he'd want a lot of help growing up" and appeared grateful for this support. Despite a nursery teacher describing Linda's son as "retarded" and "probably unable to attend mainstream school" when he was 4 years old, and Karen stating that school were "always on about ADHD" for her son, they were more resistant to reports of difficulties because of the different side of them they saw in the home environment.

Although Kate described her daughter as "she was just Becky and she was weird", she said that "nobody ever said anything" to her about the possibility of ASD throughout school. Drawing on her own experiences of teaching, she wondered whether there might have been an awareness amongst teachers which was not shared due to concerns about her response. This belief that some teachers were aware of their son's or daughter's difficulties but withheld this information was also echoed by George and Susan, Barbara and Phil, and Jane.

Other explanations and attributions included "being forgetful", "Queen of excuses", "a troublemaker", "an only child" or "born prematurely".

3.2.2. Decisions about seeking assessment in childhood and adulthood.

The recognition of differences or difficulties led the parents who considered these to be pathological in nature to pursue having their child assessed and were met with unsatisfactory responses from professionals. Barbara described a meeting at her son's school where her concerns were dismissed ("he's fine") resulting in disappointment. Similarly, George asked his son's school for an assessment, but his request was ignored:

> I asked once, “can we have him assessed? I have got the right to ask” and they never did anything, and we never took it up. (George)

He felt that his preoccupation with their business (the couple ran a pub at the time) impacted on his ability to pursue the issue further whilst his wife, Susan, felt that she “wasn’t a strong enough person” to confront the teaching staff, resulting in a sense of denial about Robert’s difficulties:

> I don’t like confrontation so I just sort of…“oh he’s alright now, he’s not too bad”, then something else would kick off. (Susan)

Although the school “saw some behaviours” in her son, Kele, Tracey said that they were reluctant to support her, so she felt she had no choice but to seek the assessment independently. However, as a single parent of three children, the cost of this was prohibitive and so she decided not to go ahead.

Despite their own and others’ recognition of differences, some parents chose not to pursue assessment. Phil and Barbara were “frightened” that Logan might have been placed in a special school “away from his friends” and he wouldn’t have “coped” with being “out of his comfort zone”. For Karen, her concern was that diagnosis would have been used to “exclude” her son from mainstream school,he would have been placed in an alternative provision with “lots of children with criminalised behaviour” and “left with teaching assistants that aren’t specialised” meaning he would “end up with challenging behaviour”.

They also voiced worries about the potential impact on their children’s self-esteem. Phil discussed how receiving a diagnosis would have been “embarrassing” for Logan because of the stigma that was around ASD when he was young. Karen having witnessed Gregory’s negative reaction to his dyslexia diagnosis previously and how he’d pulled away from extra support because of “teasing” by other students, believed he would have fought against an ASD diagnosis and so wanted to protect him from “not being the same as his friends”.

As their children reached late adolescence, some of the parents continued their search for the meaning of their behaviour with Jane and Susan invoking brain-based or mental health explanations for their sons' presentations, although both recognised these explanations didn't quite fit:

> Because that's what I was starting to think. That he was perhaps a schizophrenic…I was starting to think there was something that way, which I knew he wasn't, but I was trying to make reasons. (Jane)

Susan described thinking in her son's middle teenage years, "what's wrong with him? His brain doesn't work like ours", and how Stephen Fry's disclosure about his bipolar disorder had led her to think along the same lines.

Jane and Phil and Barbara also discussed how their sons had been misdiagnosed by doctors as having "anger management issues" because of the "meltdowns" they experienced.

For Jane, Kate, Linda and Rita, their son's or daughter's difficulties were highlighted by professionals involved in managing their mental health needs, sometimes having reached the point of "breakdown" before receiving a referral to the AS service.

Phil said that Logan's difficulties became "more noticeable" and "stood out" as he entered adulthood, and how he and Barbara were "hoping that he'd snap out of it and get better", but then when they realised that that wasn't going to happen, they chose to pursue assessment with the hope of enabling him to access support. For Karen, this involved her own recognition that Gregory was "struggling maintaining relationships", disclosing to her that he "felt different" to other people and it was drastically affecting his mental health. She considered that as he got older, she was less able to meet his needs than when he was a child and this as well as Gregory's own desire for self-understanding ("because it was his, he wanted it") prompted her to advocate for assessment.

Mary was the only parent for whom receiving a diagnosis herself in adulthood re-ignited the desire to "put a label" on her son's behaviour, having become more aware of the similarities between them. For Tracey's son, Kele, the recognition of ASD traits in one of his daughters prompted him to seek assessment, doing so independently of his mother or professionals.

3.3. Diagnosis leading to new understanding of self and child.

This theme encapsulates parents' processes of reflecting on their son or daughter's life through the new lens of AS and the changes this elicited. There are five sub-themes within this theme: Emotional reactions to diagnosis; *"When you put it all together, it does come to autism"*; New relationships and ways of interacting; Carer Identity; Sharing the diagnosis.

3.3.1. Emotional reactions to diagnosis.

A range of emotional reactions to the diagnosis were expressed and the expectation or anticipation of diagnosis appeared to play some role in determining these. Karen described feeling "just relieved" in response to the news as she had been expecting it, and similarly Rita said that her late husband had been "very satisfied…that he'd been proved right, maybe".

Tracey described experiencing a visceral physical reaction to the news of her son Kele's diagnosis ("I felt it deep in my stomach, the 'oh my gosh'") as she had not been anticipating it. Linda's belief that her poor health during her pregnancy and her desire for the pregnancy to be over had caused Peter's AS, as well her perception of AS as a "huge label" resulting in marginalisation made her feel deeply guilty and saddened.

Some parents expressed experiencing more complex reactions. Jane described "going through the guilt of 'I was a bad parent'", chastising herself for not having done more and believing that her son blamed her for not getting help, before concluding that she "couldn't have done anything more", culminating in relief and vindication that "there was something" and she had been "right all along". Similarly, George expressed relief whilst simultaneously feeling as though he'd "let Robert down a little bit".

For Kate, George and Susan, there was also a sense of being let-down by family and friends who claimed they had “always known” about their children’s difficulties when the diagnosis was shared with them but hadn’t voiced these concerns.

3.3.2. “When you put it all together, it does come to autism”.

George and Susan, Jane, Kate, Karen and Linda all reflected on the sensory sensitivities to light, sound, textures of food and clothing, and sensory-seeking behaviours (such as hand-flapping) their children had demonstrated during childhood. This was a particularly significant discovery for Jane who had previously thought her son’s responses to light were because of a “sight problem”:

> When you put it all together, it does come to autism. From his eyesight, loud noises. I couldn’t use the vacuum cleaner with Richard in the house. I always vacuumed when he was at nursery. (Jane)

The diagnosis also helped parents to make sense of their son or daughter’s “obsessions” such as planes and pylons and their tendency to voraciously “collect” items such as videos, books, stones and figurines.

For Kate, Susan and George, Jane and Karen, the diagnosis shed light on their children’s difficulties with making friends, getting on with colleagues at work and peers at university:

> Every time she had a holiday job, weekend job, it didn’t matter what it was, there was somebody she would always fall out with. “So and so’s horrible, shouting at me”. And looking back you think, it’s always happened. (Kate)

The AS diagnosis enabled Jane and Linda to understand their sons’ “meltdowns” from a new perspective. Linda described a situation in which Peter had become highly distressed and walked out of an exam at school and reflected on other “episodes” of this type of behaviour:

> …the Asperger's kind of makes that seem normal, you know. That seems to make, you know, I can kind of understand why that happened. (Linda)

Karen was the only parent who explicitly referred to the diagnosis as changing their child's identity, perhaps reflecting her investment in this explanation for her son's behaviour:

> The Gregory without Asperger's awaiting diagnosis ended on the 24th April. On the 24th April, he's Gregory with Asperger's…so he stopped being Gregory who was rude and cheeky to Gregory, actually, who's got a condition. (Karen)

However, some parents could be seen as experiencing "biographical disruption". Jane and Kate contemplated their own actions and decisions they'd made during their children's childhoods, leading them to feel guilty:

> It brought back lots of thinking about how we did deal with her and how we did cope, which made me think, yes, you know, perhaps there were lots of things I could have done differently. (Kate)

However, both had managed to resolve this guilt to some extent. For Jane, this was through the recognition that she "couldn't have done anything more", whilst for Kate, it was through knowing that "there was something else happening (AS) that maybe I could have or couldn't have dealt with at that time".

3.3.3. New relationships and interactions.

Karen was very clear in her belief in the necessity and importance of parents and families taking responsibility for changing their behaviour and communication when their son or daughter received a diagnosis of AS in order to support that person to "embrace" their identity:

> So, you can't go, "well, they've got that label", and carry on the same way. And I think that's where a lot of parents struggle and I think a lot of parents think "right, I've got a diagnosis, so end of. No! That's just the

> start and you've got to look how you then are as a family and how are we going to respond to this as a family? (Karen)

She went on to discuss how she had recognised when she had adapted her behaviour to meet Gregory's needs in light of his diagnosis, he appeared calmer, more confident and had "increased in maturity" and that "made things better for all of us".

Jane, Kate, Karen, Linda and Phil described various ways in which the knowledge of the diagnosis had allowed them to rethink their attributions for their son or daughter's behaviour and so had changed their responses, emotional reactions and relationships. Karen described how her response to clashes with Gregory had changed and she had noticed that "he shares more and we problem solve quicker" because of this:

> So what I would do previously, he'd be rude and then I'd say "no, I can't talk to you, you've been too rude". And then, obviously, that just makes him anxious…. so, I don't do that now. I'll just say, OK, he's back to normal, that's fine. (Karen)

Similarly, Jane talked about how she and Richard had developed a mutual understanding of when he wished to be left alone which meant she didn't feel hurt or rejected:

> If he wants to shut his self in his room, me and him have now got a thing where he'll say, "you're getting on me nerves" and I know then it's quiet time. I don't take it personally, whereas once upon a time I would have done. (Jane)

Kate and Linda discussed their attempts at "guiding" their husbands' interactions with Becky and Peter to improve relationships with them. Kate described how when she and Becky's father visited her, she prompted him to use "simple sentences, make sure she's looking at you, don't use too many

metaphors or ambiguities" and afterwards, would evaluate together how the conversations had gone:

> …five or ten minutes driving away we'll be like, you know, could we have done that differently, what else could you do? That worked well…(Kate)

Likewise, Linda had spoken to her husband, Peter's stepfather, about how Peter might struggle to understand his sense of humour and encouraged him "not to goof about" because it made him uncomfortable.

Kate expressed that Becky's diagnosis had allowed her to feel "definitely closer" to her daughter as it enabled her to understand the ruptures in their relationship and to begin to heal:

> …It gave us a reason for why the past was so difficult at times, which was actually helpful in many ways…and it felt like she sort of breathed a big sigh of relief and so could we and go, "right, you know, our relationship can be slightly different now, we know each other a bit better." (Kate)

Because of this shift, Kate thought that Becky seemed able to "relax a bit more" and was "keen to spend time" with her now, which Kate thought was due to Becky knowing that she had different "strategies" for approaching interactions with her.

Jane reflected on how Richard's relationship with his father had previously been "awful", but that the diagnosis was "as if somebody turned a light on", transforming their relationship. She described how she had made a conscious decision to "step back" from her relationship with Richard to allow him and his father to "build trust" and "mend bridges".

Tracey and Linda seemed less sure about whether to and how to change considering their sons' diagnoses. Tracey expressed that Kele's diagnosis had left her with questions about the nature of AS and how the family should be supporting him now:

> We have no understanding at the moment of what it is so we're still carrying on as normal with this diagnosis but what does that mean? How are we supposed to adapt and are we supposed to do anything different? It's thrown a spanner in really, because before, it was "ok, that's Kele, that's how he is and we deal with that accordingly" so now we've got that, should we be different? (Tracey)

Kate described how her prompts and reminders of "strategies" had improved her husband's confidence in speaking to Becky on the telephone (something which he previously would have avoided) and he was more willing to discuss things about her, which meant she was no longer "bearing all the burden":

> I'll say to him, "I've got to tell you something about Becky and you need to listen and take in the implications of that". "Oh alright". Whereas before, he'd be like, "Oh, I can't deal with it. I can't talk about that". It was too difficult for him". (Kate)

Tracey was the only parent who stated that the diagnosis had created "division" in her close family and had left her feeling "further apart" from her son. She talked about how Kele's brother had been very accepting of his diagnosis and said that he had been "finding excuses for all his behaviours", whilst she and his sister were concerned about "trying not to enable certain things". Tracey said that this difference in perspectives meant that Kele felt she was being unsupportive and as she was not willing to "capitulate", they had reached an "impasse" with a breakdown in communication.

Parents for whom the diagnosis had had a more limited impact, such as Rita, Mary, George and Susan and Barbara, described how their behaviour and communication had not changed because they did not see a need for this, and that their relationships with their sons had stayed the same:

> I mean my attitude to him is not going to change because of the diagnosis really. I'll still carry on the same. (Rita)

3.3.4. Sharing the diagnosis.

Karen discussed how she encouraged Gregory to be open about his diagnosis himself so that "people have an awareness about who he is and what he's about", due to his tendency to accidentally cause offence by making personal jokes.

Jane described her experience of sharing Richard's diagnosis with her family with the expectation that it would result in more support from them, but this not being forthcoming:

> My family now are, "oh, he's got his diagnosis, you're getting all the help you need". Hello? We're getting nothing! We thought you'd give us a bit of help…my sisters and other people have all suddenly disappeared. (Jane)

Jane also discussed her personal motivation for sharing Richard's diagnosis. Throughout Richard's life, she had felt she had to "hide" his difficulties keeping them "within our four walls", even concealing some of the more difficult experiences from her husband. The diagnosis appeared to be cathartic for her, legitimising Richard's behaviour and allowing her to "be more open" with people about the day-to-day reality of her life as a carer.

Tracey stated that she hadn't spoken to anyone outside of the immediate family out of respect for Kele who was "a private person".

Kate and Karen discussed the potential drawbacks of their children sharing their diagnosis with employers. Kate expressed her disappointment with how her daughter's employers had responded to her disclosure of her diagnosis ("they're all too busy to think perhaps we should be dealing with her in a different way") and voiced her concern about Becky's prospects if she chose to share her diagnosis with potential future employers:

> There would be employers who would say, "no, we can't cope with it" definitely. And I know that happens in the real world. People do…there would probably be plenty of jobs she could do where people would be

much more cooperative and supportive, but I bet there are plenty where they won't be. (Kate)

Karen discussed how her husband was "worried" that Gregory sharing his diagnosis would "stop him having choices" relating to work, specifically concerning his ability to join the Army if he wished to do so.

3.3.5. Carer identity.

Parents discussed numerous areas in which their son or daughter required their support, from practical tasks such as changing lightbulbs and managing finances to social and emotional support with managing anxiety, facilitating friendships and advocating for their rights in the workplace.

Karen described how being referred to as a "carer" had encouraged her to reflect on how other "young people his age are having less prompting, Gregory's prompting is getting less but not the same as if he didn't have a diagnosis" and how she recognised that his diagnosis meant "he'll always need me to do certain things", perhaps more so than parents of other young people.

For Rita this shift was more subtle. She considered that she had always been a carer for Anthony as he had not "progressed" like her other children who "did things naturally, like, you know, they left school, got jobs and got married", but that prior to the diagnosis she considered herself to be a carer for somebody with a mental health problem:

> …over the years he's had this depression and that, even when I was at work, if he was in a bad place, I would sit up half the night with him, even though I'd got to go to work in the morning. (Rita)

Mary didn't "class" herself as a carer as Robert is "able-bodied" and mostly independent. After Kele's diagnosis, Tracey compared his needs to those of her other children and reflected on how the support she provided him

could be seen as caring, but she continued to see herself as his mother rather than his carer:

> I haven't ever thought of myself as a carer. I've thought of myself as a mother, so I've mothered him and maybe I've had to mother him more, but they're all individuals so you give them what they need… I might have been doing some of those things as in as an adult, him coming back and living at my house and supporting him in those ways, financially supporting him and being there for him, but I've always seen it as being a mother without realising that some of those things might have been down to his Asperger's. (Tracey)

Tracey expressed her struggle at reconciling her son's age and her perception of his abilities with the diagnosis which perhaps contributed to her not accepting the carer label:

> He's an adult. How much can I do? I think that's the problem I have as a mother of a 35-year-old man. He is independent, he's perfectly capable of dealing with it himself. (Tracey)

Jane voiced her frustration at how the social care system did not understand the needs of individuals like her son, leading to the failure to recognise the significant role she and her husband play in supporting and caring for Richard, and undermining the value and importance of this:

> 'cos in our eyes, he's disabled, but he's not registered disabled so we're not even his carers in other people's eyes. (Jane)

3.4. *Parents' information and support needs.*

This theme encompasses parents' search for information and support post-diagnosis. There are three sub-themes within this theme: Barriers to seeking support; Decisions to seek further support; and *"…if somebody could just hold our hands whilst we hold his".*

3.4.1. Decisions to seek further support.

Both Kate and Karen had worked with people with ASD previously and cited the knowledge they had gained through this as being helpful:

> I think maybe if I was somebody who hadn't worked in education, if I hadn't had experience in the past, I might need more support. (Kate)

Although Phil and Kate felt adequately supported by their partners and to a lesser extent their friends and families, they recognised the potentially different requirements of single parents and individuals who are less well connected:

> Some people have got nobody to talk to. To have someone at the end of the phone or to arrange to meet. That's what some people want, but we're ok. We talk to each other. We've got friends. (Phil)

Rita described feeling guilty about the possibility that Anthony's brother or sister would one day have to take over caring responsibility from her due to the lack of other options:

> This is the worry you know, because they're so busy. They've got jobs and what have you. Have they got time for Anthony? Would they want to? It's a, you know, you feel you're putting a burden on them. (Rita)

Relating to unhelpful conversations she had had with social care, Jane's concern for Richard if she and her husband were no longer around was his inability or ineligibility to access external support to "help him function" due to his perceived independence and coping skills:

> He is high functional. They are capable but can't. They're the ones that are gonna slip under the net. (Jane)

Although Karen had previously shared Jane and Rita's anxiety, describing her worry that Gregory would "end up on his own in a one bedroom flat…ordering food off the internet…and his interaction all done through social

media", she had managed to overcome this concern through "supporting him differently" and had "seen him grow" and "do more things" because of this.

Only Susan explicitly stated that she was not worried about Robert's future, taking a very pragmatic approach which may be related to his fairly low-level support requirements:

> …we just live with him as he is at the moment because given how's been over the years, he could change again. I don't know.

3.4.2. Barriers to seeking support.

Several parents described their difficulties in accessing relevant, easily digestible, good quality information about AS. Jane and Linda both appeared to be overwhelmed by the information available on the internet. Linda especially was concerned that looking online might confirm her worst fears about marginalisation of people with AS and perhaps avoided searching to protect herself from this unwanted knowledge:

> I mean obviously you can look online, but you know, if you look up online, you get ten different completely conflicting things about it, won't you? I guess if you put in the word, it would come up with, "no, people can't live normal lives" and "yes, they can". It would be a completely confusing array…of hearsay and scaremongering. (Linda)

Tracey highlighted a lack of information about high-functioning individuals like her son and so had been reading the blogs and stories of people with high-functioning ASD. However, she had not found these helpful and was still struggling to reconcile her experiences of working as a Teaching Assistant with children with ASD with how AS was "manifesting" and "showing itself" in Kele.

As Kele was receiving some post-diagnostic support, Tracey appeared to feel excluded and expressed a desire for the inclusion of parents and families in

this process to build their knowledge and skills in supporting their family member:

> …it's a holistic way of moving on which I think would be of more benefit. We're always gonna be here. He's not always gonna have these sessions he's having, so he might have an understanding, but no-one else has. (Tracey)

Although Jane had been proactive in her attempts to secure support, these had been met with obstacles. She talked about how she had joined online support groups for parents of children with ASD and for adults recently diagnosed to attempt to fulfil her need for social support, but these had been unsatisfactory and there was a sense of disappointment and frustration regarding this:

> They're not what I'm looking for. Yes, it's nice to read that somebody is going through what you went through. The odd time I will put a comment that "they're not on their own". But they're not on their own. They're getting help. (Jane)

She also described how she had tried to access formal support and benefits for Richard which in the context of her previous experiences with professionals had caused her anxiety, but had been shown a lack of understanding by the person she spoke to:

> I plucked up the courage one day to ring one number and she said, "oh well, we only really deal with children". But there's adults out there! "Why are you applying now?" (Jane)

Jane described feeling "very alone" and like she and her husband "haven't got a clue what we're doing", expressing doubt about "whether we're doing right for Richard".

3.4.3. *"…if somebody could just hold our hands whilst we hold his".*

Several parents expressed a desire for further information than that provided by the service following their child's diagnosis. Given her confusion and concern regarding information online, Linda expressed that she wanted "proper guidance" and "some pointers" about which websites to access for reliable, unbiased information about AS. However, for Jane, Rita and Karen, this was more about signposting to services that could provide information about the rights of people with AS in the workplace, access to benefits and supported living accommodation to allow them to meet their sons' support needs:

> …like if we want to move him out, somebody to say "if you do this, this and this, and get in touch with these people". We just don't know who to get in touch with. (Jane)

As parents to sons with very high support needs, Barbara and Jane both expressed a need for a break from caring. As Logan had moved out from Barbara and Phil's house to live with his wife who was his secondary source of support, it had become easier for them to go on holiday together. However, as Richard has very significant mental health support needs, Jane felt unable to leave him for the fear that he'd be a risk to himself:

> We've not had a holiday for years and years because we daren't leave him. Well, we did. We went away at Christmas, but we ended up with the crisis team and the police. (Jane)

She went on to discuss the inadequate options for respite provision for individuals like Richard who do not have an intellectual disability, but require support in their everyday lives:

> I looked up a place where you can get respite, but I don't think Richard would want that. He's not stupid, he's just lonely. (Jane)

Karen suggested the idea of a "buddy system" whereby when an individual is diagnosed in adulthood, their family is paired with another family in

a similar situation so that they can support each other via telephone or face-to-face contact. Linda's preference was for email contact with other parents to help her feel that she's not the "only person".

Kate and Tracey both suggested the possibility of a professional taking on a "mediator" role between the individual diagnosed and a family member who was perhaps finding it more difficult to reconcile the diagnosis to allow a shared understanding and increased empathy:

> So I think it would be nice if after the diagnosis, to be able to talk about it. What it means, what it means to Kele. Whether the person that's talking to Kele, we have a three-way conversation? I understand there's confidentiality, but if he's there we can sort that out…how does he see it and how does he feel, then I can state my view. (Tracey)

4. Extended Discussion

4.1. Discussion of findings in relation to past literature.

All parents reported some recognition of unusual behaviour in their son or daughter in childhood as in Raymond-Barker et al.'s (2016) study, but where parents voiced concerns, they were dismissed or ignored and there was some suspicion that teachers did not feel confident in sharing concerns. The lack of recognition or sharing of concerns about AS by medical and education professionals involved with children highlights a need for increased training and awareness of ASD symptoms to promote earlier diagnosis. As some parents also described how their sons had been misdiagnosed with anger management issues, this need extends to health professionals working with adults. They should also be made aware of local assessment and diagnostic referral pathways to ensure a smooth process where difficulties are recognised.

Lazarus and Folkman's (1984) process model of stress and coping is helpful in understanding the responses of parents to their child's diagnosis. Due to individual beliefs influenced by societal narratives about the diagnosis having

negative connotations, it was perceived by some parents as potentially harmful, threatening or challenging. When these individuals appraised their coping resources, such as existing knowledge, social support, access to education, self-efficacy and problem-solving skills, they were deemed to be lacking. Having an external locus of control (Rotter, 1975) may explain why some parents were less active in their information-seeking and coping attempts, stating that they desired contact with a professional to support them in understanding their son or daughter's diagnosis. However, other parents took responsibility for actively finding the information they wanted themselves, suggesting they held an internal locus of control.

Given that some parents appeared to be experiencing high levels of psychological distress in response to their child's diagnosis and were struggling to understand whether and how to make changes in light of this, it is possible that these parents could benefit from some short-term psychological intervention to support them in this process. As Hickey et al. (2018) suggested, an externalisation approach may be useful for parents who hold personal causal and internal controllability attributions for their child's behaviour, allowing them to shift these attributions and encouraging acceptance. However, this would not be necessary or appropriate for all parents and would obviously have financial implications for services tasked with providing this intervention.

As found by Raymond-Barker et al. (2018), some parents in the current study also expressed concerns about who would meet their son or daughter's care and support needs if they were no longer able to, and the lack of appropriate services for meeting their child's needs. Similarly, some parents in this study also voiced a desire for professional support in understanding and responding to their son or daughter's needs, suggesting that this need is common amongst parents in this situation.

4.2. Limitations.

Despite allowing more time to interview couples and using prompt questions to encourage each individual to express their views on all questions asked, it was apparent that in both the couple interviews one individual spoke considerably more, and so consequently the other is less represented in the dataset. However, it is possible that if the option of being interviewed with their wives had not been offered, fathers may have chosen not to take part. Therefore, at least this way their voices were somewhat included.

Participants were interviewed three to six months after their son or daughter received their diagnosis, which was intended to allow them time to process and adapt. However, it is possible that over this time, their memory regarding their feelings and experiences had faded or changed and that their prospective accounts would be different.

As in most other research with parents of children with ASD, there was an over-representation of mothers in the sample. This is possibly due to the recruitment strategy as mothers are more likely than fathers to have contact with services regarding their children. It is important that future research endeavours to encourage the participation of fathers to understand any differences in their experiences and needs.

Only one parent of a daughter was included in the sample, which might reflect the smaller number of women and girls diagnosed with AS or ASD. As it is recognised that females may present very differently to males, parents of women diagnosed in adulthood may have different experiences and needs which should be explored in future studies.

The sample lacked ethnic diversity as the majority of participants were white British. It is possible that individuals from other ethnic and cultural backgrounds would hold different conceptualisations of AS and the roles of parent and carer, therefore have different experiences which it is important that future research attempts to capture.

As the current study was exploring the experiences of parents whose child had received a diagnosis of AS, by definition, it excluded those who had recognised difficulties in their child's early life but had not chosen to pursue diagnosis in adulthood. Gaining the views of this cohort may enrich the understanding of the decision-making process around seeking diagnosis in adulthood, and the provision of information and support to parents who are unsure whether to pursue assessment or not.

4.3. Clinical implications.

As several parents voiced their desire for a peer support network or group, this should be considered by service commissioners, especially as it would likely be more time- and cost-effective than clinicians meeting with parents individually. The possible benefits of a post-diagnosis support group would be gaining an enhanced understanding of what the diagnosis means, normalisation and the sharing of coping strategies and informational resources. Parents also identified a gap in online resources and interactive support forums for people in their situation, which it is important to address.

4.4. Future research.

A study using a longitudinal design could be conducted to explore in more depth how parents adapt to and accept their son or daughter's diagnosis, interviewing them prior to the assessment to understand their expectations of diagnosis, shortly after the diagnosis has been given to capture their initial response to this and then again a few weeks later to establish when and how the changes demonstrated in the current study occur. However, the repeated interviews would be burdensome on the participant and there is likely to be attrition.

4.5. Critical reflection.

I have chosen to reflect on what initially motivated me to undertake this study, as well as the development and conduct of the study, what I have learned about doing research generally, and the specific insights from this particular project.

Although I had heard the word autism before, I first truly became aware of the breadth and heterogeneity of the autism spectrum when volunteering on a holiday playscheme for children with ASD as a teenager. I met children with differing levels of verbal ability from those who were completely non-verbal to those with highly developed vocabularies, differing levels of desire for social interaction, and a diverse range of special interests. I also began to gain an understanding of sensory differences with my lasting memory being of a little boy who loved repeatedly continually throwing feathers in the air and watching them flutter to the ground. It was my experience on this playscheme that cemented my career-long interest in ASD.

My time working as a support worker for adults with ASD and complex needs in the community made me think more deeply about the role of parents and other family members in supporting young people from adolescence into adulthood. Many of the individuals I worked with either still lived with their parents or remained in frequent contact with them, and required a significant amount of support from them with everyday living skills and in managing their psychological wellbeing. This put some parents under a huge amount of strain which had a detrimental impact on their psychological wellbeing, and there did not seem to be much readily accessible support available to them in their own right.

Some years ago, my friend's little girl was diagnosed with ASD and over time, I have watched the family accept and adapt to the diagnosis. They were initially very proactive in exploring different strategies to encourage her to interact and communicate, but with limited impact. Her father seemed to find the lack of progress especially difficult to deal with and he became more distant in his relationship with her. However, as the family have come to gain a better understanding of ASD, their daughter's own individual communication style and strengths, it has had a positive impact on their relationships.

Whilst working in an Adult Community Learning Disability Team, I was involved in diagnosing a young man with ASD. His mother was heavily involved in the assessment process and was relieved at the outcome as she had suspected ASD for many years. This experience, and the experience of my friend's family made me wonder whether there were any parallels between parents' experiences of their son or daughter receiving an ASD diagnosis as a child and as an adult, and whether all parents of individuals diagnosed in adulthood would share this response. It was this wondering which provided the motivation for the study.

Despite the study being not particularly ethically contentious, the process of gaining ethical approval was arduous, time-consuming and a little confusing. Attending the Health Research Authority Research Ethics Committee was mildly anxiety-provoking as I did not really know what to expect or what was going to be asked of me, but I felt reasonably prepared and was fairly confident that approval would be given. When I received the email stating that the committee was unable to come to an ethical opinion on the basis of the information I had provided, I was both disappointed and frustrated that this would result in yet more delay in recruitment. However, in hindsight, I appreciate that the suggested revisions to the interview schedule did improve the clarity and the flow of questions probably resulting in better quality data. Having been through the process of gaining ethical approval, I feel I have a better understanding of the organisations involved and their roles as well as the likely timeframes so I would feel more confident if I were to conduct another project. It also made me wonder whether Psychologists in clinical practice are reluctant to do research partly because of the laborious ethical review processes.

Having seen the numbers of individuals diagnosed annually by the service I was recruiting from, I was initially confident that I would be able to achieve a sample of 12 to 15 participants relatively easily. However, recruitment was slow to get off the ground, which left me concerned about the viability of the project. I expressed this concern to my supervisor, and we decided together

that approaching similar services would be sensible, so I amended my ethics application to reflect this (see Appendix C). This amendment turned out to be unnecessary as there was a flurry of recruitment and 15 individuals agreed to take part. This experience has taught me as with ethical approval, recruitment is also likely to take longer than anticipated and generous allowances for this should be made when planning project timeframes to increase the possibility of recruitment targets being met.

Although 15 people agreed to take part, when it came to scheduling interviews, due to personal circumstances two individuals decided not to take part. Another participant arranged interviews on a couple of occasions, but then cancelled last minute or on the last occasion, did not attend and did not respond to my attempts to contact them. Although I was disappointed, I wondered whether this individual may have had other care-giving responsibilities which made it difficult for them to commit. I also reflected on the potential role of differential power dynamics and how this individual may have felt unable to say “no” to taking part because they were asked by someone with perceived greater power and influence over service access than themselves. Although I was disappointed not to have achieved the minimum desired number of participants, I believe that the interviews conducted resulted in an interesting data set which met the study aims.

Initially, I was nervous about interviewing the participants as I had limited prior experience of using semi-structured interviews. Throughout the course of the interviews, I felt more confident and able to relax. However, I found it very difficult to maintain the stance of objective, detached researcher as opposed to the therapist role I usually occupy, especially in the face of high emotion and the distressing experiences recounted. Supervision was useful in supporting me to maintain the researcher position by encouraging me to focus on the potential positive changes that may be achieved through the dissemination of this research which could help many families.

One individual took part in an interview but chose to retract their data. Although I was disappointed as they were highly eloquent and expressed views which other participants did not, I was not surprised at their decision as they appeared anxious during the interview. It is likely that they felt exposed and vulnerable given that it was the first time they had openly acknowledged their child's difficulties outside of the family, and were probably concerned with the prospect of being identified from their account. Afterwards I wondered whether there was anything more I could have done as an interviewer to help them to feel more secure, but I don't think there was. I hope that through sharing their story with me, they will feel more confident in discussing their needs and experiences with professionals in future, although I appreciate that this will take time.

When it came to transcription, I originally hoped that I would be able to transcribe all of the interviews myself. However, due to time constraints, this was not possible, which is unfortunate as the process of transcription allowed me a more in-depth knowledge of those interviews. Despite having fewer participants than intended, analysis was highly overwhelming to begin with and I felt like I was drowning in data, but having been assured by my supervisor that I would feel like this helped me to accept this and move on. Supervision was vital in organising my chaotic provisional maps into coherent themes and sub-themes. I still found it difficult to let go of some of the interesting content which wasn't relevant to answering the research question and was left with the feeling that the account I had presented was not the whole story.

Even though I was aware of the increased likelihood of people with AS or ASD experiencing mental health problems, I was still shocked by the extent of the mental health needs of the adult sons and daughters of parents in this study with all having experienced anxiety and low mood and over half having considered or attempted suicide. Like the parents in this study, I was frustrated by the lack of post-diagnostic support available to them and I am hopeful that

bringing the focus to parents of adults will encourage acknowledgement of their needs and a shift in practice.

Having completed the project, I maintain that it was an important topic to research, adding to a growing body of literature concerning adult diagnosis of AS. I believe the findings are useful in developing knowledge about the impact of AS diagnosis beyond the individual and in understanding the needs of parents in accepting and adapting to this. The findings are most relevant to clinicians directly involved in the assessment and diagnosis of adults, but also to parents whose son or daughter is going through the diagnostic process or has received a diagnosis in adulthood.

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Appendices

Appendix A: Initial letter of ethical approval (University)

University of Nottingham
UK | CHINA | MALAYSIA

Our reference: RGS 18006
IRAS Project ID: 235293

0115 8467906
sponsor@nottingham.ac.uk

Health Research Authority
Research Ethics Committee

Research and Innovation
University of Nottingham
East Atrium
Jubilee Conference Centre
Triumph Road
Nottingham
NG8 1DH

Dr Thomas Schröder
Room B12 YANG Fujia Building
Jubilee Campus
Wollaton Road
Nottingham
NG8 1BB

18th April 2018

Dear Sir or Madam,

Sponsorship Statement

Re: Exploring the experiences of parents whose child has received a diagnosis of Asperger syndrome in adulthood

I can confirm that this research proposal has been discussed with the Chief Investigator and agreement to sponsor the research is in place.

An appropriate process of scientific critique has demonstrated that this research proposal is worthwhile and of high scientific quality.*

Any necessary indemnity or insurance arrangements will be in place before this research starts. Arrangements will be in place before the study starts for the research team to access resources and support to deliver the research as proposed.

Arrangements to allocate responsibilities for the management, monitoring and reporting of the research will be in place before the research starts.

The duties of sponsors set out in the NHS Research Governance Framework for Health and Social Care will be undertaken in relation to this research.**

* Not applicable to student research (except doctoral research).
** Not applicable to research outside the scope of the Research Governance Framework.

Yours faithfully

Angela Shone
Head of Research Governance
University of Nottingham

world-changing research
from the University of Nottingham

Appendix B: Initial letter from REC committee

NHS
Health Research Authority

East Midlands - Leicester South Research Ethics Committee
The Old Chapel
Royal Standard Place
Nottingham
NG1 6FS

06 June 2018

Dr Thomas Schroder
Co-Director Trent DClinPsy course
University of Nottingham
B12 YANG Fujia Building
Jubilee Campus, Wollaton Road
Nottingham
NG8 1BB

Dear Dr Schroder

Study Title:	**Exploring the experiences of parents whose child has received a diagnosis of Asperger's syndrome in adulthood**
REC reference:	**18/EM/0149**
Protocol number:	**18006**
IRAS project ID:	**235293**

The Research Ethics Committee reviewed the above application at the meeting held on 24 May 2018. Thank you to Miss Hannah Legg for attending to discuss the application.

Provisional opinion

The Committee is unable to give an ethical opinion on the basis of the information and documentation received so far. Before confirming its opinion, the Committee requests that you provide the further information set out below.

Authority to consider your response and to confirm the Committee's final opinion has been delegated to the Chair.

Further information or clarification required

1. The study should not be introduced to the parents at the diagnostic appointment. Please re-consider the timing of the initial approach. In addition, study documentation should be posted via the clinic directly, with an invitation letter, to parents who do not attend the pre or post diagnostic appointment, rather than being sent via the adult client.
2. The Participant Information Sheet must be updated as follows;
    a. To ensure it is clear within the document that the interviews will be about the parents and their experiences and feelings.

   b. To detail that the study is being undertaken for educational purposes. This information should also be added to the poster advertisement.
   c. To mention the use of audio recording.
   d. To state that agreeing or not agreeing to take part in the study will have no effect on their son or daughters care.
   e. To contain the name of the REC.
   f. To clarify who will complete the transcription of interviews.
   g. The section titled "What are the possible disadvantages and risks of taking part?" should be updated to state that there is no guaranteed benefit from taking part in the study.
   h. To include signposts for the participant in the event of distress.
3. The Consent Form should be updated as follows;
   a. A box should be added to allow a participant to opt in to receive a copy of the results.
   b. To refer to the date and version of the Participant Information Sheet within point one.
4. Please submit a copy of the Facebook advert for REC review.
5. The text within the purple box of the study poster is not easily legible. Please ensure all text is clearly presented.
6. The interview schedule should be revised so that it is clear as to what is being asked. The following changes are suggested;
   a. Specific prompts and follow ups are suggested at questions two, three, six, eight, nine and eleven.
   b. Parents should be asked about their son or daughter rather than 'child'.
   c. It is queried if the use of the term 'carer' within question ten the interview schedule could come as a shock to the parent. Consideration should be given to use of an initial which asks the parent if they consider themselves a carer first, or if they envisage becoming a carer in the future.
   d. It should be made clear in question two of the document what 'anything else' could refer to.
   e. Question eleven is considered quite long, particularly as participants will not see the question written down. It is suggested that the question be shortened.
   f. Questions 11 a to d should each begin with " Did you or do you…". Consideration should also be given to using supplementary follow ups such as; "How do you feel these may be met?" "Has this happened" and "Are these/have these been met?"

If you would find it helpful to discuss any of the matters raised above or seek further clarification from a member of the Committee, you are welcome to contact the REC Manager.

When submitting a response to the Committee, the requested information should be electronically submitted from IRAS. Please refer to the following guidance for instructions on how to submit a response to provisional opinion electronically from IRAS:
https://www.myresearchproject.org.uk/help/hlpethicalreview.aspx#After-submit-to-REC

Please submit revised documentation where appropriate underlining or otherwise highlighting the changes which have been made and giving revised version numbers and dates. You do not

have to make any changes to the REC application form unless you have been specifically requested to do so by the REC.

The Committee will confirm the final ethical opinion within a maximum of 60 days from the date of initial receipt of the application, excluding the time taken by you to respond fully to the above points. A response should be submitted by no later than 06 July 2018.

Summary of the discussion at the meeting

Social or scientific value; scientific design and conduct of the study

The Committee noted the study aims to interview parents of adult children who have recently received a diagnosis of Asperger's Syndrome. The Committee understood Asperger's to have been placed under an umbrella diagnosis of 'Autism Spectrum Disorder' and queried if Asperger's is still given as a diagnosis in Nottingham. *The applicant explained that Asperger's is subsumed as Autism Spectrum Disorder within DSM-5 which is used in the United States, but explained the* International Classification of Diseases (ICD) *is the most commonly-used diagnostic manual in the UK, which for now still includes Asperger's Syndrome as a separate diagnosis.* The Committee queried if there would be enough potential participants available with confirmed diagnoses. *The applicant confirmed so and stated that there is a rising awareness of Asperger's Syndrome following media attention and there are rising rates of people seeking a diagnosis.*

The Committee queried the expected age range of the adult children and asked if the study would include population of 18-30 year old adults with Asperger's living at home, or those newly diagnosed aged 50. *The applicant confirmed that the offspring would be aged 18 years and over, and added that they may be in their 50's, but accepted that it is more likely they will be on the younger side. The applicant highlighted that persons could be diagnosed at any age, as some adults may have been dismissed as children, and only diagnosed as their symptoms became more apparent in adulthood.* The Committee queried if the study is more likely to receive a younger cohort. *The applicant agreed that an older cohort may be unlikely, but noted that parents do tend to be more involved, with older sons or daughters with Asperger's.* The Committee noted it would be possible the person with Asperger's could be married. *The applicant agreed so, but added that they are only looking at the experiences of parents in this study.*

The Committee commented on the interview schedule and considered it to be unclear in places as to what was being asked. The Committee asked the applicant if the interview questions had been subject to patient and public involvement. *The applicant confirmed so, and stated that the feedback showed the questions to be understandable. The applicant welcomed any suggestions from the Committee for improvement.* Following the meeting the Committee highlighted a number of areas for recommended change. In particular, it was suggested that specific prompts and follow ups be added to questions two, three, six, eight, nine and eleven, so that they are standardised and can be used for all participants if they require them. The Committee suggested that the parents be asked about their son or daughter rather than 'child'. The Committee commented that the use of the term 'carer' within question ten the interview

schedule could come as a shock to the parent, and suggested an initial question be added which asks the parent if they consider themselves a carer first, or if they envisage becoming a carer in the future. It was suggested that it be made clear in question two of the document what 'anything else' could refer to. The Committee recommended that question eleven be shortened, and suggested that a prompt such as "if so, what needs do you have, and have these needs been met?" would be useful. The Committee suggested that questions 11 a to d begin with "Did you or do you…" and added that supplementary follow ups should be used, for example; "How do you feel these may be met?" "Has this happened" and "Are these/have these been met?".

The Committee queried the interview transcription arrangements. *The applicant explained she would undertake some of the transcriptions, but a service would also complete some, due to the volume. The applicant assured the Committee that the service is regularly used by the University, and there is a confidentiality agreement in place.* The Committee stated in private discussion that it should be clarified within the Participant Information Sheet who will complete the transcription.

Recruitment arrangements and access to health information, and fair participant selection

The Committee understood the study would be introduced to parents of adults diagnosed with Asperger's Syndrome at the diagnostic appointment and considered this to be inappropriate timing. *The applicant agreed that the introduction of the study on top of the news of the diagnoses would be a lot for people to take in, and suggested that the introduction to the study be moved to a post diagnostic support session.* The Committee agreed with this suggestion.

The Committee noted in private discussion the Participant Information Sheet and Consent Form would be passed on or posted parents who do not attend the post diagnostic support appointment, by the adult client. The Committee did not consider it suitable for the information to be sent via the adult client and agreed that it would be preferable for the clinic to send out the documents directly, along with an invitation letter.

Care and protection of research participants; respect for potential and enrolled participants' welfare and dignity

The Committee discussed whether the person with Asperger's Syndrome should provide consent for their parents to be interviewed and asked the applicant if the interviews would be conducted with approval from their son or daughter. *The applicant acknowledged the Committees concern and agreed that this matter was also raised by the Nottinghamshire Healthcare Research and Development Department. The applicant assured the Committee that the interviews would focus on the experience of the parent, including their feelings, identity and role, rather than on the child. The applicant explained that many of the parents take part in the service in their own right, and stated she would be surprised if any of the offspring vetoed their parent taking part in the interview. The applicant highlighted that it is also important not to deny a parent their own right to talk.* The Committee considered this point further in private discussion. Some members remained in agreement that informal consent of the son or daughter

should be sought to allow their parent to be interviewed. However, the majority of the Committee accepted that as the interview would focus on the parent themselves consent was not required. It was agreed that the Participant Information Sheet must clearly state that the interviews are about the parents experiences. The Committee agreed it was helpful to know that the matter had also been considered by the researchers, who do not anticipate it to be an issue.

Informed consent process and the adequacy and completeness of participant information

The Committee discussed the Participant Information Sheet and Consent Form prior to the applicant attending the meeting, and highlighted a number of areas for change. The Committee informed the applicant that the requests for changes would be communicated via the decision letter. *The applicant acknowledged the request.*

The Committee agreed the Participant Information Sheet should be updated to mention the use of audio recording and to also detail the name of the REC.

The Committee noted neither the Participant Information Sheet nor the advertisement poster inform that the study is being undertaken for educational purposes, and agreed this information should be included.

The Committee commented that the Participant Information Sheet should state that the readers' decision to take part in the study would have no effect on their son or daughters care.

The Committee asked that the section of the information sheet titled; "What are the possible disadvantages and risks of taking part?" be updated to state that there is no guaranteed benefit from taking part in the study.

The Committee asked that the participant be sign posted within the information sheet as to where to go in the event of distress.

The Committee noted reference to a Facebook advert within the application, and agreed a copy of this must be submitted.

The Committee commented on the poster advertisement prior to the applicant attending the meeting and highlighted that the text within the purple box is not easily legible. It was asked that it be ensured the text is clearly presented.

The Committee asked that a box be added to the Consent Form to allow a participant to opt in to receive a copy of the results.

The Committed requested point one of the Consent Form be updated to include the date and version of the Participant Information Sheet.

Other ethical issues were raised and resolved in preliminary discussion before your attendance at the meeting.

Please contact the REC Manager if you feel that the above summary is not an accurate reflection of the discussion at the meeting.

Documents reviewed

The documents reviewed at the meeting were:

Document	*Version*	*Date*
Copies of advertisement materials for research participants [POSTER ParentsexperiencesoftheiradultchildsAspergersdiagnosis final V1.0 12.04.2018]	Final 1.0	12 April 2018
Evidence of Sponsor insurance or indemnity (non NHS Sponsors only) [Insurance document IRAS Project ID 235293]	Final 1.0	12 April 2018
HRA Schedule of Events [Schedule of Events IRAS Project ID 235293]	Final 1.0	12 April 2018
HRA Statement of Activities [Statement of Activities IRAS Project ID 235293]	Final 1.0	12 April 2018
Interview schedules or topic guides for participants [INTERVIEW SCHEDULE ParentsexperiencesoftheiradultchildsAspergersdiagnosis final V1.0 12.04.2018]	1.0	12 April 2018
IRAS Application Form [IRAS_Form_03052018]		03 May 2018
Letter from sponsor [Sponsor Letter IRAS Project ID 235293]	Final 1.0	12 April 2018
Participant consent form [CONSENT FORM ParentsexperiencesoftheiradultchildsAspergersdiagnosis final V1.0 12.04.2018]	Final 1.0	12 April 2018
Participant information sheet (PIS) [PARTICIPANT INFORMATION SHEET ParentsexperiencesoftheiradultchildsAspergersdiagnosis final V1.0 12.04.2018]	Final 1.0	12 April 2018
Research protocol or project proposal [PROTOCOL ParentsexperiencesoftheiradultchildsAspergersdiagnosis final V1.0 12.04.2018]	Final 1.0	12 April 2018
Summary CV for Chief Investigator (CI) [Staff CV Thomas Schroder]	1	12 April 2018
Summary CV for student [Hannah Legg CV]	Final 1.0	12 April 2018
Summary CV for supervisor (student research) [CV Alinda Gillott]	Final 1.0	16 January 2018
Summary CV for supervisor (student research) [CV Anna Tickle]	Final 1.0	01 July 2017
Summary CV for supervisor (student research) [CV Sarah Ramsden]	Final 1.0	12 April 2018

Membership of the Committee

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

Health Research Authority

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.

18/EM/0149	**Please quote this number on all correspondence**

Yours sincerely

Wallace

pp

Mr John Aldridge
Chair

Email: NRESCommittee.EastMidlands-LeicesterSouth@nhs.net

Enclosures: *List of names and professions of members who were present at the meeting and those who submitted written comments.*

Copy to: *Ms Angela Shone*
Ms Shirley Mitchell, Nottinghamshire Healthcare NHS Foundation Trust

NHS
Health Research Authority

East Midlands - Leicester South Research Ethics Committee

Attendance at Committee meeting on 24 May 2018

Committee Members:

Name	*Profession*	*Present*	*Notes*
Mr John Aldridge (Chair)	Retired Senior Lecturer in Nursing	Yes	
Mr Derek Butters	Industrial Pharmacy Consultant and Locum Pharmacist	Yes	
Mr Alan Caswell	Retired Nurse	Yes	
Mrs Jeanne-Anne Charly	Staff Nurse	Yes	
Ms Elizabeth Gibbons	Senior Research Scientist	Yes	
Miss Catherine Hudson	Personal Assistant	Yes	
Dr Brendan Laverty	Retired Head of Research Governance	Yes	
Mrs Jill Marshall	Retired Training and Development Manager	Yes	
Ms Rachel Neilan	Volunteer	Yes	
Mrs Sarah Elizabeth Westwater-Wood	Lecturer	Yes	

Also in attendance:

Name	*Position (or reason for attending)*
Miss Silje Dybing	REC assistant
Miss Lindsey Wallace	REC Manager (Minutes)

Appendix C: Researcher's response to the REC Committee

28th June 2018

To whom it may concern,

Study title: Exploring the experiences of parents whose child has received a diagnosis of Asperger's syndrome in adulthood

REC reference: 18/EM/0149

IRAS project ID: 235293

Thank you for reviewing the documents for our proposed study and offering some useful feedback. Some changes have been made in line with the suggestions from the committee, whilst others have not for reasons which will be discussed below:

1. The study should not be introduced to the parents at the diagnostic appointment. Please re-consider the timing of the initial approach. In addition, study documentation should be posted via the clinic directly, with an invitation letter, to parents who do not attend the pre or post diagnostic appointment, rather than being sent via the adult client.

I have been in discussion with my supervisors, the Sponsor and the Research and Development department regarding the objection to the study being introduced at the diagnostic appointment and the request that we re-considered the timing of the initial approach, and the objection to study invitations being delivered to parents who do not attend appointments by their adult son/daughter.

It would be difficult to approach participants in any other way than what has already been suggested. In terms of the process of diagnosis, the client only sometimes attends with their parent for the initial screening assessment. They then wait for an average of 6 months for the diagnostic assessment appointment to which parents are invited. Finally, the client attends a one-off post diagnostic workshop to which parents are ordinarily not invited due to room capacity. Therefore, the diagnostic appointment might be the only time parents actually attend the clinic. We acknowledge that there would perhaps be an issue with giving the diagnosis and then immediately requesting their involvement in the project, but we suggest that the study could be introduced briefly, and parents could register

their interest by leaving their contact details. They would not be contacted straight away to allow them time to consider participating. If they were interested, the Participant Information Sheet would then be sent to them.

The other issue is that unless we ask the parents to register their interest at the diagnostic appointment, we won't necessarily have their contact details as appointment letters are sent to the clients themselves. Also, if we did have their contact details and sent them the study information without their agreement that they could be used for this purpose, then this would be deemed an Information Governance breach.

2. The Participant Information Sheet must be updated as follows:

a. To ensure it is clear within the document that the interviews will be about the parents and their experiences and feelings.
b. To detail that the study is being undertaken for educational purposes. This information should also be added to the poster advertisement.
c. To mention the use of audio recording.
d. To state that agreeing or not agreeing to take part in the study will have no effect on their son or daughters care.
e. To contain the name of the REC.
f. To clarify who will complete the transcription of interviews.
g. The section titled “What are the possible disadvantages and risks of taking part?” should be updated to state that there is no guaranteed benefit from taking part in the study.
h. To include signposts for the participant in the event of distress.

All of the suggested amendments were made to the Participant Information Sheet (please see updated document attached).

The Participant Information Sheet was updated to be compliant with GDPR following consultation with the R&D department. The new wording is approved by the sponsor and is consistent with what the HRA have recommended.

3. The Consent Form should be updated as follows:

a. A box should be added to allow a participant to opt in to receive a copy of the results.
b. To refer to the date and version of the Participant Information Sheet within point one.

Both of the suggested amendments were made (please see updated document attached).

4. Please submit a copy of the Facebook advert for REC review.

The Facebook advert will be a photo of the poster which will appear in clinic, so I have just attached this to this section. There will also be the following line of text attached to the poster: Would you like to take part in our research study "Exploring the experiences of parents whose child has received a diagnosis of Asperger's Syndrome in adulthood"?

5. The text within the purple box of the study poster is not easily legible. Please ensure all text is clearly presented.

The poster was amended as suggested to be more easily legible.

6. The interview schedule should be revised so that it is clear as to what is being asked. The following changes are suggested:

a. Specific prompts and follow ups are suggested at questions two, three, six, eight, nine and eleven.
b. Parents should be asked about their son or daughter rather than 'child'.
c. It is queried if the use of the term 'carer' within question ten the interview schedule could come as a shock to the parent. Consideration should be given to use of an initial which asks the parent if they consider themselves a carer first, or if they envisage becoming a carer in the future.
d. It should be made clear in question two of the document what 'anything else' could refer to.
e. Question eleven is considered quite long, particularly as participants will not see the question written down. It is suggested that the question be shortened.
f. Questions 11 a to d should each begin with "Did you or do you…". Consideration should also be given to using supplementary follow ups such as; "How do you feel these may be met?" "Has this happened" and "Are these/have these been met?"

Some changes have been made in line with the suggestions from the committee. However, some of the suggested prompts have not been included because, following discussion with project supervisors, they were thought not to be in line with the epistemological stance of the methodology, i.e. because they were closed questions with inherent assumptions that might guide participants to give a particular answer that might not have otherwise occurred to them.

The term "label" has been replaced with "diagnosis" as on reflection, diagnosis is technically what it is, and label could imply connotations about the existence of the condition.

The removal of "for you" from Question 4 was not accepted as the aim of this inclusion is to help parents to focus on the expectations for themselves. Without this, they may talk about their hopes for further support for their son or daughter, which is not as relevant to the focus of the study.

“Carer” was removed from Question 11 and replaced with “parent” based on comments on Question 10.

I hope these responses provide sufficient clarification, please do not hesitate to contact us if you require any further information. Thank you in advance for your consideration. I look forward to your response.

Documents attached:

Document	Version	Date
Participant Information Sheet	Final 2.0	21/06/2018
Consent Form	Final 2.0	21/06/2018
Interview Schedule	Final 2.0	21/06/2018
Poster	Final 2.0	21/06/2018
Advert	Final 1.0	21/06/2018

Yours sincerely,

Hannah Legg

Appendix D: REC confirmation of ethical approval

Health Research Authority

East Midlands - Leicester South Research Ethics Committee

The Old Chapel
Royal Standard Place
Nottingham
NG1 6FS

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

16 July 2018

Dr Thomas Schroder
Course Co-Director DClinPsy course
University of Nottingham
B12 YANG Fujia Building, University of Nottingham
Jubilee Campus, Wollaton Rd
Nottingham
NG8 1BB

Dear Dr Schroder

Study title:	**Exploring the experiences of parents whose child has received a diagnosis of Asperger's syndrome in adulthood**
REC reference:	**18/EM/0149**
Protocol number:	**18006**
IRAS project ID:	**235293**

Thank you for your letter of 28 June 2018, 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

18/EM/0149	Please quote this number on all correspondence

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

Yours sincerely

pp

Mr John Aldridge
Chair

Email:NRESCommittee.EastMidlands-LeicesterSouth@nhs.net

Enclosures: "After ethical review – guidance for researchers"

Copy to: *Ms Angela Shone*
Ms Shirley Mitchell, Nottinghamshire Healthcare NHS Foundation Trust
Miss Hannah Legg

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

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/

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).

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 [POSTER ParentsexperiencesoftheiradultchildsAspergersdiagnosis final V2.0 21.06.2018]	Final 2.0	21 June 2018
Copies of advertisement materials for research participants [ADVERT ParentsexperiencesoftheiradultchildsAspergersdiagnosis final V1.0 21.06.2018]	Final 1.0	21 June 2018
Evidence of Sponsor insurance or indemnity (non NHS Sponsors only) [Insurance document IRAS Project ID 235293]	Final 1.0	12 April 2018
Interview schedules or topic guides for participants [INTERVIEWSCHEDULE ParentsexperiencesoftheiradultchildsAspergersdiagnosis final V2.0 21.06.2018]	Final 2.0	21 June 2018
IRAS Application Form [IRAS_Form_02072018]		02 July 2018
Letter from sponsor [Sponsor Letter IRAS Project ID 235293]	Final 1.0	12 April 2018
Other [Response to REC]	Final 1.0	28 June 2018
Participant consent form [CONSENT FORM ParentsexperiencesoftheiradultchildsAspergersdiagnosis final V2.0 21.06.2018 edit]	Final 2.0	21 June 2018
Participant information sheet (PIS) [PARTICIPANT INFORMATION SHEET ParentsexperiencesoftheiradultchildsAspergersdiagnosis final V2.0 21.06.2018]	Final 2.0	21 June 2018
Research protocol or project proposal [PROTOCOL ParentsexperiencesoftheiradultchildsAspergersdiagnosis final V2.0 28.06.2018]	Final 2.0	28 June 2018
Summary CV for Chief Investigator (CI) [Staff CV Thomas Schroder]	1	12 April 2018
Summary CV for student [Hannah Legg CV]	Final 1.0	12 April 2018
Summary CV for supervisor (student research) [CV Alinda Gillott]	Final 1.0	16 January 2018
Summary CV for supervisor (student research) [CV Anna Tickle]	Final 1.0	01 July 2017
Summary CV for supervisor (student research) [CV Sarah Ramsden]	Final 1.0	12 April 2018

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 HRA and HCRW Approval (England and Wales)/ NHS permission for research is available in the Integrated Research Application System, at 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.

Appendix E: Request for amendments (IRAS)

Notification of Non-Substantial/Minor Amendments(s) for NHS Studies

This template **must only** be used to notify NHS/HSC R&D office(s) of amendments, which are **NOT** categorised as Substantial Amendments.
If you need to notify a Substantial Amendment to your study then you MUST use the appropriate Substantial Amendment form in IRAS.

Instructions for using this template

- For guidance on amendments refer to http://www.hra.nhs.uk/research-community/during-your-research-project/amendments/
- This template should be completed by the CI and optionally authorised by Sponsor, if required by sponsor guidelines.
- This form should be submitted according to the instructions provided for NHS/HSC R&D at http://www.hra.nhs.uk/research-community/during-your-research-project/amendments/which-review-bodies-need-to-approve-or-be-notified-of-which-types-of-amendments/ . If you do not submit your notification in accordance with these instructions then processing of your submission may be significantly delayed.

1. Study Information

Full title of study:	Exploring the experiences of parents whose child has received a diagnosis of Asperger's Syndrome in adulthood
IRAS Project ID:	235293
Sponsor Amendment Notification number:	MA01
Sponsor Amendment Notification date:	05/10/2018
Details of Chief Investigator:	

Name [first name and surname]	Dr Thomas Schroder
Address:	Room B12 YANG Fujia Building Jubilee Campus Wollaton Road Nottingham
Postcode:	NG8 1BB
Contact telephone number:	0115 846 8181
Email address:	thomas.schroder@nottingham.ac.uk
Details of Lead Sponsor:	
Name:	Ms Angela Shone (University of Nottingham)
Contact email address:	sponsor@nottingham.ac.uk
Details of Lead Nation:	
Name of lead nation *delete as appropriate*	England
If England led is the study going through CSP? *delete as appropriate*	Yes / No
Name of lead R&D office:	Nottinghamshire Healthcare Research and Innovation Team

2. Summary of amendment(s)

This template **must only** be used to notify NHS/HSC R&D office(s) of amendments, which are **NOT** categorised as Substantial Amendments.
If you need to notify a Substantial Amendment to your study then you MUST use the appropriate Substantial Amendment form in IRAS.

No.	Brief description of amendment *(please enter each separate amendment in a new row)*	Amendment applies to *(delete/ list as appropriate)*		List relevant supporting document(s), including version numbers *(please ensure all referenced supporting documents are submitted with this form)*		R&D category of amendment *(category A, B, C)* *For office use only*
		Nation	**Sites**	**Document**	**Version**	
1	Addition of Sheffield Adult Autism and Neurodevelopmental Service, Sheffield Health and Social Care NHS Foundation Trust as recruitment site	England	All sites or list affected sites			New NHS/HSC site
2	Addition of Autism Spectrum Conditions Service, Sussex Partnership NHS Foundation Trust as recruitment site	England	All sites or list affected sites			New NHS/HSC site
3	Addition of ASD Assessment Service, Derbyshire Healthcare NHS Foundation Trust as recruitment site	England	All sites or list affected sites			New NHS/HSC site
4	Addition of Alongside Autism (private support organisation) as recruitment site					
5	Addition of the National Autistic Society (charitable organisation) as a recruitment site					

6	Inclusion of “snowball sampling” (word of mouth) as recruitment method				

[Add further rows as required]

3. Declaration(s)

Declaration by Chief Investigator

- I confirm that the information in this form is accurate to the best of my knowledge and I take full responsibility for it.
- I consider that it would be reasonable for the proposed amendment(s) to be implemented.

Signature of Chief Investigator:  ……

Print name: Thomas Schröder……

Date: 05/10/18

Optional Declaration by the Sponsor's Representative (as per Sponsor Guidelines)

The sponsor of an approved study is responsible for all amendments made during its conduct.

The person authorising the declaration should be authorised to do so. There is no requirement for a particular level of seniority; the sponsor's rules on delegated authority should be adhered to.

- I confirm the sponsor's support for the amendment(s) in this notification.

Signature of sponsor's representative: ……

Print name:……

Post: ……

Organisation:……

Date:……

Appendix F: Approval of amendments (IRAS)

From: hra.amendments@nhs.net [mailto:noreply@harp.org.uk]
Sent: 12 October 2018 14:33
To: thomas.schroder@nottingham.ac.uk; sponsor@nottingham.ac.uk
Cc: Mitchell Shirley - Head of Research and Innovation; R and I Enquiries; Hannah.Legg@nottingham.ac.uk
Subject: IRAS Project ID 235293. HRA Approval for the Amendment

Dear Dr Schroder,

IRAS Project ID:	235293
Short Study Title:	Parents' experiences of their adult child's Asperger's diagnosis
Amendment No./Sponsor Ref:	MA01
Amendment Date:	05 October 2018
Amendment Type:	Non Substantial Non-CTIMP

I am pleased to confirm **HRA and HCRW Approval** for the above referenced amendment. This approval does not cover the use of snowball sampling as this is no longer to be used.

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

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/.

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

Kind regards

Ashley Totenhofer
Technical Assurance Officer
Health Research Authority
Ground Floor | Skipton House | 80 London Road | London | SE1 6LH
E.hra.amendments@nhs.net
W. www.hra.nhs.uk

Sign up to receive our newsletter HRA Latest.

Appendix G: Participant Information Sheet

Nottinghamshire Healthcare NHS
NHS Foundation Trust

Participant Information Sheet
(Final Version 2.0 Date: 21/06/2018)
IRAS Project ID: 235293

Title of Study: Exploring the experiences of parents whose child has received a diagnosis of Asperger's Syndrome in adulthood

Name of Researcher(s): Hannah Legg, Trainee Clinical Psychologist
Dr Alinda Gillott, Consultant Clinical Psychologist
Dr Anna Tickle, Clinical Psychologist
Dr Sarah Ramsden, Clinical Psychologist

We would like to invite you to take part in our research study. Before you decide we would like you to understand why the research is being done and what it would involve for you. One of our team will go through the information sheet with you and answer any questions you have. Talk to others about the study if you wish. Ask us if there is anything that is not clear.

What is the purpose of the study?

Adult diagnosis of Asperger's Syndrome is a fairly new phenomenon so little is currently known about how it impacts on the person receiving the diagnosis themselves, and even less is known about the experiences of the parent of the adult child.

Our aim is to explore the experiences of parents whose adult child has recently been diagnosed with Asperger's Syndrome in terms of their feelings and reactions to the diagnosis, how they make sense of the diagnosis, any impact it has had on their relationship with their son or daughter and how it has potentially changed their understanding of their child now and when they were children.

Why have I been invited?

You are being invited to take part because you are a parent of an adult (aged 18+) who was diagnosed with Asperger's Syndrome recently by the Asperger Service in Nottingham. We are inviting fifteen participants like you to take part.

Do I have to take part?

It is up to you to decide whether or not to take part. If you do decide to take part, you will be given this information sheet to keep and be asked to sign a consent form. If you decide to take part you are still free to withdraw at any time and without giving a reason. This would not affect your legal rights. Whether you agree or do not agree to take part in the study will have no effect on your son or daughter's care.

What will happen to me if I take part?

If you do decide to take part, you will be contacted by the lead researcher to take part in a one-off interview about your experiences. This interview would take place at either the Asperger Service in Nottingham or the University of Nottingham. However, if it is difficult for you to travel, it would be possible to interview you in your own home, or to conduct the interview over the telephone or Skype. The interview would last between 60 to 90 minutes and will be audio-recorded. You would be asked for some limited personal information such as your age, gender, occupation, your relationship to the person with Asperger's Syndrome, how old they are and how long ago they were diagnosed. You would then be asked some questions about your experiences of caring for your child and any differences the diagnosis has made to you. Interviews will be transcribed either by the lead researcher or by a paid transcriber who will have signed a confidentiality agreement.

Expenses and payments

Participants will be offered travel expenses for any visits to the Asperger Service or the University of Nottingham incurred as a result of participation.

What are the possible disadvantages and risks of taking part?

As the questions will be asking about a topic which you may find difficult to talk about, it is possible that you may become distressed or upset during the interview. The interviewer will monitor your level of distress throughout and will use their clinical skills to support you to manage any distress you feel. Breaks will be offered and the interview will be stopped if necessary. If you are experiencing longer term distress, you will be advised to contact your GP. You may also be directed to the Autism Helpline hosted by the National Autistic Society (Telephone: 0808 800 4104
Helpline opening hours: Monday-Thursday 10am-4pm, Friday 9am-3pm (excluding Bank holidays)) for further support in relation to having a son or daughter with Asperger's Syndrome.

What are the possible benefits of taking part?

We cannot promise the study will help you personally, but the information we get from this study will help us to better understand any impact that adult children's diagnosis of Asperger's Syndrome has on parents and may help to shape any future support given to parents in the same situation. There is no guaranteed benefit from taking part in the study.

What if there is a problem?

If you have a concern about any aspect of this study, you should ask to speak to the researchers who will do their best to answer your questions. The researcher's contact details are given at the end of this information sheet. If you remain unhappy and wish to complain formally, you can do this by contacting the Patient Advice and Liaison Service (Telephone: 0115 993 4542;
Email: complaints@nottshc.nhs.uk; Address: Patient Experience Team, Moorgreen House, Highbury Hospital, Nottingham, NG6 9DR).

Will my taking part in the study be kept confidential?

We will follow ethical and legal practice and all information about you will be handled in confidence.

If you join the study, we will use information collected from you during the course of the research. This information will be kept **strictly confidential**, stored in a secure and locked office, and on a password protected database at the University of Nottingham. Under UK Data Protection laws the University is the Data Controller (legally responsible for the data security) and the Chief Investigator of this study (named above) is the Data Custodian (manages access to the data). This means we are responsible for looking after your information and using it properly. Your rights to access, change or move your information are limited as we need to manage your information in specific ways to comply with certain laws and for the research to be reliable and accurate. To safeguard your rights we will use the minimum personally – identifiable information possible.

You can find out more about how we use your information and to read our privacy notice at:

https://www.nottingham.ac.uk/utilities/privacy.aspx.

The data collected for the study will be looked at and stored by authorised persons from the University of Nottingham who are organising the research. They may also be looked at by authorised people from regulatory organisations to check that the study is being carried out correctly. All will have a duty of confidentiality to you as a research participant and we will do our best to meet this duty.

It is possible that your interview will be transcribed by a paid transcription service. The transcription service will have a secure system for data transfer, access, and storage and the individual transcriber will be required to complete a Confidentiality Agreement before any transcription takes place.

Your contact information (address, telephone number, email address) will be kept for roughly three months after the end of the study so that we are able to contact you about the findings of the study (unless you advise us that you do not wish to be contacted). This information will be kept separately from the research data collected and only those who need to will have access to it. All other data (research data) will be kept securely for 7 years. After this time your data will be disposed of securely. During this time all precautions will be taken by all those involved to maintain your

confidentiality, only members of the research team will have access to your personal data.

In accordance with the University of Nottingham's, the Government's and our funders' policies we may share our research data with researchers in other Universities and organisations, including those in other countries, for research in health and social care. Sharing research data is important to allow peer scrutiny, re-use (and therefore avoiding duplication of research) and to understand the bigger picture in particular areas of research. Data sharing in this way is usually anonymised (so that you could not be identified) but if we need to share identifiable information we will seek your consent for this and ensure it is secure. You will be made aware then if the data is to be shared with countries whose data protection laws differ to those of the UK and how we will protect your confidentiality.

Although what you say in the interview is confidential, should you disclose anything to us which we feel puts you or anyone else at any risk, we may feel it necessary to report this to the appropriate persons.

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

Your participation is voluntary and you are free to withdraw at any time, without giving any reason, and without your legal rights being affected. If you withdraw we will no longer collect any information about you or from you but we will keep the information about you that we have already obtained as we are not allowed to tamper with study records and this information may have already been used in some analyses and may still be used in the final study analyses. To safeguard your rights, we will use the minimum personally-identifiable information possible.

Who is organising and funding the research?

This research is being organised and funded by the University of Nottingham. It is being conducted for educational purposes as part of the Lead Researcher's qualification of Doctorate in Clinical Psychology.

Who has reviewed the study?

All research in the NHS is looked at by independent group of people, called a Research Ethics Committee, to protect your interests. This study has been reviewed and given favourable opinion by East Midlands - Leicester South Research Ethics Committee.

Further information and contact details

Lead Researcher: Hannah Legg, Trainee Clinical Psychologist
Email Address: Hannah.Legg@nottingham.ac.uk
Telephone Number: TBC

Field Supervisor: Dr Alinda Gillott, Consultant Clinical Psychologist
Email Address: Alinda.gillott@nottshc.nhs.uk
Telephone Number: 0115 854 2207

Academic Supervisor: Dr Anna Tickle, Clinical Psychologist

Email Address: anna.tickle@nottingham.ac.uk
Telephone Number: 0115 823 2203

Second Supervisor: Dr Sarah Ramsden, Clinical Psychologist
Email Address: sramsden@lincoln.ac.uk
Telephone Number: 01522 835742

Chief Investigator: Thomas Schroder, Course Director of Trent Doctorate in Clinical Psychology
Email Address: Thomas.schroder@nottingham.ac.uk
Telephone Number: 0115 846 8181

Appendix H: Poster and Facebook advertisement

Appendix I: Consent form

CONSENT FORM
(Final Version 2.0: 21/06/2018)

Title of Study: Exploring the experiences of parents whose child has received a diagnosis of Asperger's Syndrome in adulthood

IRAS Project ID: 235293

Name of Researcher: Hannah Legg

Name of Participant: **Please initial box**

1. I confirm that I have read and understand the information sheet version number 2.0 dated 21st June 2018 for the above study and have had the opportunity to ask questions. ☐
2. I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason, and without my legal rights being affected. I understand that should I withdraw more than one week after I have been interviewed, then the information collected so far cannot be erased and may still be used in the project analysis. ☐
3. I understand that data collected in the study may be looked at by authorised individuals from the University of Nottingham, the research group and regulatory authorities where it is relevant to my taking part in this study. I give permission for these individuals to have access to these records and to collect, store, analyse and publish information obtained from my participation in this study. I understand that my personal details will be kept confidential. ☐
4. I understand that the interview will be audio recorded and that anonymous direct quotes from the interview may be used in the study reports. ☐
5. I understand that my audio recorded interview may be transcribed by an independent transcription service. ☐
6. I agree to take part in the above study. ☐
7. Please initial this box to allow us to retain your contact details to send you a summary of the study results. ☐

Name of Participant	Date	Signature
Name of Person taking consent	Date	Signature

2 copies: 1 for participant, 1 for the project notes

Appendix J: Demographic questionnaire

About you:

Gender (please circle): Male Female Other _____ Prefer not to say

What is your relationship to the person diagnosed with Asperger syndrome? (Please circle):

Biological parent Adopted parent Foster parent Step-parent

Other relative: _____

What is your ethnic group?

Your relationship status (tick one): Single, never married
Married or domestic partnership
Divorced
Separated

Your employment Status (tick all that apply): Unemployed
Studying at college/university
Working full-time
Working part-time
Retired
Doing volunteer work
Other, please specify_____

Are you the primary caregiver/support for this person? (Please circle) Yes / No

How many hours do you spend on average caring for this person each week? _____ hours

How long have you been a carer for this person? _____ years All of their life

About the person you care for:

How old is the person you care for? ___ years Prefer not to say

Gender (please circle): Male Female Other _____ Prefer not to say

Relationship status (tick one): Single, never married
Married or domestic partnership
Divorced
Separated

Age at diagnosis: _____ years

Diagnosis (tick one): Asperger syndrome
Autism
Autism spectrum disorder
Other: _____

Additional difficulties (tick any that apply): Borderline Intellectual/learning disability
Attention deficit hyperactivity disorder (ADHD)
Tourette syndrome/ Tic disorder
Dyslexia
Dyspraxia/DCD
Anxiety
Depression
Epilepsy
Sleep disorders
Other, please specify_____

Who is the main source of support for the person? (tick one): You the respondent
Other family member
Paid carer/support worker
External service

Living Arrangements (tick one): Living independently
In the family home
In supported accommodation
Other, please specify_____

Employment Status (tick all that apply): Unemployed
Studying at college/university
Working full-time
Working part-time
Doing volunteer work
Other, please specify_____

Appendix K: Interview schedule

1. What support (if any) do you currently provide your son/daughter?

2. Did you ever seek an assessment for your son/daughter as they were growing up or is this their first time of seeking a diagnosis? (either for Asperger's syndrome or other developmental conditions)

Prompt: If yes, what conditions? What was the outcome?

If it hadn't been considered before, where you surprised when they said they were going to be assessed?

3. What was your understanding of Asperger's Syndrome before your son/daughter received this diagnosis?

Prompts: Had you heard of it?

4. When you came to the diagnostic assessment, what were your expectations of diagnosis for you?

a. Did you expect it to change the way you think of yourself or your son/daughter?

b. Did you expect to have any emotional reactions?

c. Did you think it would make any difference to your relationship with your son/daughter?

d. Did you think it would make any difference to your family?

5. How has your understanding of Asperger's Syndrome changed since they received the diagnosis?

6. Does the diagnosis of Asperger's Syndrome make sense to you for your son/daughter?

Prompt: Is there another label you feel is more appropriate?

7. Has the diagnosis had any impact on how you see or understand your son/daughter? If so, what?

8. Has the diagnosis had any impact on your relationship with your son/daughter? If so, what?

Prompts: Do you feel closer? Further apart?

9. Has your son/daughter's diagnosis made any difference to how you see yourself?

Prompts: As a parent? As a person?

10. Do you consider yourself to be a carer for your son/daughter?

Prompts: If so, how do you feel about being a carer for a person with Asperger's Syndrome?

11. What support needs do you have as a carer for your son/daughter?

a. Did or do you have any emotional support needs?

b. Did or do you have any needs accepting and adjusting to the diagnosis?

c. Did or do your family have any emotional support needs?

d. Did or do your family have any needs accepting and adjusting to the diagnosis?

Appendix L: Confidentiality Agreement for Transcriber

UNIVERSITY OF LINCOLN

General Data Protection Regulation Confidentiality Agreement for Transcribers

This Agreement is made as of 16.12.2018 (Date), by and between the University of Lincoln, with principal offices at Brayford Pool Lincoln LN6 7TS (the University) and Helen Smith with principal offices at [redacted] (the Transcriber).

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This Agreement shall be governed by and construed in accordance with the laws of England and the parties hereby submit to the exclusive jurisdiction of the English courts.

Signed for and on behalf of HELEN SMITH.

Signed: HSmith Name: HELEN SMITH

Title: Transcriber Date: 16/12/2018

Signed for and on behalf of the University of Lincoln

Signed: ..... Name: .....

Title: ..... Date: .....

Parents' experiences of their adult child's Asperger diagnosis - Protocol Version 1.0 Date: 01/02/2018

Appendix M: Excerpt from worked transcript

Line number	Transcript	Code	Potential theme
1	H: What support if any do you currently provide		
2	Richard?		
3			
4	JANE: we're his carers. We find now we can't go	Carers	Definition of carer
5	anywhere and leave him alone because he self-	Son self-harms	
6	harms, he goes into deep depression. When he's at	Son has depression	Son's mental health needs
7	work, he's fine, but we're his carers from the moment		
8	he gets up to the moment he goes to bed.	Full-time carers	
9			
10	H: so what sort of things do you support Richard		
11	with?		
12			
13	JANE: well he doesn't do anything. He doesn't do any		
14	cooking, he can't keep a place tidy, he can't go	Son can't do things	Definition of carer
15	shopping, so really I do everything for him.	Do everything for him	
16			
17	H: so it sounds like he's quite dependent on you.		
18			
19	JANE: He's very dependent which worries us.	Son very dependent	Carer role
20		which worries us	Concerns about the future
21	H: has he always lived with you?		
22			
23	JANE: apart from…he got married and he left home	Son got married and left	
24	for 2 years, but he's come back and he's worse than	home	
25	he was before then. It's drained everything out of him,	Son come back worse	
26	everything that we worked to build, she's knocked out	Wife drained everything	
27	of him.	out of son	

28 29 30 31 32 33 34 35 36 37 38 39 40 41 42 43 44 45 46 47 48 49 50 51 52 53 54 55 56 57	H: how long ago was it that he was married and living with his partner? JANE: they split up November last year, so he's been back home nearly a year. H: do you know if things were different in terms of his support needs when he was living away? JANE: umm…no I don't think…when Richard moved away, his support needs, yes they were there, but I suppose because we always did them, it was routine and natural for us. Where for partner, she needed help as much as Richard did, they were two wrong people together. She couldn't handle him, she fired him up, she did the opposite of what everyone else was working to do. She would lock him in a room if he was having a meltdown. H: oh gosh. JANE: She was verbally abusive, she couldn't leave him alone when he was having a meltdown, where we would walk away and leave the situation, she would fire it… H: so she'd kind of antagonise him? JANE: she was forever at it.	Son's support needs as routine and natural Wife fired him up Wife was verbally abusive	Carer role

58 59 60 61 62 63 64 65 66 67 68 69 70 71 72 73 74 75 76 77 78 79 80 81 82 83 84 85 86 87	H: ok, so he's been back almost a year now…you cook for him, you do the cleaning… JANE: I do his washing, his ironing, we clean his car. We provide everything for him. H: what does Richard do for work? JANE: he works for Richard in IT. H: ok JANE: he loves his computers. That's his world. He comes home from work and he's on the computer with what my husband calls his "unreal friends". Not to Richard we don't do it! H: as in there's people he speaks to online? JANE: that he's never met. He plays games and he interacts with people that way. H: so it sounds like you have to do the majority of domestic tasks JANE: I have to get him up for work, otherwise he wouldn't go. If we didn't wake him up, walk round after him in the morning, he wouldn't go. H: ok. What about personal care and getting himself dressed?	Provide everything for son Son works in IT Computers are son's world Son interacts with people online Have to get son up for work	

88			
89	Jane: yeah, it takes him a long time, but he can. In		
90	his younger days, he wouldn't shower, but now he		
91	over-showers, he'll have 2 showers a day, he'll		
92	change his underwear 3 times a day. He's quite		
93	obsessive with it.		
94			
95	H: what about managing money, is he able to do…		
96			
97	Jane: no.		
98		Son can't manage own	
99	H: yeah, so it sounds like you provide him a lot of	finances	
100	care and support…		
101			
102	Jane: to help him function. And our worry is, if we're		
103	not here, who's going to help him function?	Provide care to help him	
104		function	
105	H: yeah, yeah, it's an understandable worry. Did you	Who's going to help if	
106	ever seek an assessment for Richard as he was	we're not here?	
107	growing up or is it your first time of seeking		
108	diagnosis?		
109			
110	Jane: it's the first time seeking diagnosis, but we		
111	knew at an early age…we used to say he was	Knew son was different	Early recognition of difference
112	different from the other children, but we didn't know	from early age	– parents
113	why and we went to see a paediatrician about him not	Didn't know why he was	
114	walking and his fear of the wind, but all the time it	different	
115	was put back that I was just a worrying mother, and	Saw paediatrician when	
116	you know, these things would put themselves right.	son was little	
117	And he's very bright. Richard can hide things.	Called a worrying mother	

118		Son can hide things	
119	H: I see. So you'd recognised he was different and		
120	this fear of the wind…		
121			
122	Jane: bright lights, noise…he went for hearing tests,		
123	but no matter who I went to see, the doctor always	Son went for hearing tests	Seeking explanation for difference – paeds, hearing tests
124	said it was me. It was me that they decided to put on		
125	anti-depressants and I was going for help for Richard,	Doctor always said it was Mum	
126	but all the time it was I'm spoiling him, I was wrapping		
127	him in cotton wool. But they weren't living with him.	Doctor put her on antidepressants	Communication with professionals – "worrying mother"
128			
129	H: so it sounds like you were met with a lack of	Told spoiling him/wrapping him in cotton wool	
130	understanding.		Explanations for behaviour – professionals
131			
132	Jane: yeah, it was…I suppose when Richard was	They weren't living with him	
133	under the age of 13, I could control, I could put		
134	routines in place, I could make him do things. We	When younger, could control and put routines in	
135	went to places. He had to socialise. He had a tenor		
136	voice, he's got the most beautiful singing voice, so he		
137	went to all the operatic societies. I kept him busy so	Made son do things	
138	he never sat, because if he sat, he was on the	Made son socialise	
139	computer. He got on better with older people than	Kept son busy	
140	people his own age, so that's what he did. But at that		
141	point, I didn't know the anxiety it was causing him.		
142	We got him into the Richard choir, but they went	Didn't know social interaction causing anxiety	Reflection on past – guilt at decisions made with new knowledge
143	away on courses for two weeks at a time, three times		
144	a year. I didn't know, I was sending him, he couldn't		
145	make friends…they must have been the worst times	Son couldn't make friends	
146	of his life.		
147			

148 149 150 151 152 153 154 155 156 157 158 159 160 161 162 163 164 165 166 167 168 169 170 171 172 173 174 175 176 177	H: I was wondering about how he got on socially. You said he went and did these things… Jane: he didn't socialise…if he walked into a room and there was a group of people talking, Richard won't go and join that conversation, not unless somebody turns around and says "Richard" and brings him in. he can't join H: he has to be invited almost… Jane: but they used to say at school, if they gave a piece of work out to do, if they didn't say "Richard", he didn't think he'd got to do it. And he was a big swimmer, we used to get to swimming club and we'd be the first ones there, but Richard would be at the back of the queue and the last one in the pool. You know, and he'd play on his own in the playground. He was a lonely little boy, but… H: so you'd recognised these things… Jane: I'd recognised there was a difference, but it hadn't crossed my mind that he was autistic because he was so clever. It never ever, but once you start reading everything, Richard, everything I pick up, I think "oh gosh", that was him, you know, but I didn't realise. Perhaps if somebody had said those words when he was 4 or 5, I'd have read up on it and I'd have pushed for more help….There was one school,	Choir trips must have been worst times of his life Son didn't socialise Son would find it hard to join conversations Son struggled to follow instructions at school Son would play on own at school Lonely little boy Autism never crossed mind because he was clever Started reading about autism – that was him	Pre-diagnosis perceptions of autism Reflection on past – regret at lack of awareness

178 179 180 181 182 183 184 185 186 187 188 189 190 191 192 193 194 195 196 197 198 199 200 201 202 203 204 205 206 207	because Richard changed school several times because of bullying, not fitting in, so we moved him several times, and he was at private school, then we moved him to Richard and that head is the only one that on his school report put “Richard needed to work on his social skills, he’d got a social problem” and that was year 6. H: so he was what, 11? And that was the first time it had been flagged by anyone? Jane: first time. The private school wanted the money is what we’ve decided now. He was bright, he was going to get them the marks. He needed the social support, not the academic. You can give Richard something and he can do it. He did speech and drama and I’d say to him “have you learned that poem?” and he’d say “oh, I’ll do it, I’ll do it” and he’d sit in the car and read it, and he’d remember it. H: so when he was 25 that was the first time you… Jane: well we didn’t. he was…I moved away for a little while to Dorset, that is where me and my husband want to live. ‘cos Richard had got married we thought “right, it’s the time”. I didn’t really get on with my daughter-in-law, because I felt, I could see what she was doing to Richard. she told him he couldn’t contact me, that he’d got to break all ties, so I took myself away from the situation and I moved to	If someone had said when he was little Would have pushed for more help Changed school several times because of bullying Headteacher only one to recognise social skills probs Needed social not academic support Parents moved away when son married	

208 209 210 211 212 213 214 215 216 217 218 219 220 221 222 223 224 225 226 227 228 229 230 231 232 233 234 235 236 237	Dorset and got a job which caused Richard to have a breakdown. And he ended up at the crisis team, and that's where it all really started from because he kept having to be referred back to the crisis team. They picked up the autism and they referred him to here. H: so it took you to move away, to lose his main support… Jane: even though Richard had self-harmed, he'd cut his wrists, we'd been to the hospital, but he did that just before his 18th birthday, and once he hit 18, the doctors wouldn't talk to me. H: I see, because of confidentiality. Jane: so he went to see somebody twice and never went again. H: I take it that he didn't talk to you about… Jane: Richard doesn't talk about anything. He doesn't confide in anyone…and that is normal from a little boy. I never knew what they did at school, if they went on a school trip, he would probably tell me 8 months down the line. Something would come out and I'd say "ooh, when did you do that?". So he'd never talked about his split-up with partner, nothing. And I don't pry.	Son had "breakdown" Son crisis team involvement Crisis team recognised autism and referred to AS service Self-harm – hospital doctors wouldn't talk to Mum when son was teenager Son doesn't confide in anyone	Recognition of differences – late professional recognition Route to diagnosis – professional referral Son's mental health needs

238 239 240 241 242 243 244 245 246 247 248 249 250 251 252 253 254 255 256 257 258 259 260 261 262 263 264 265 266 267	H: you respect his boundaries. Jane: I don't know whether I'm wrong, but I don't want to cause a meltdown. I don't want to cause that upset for me, I suppose that's the thing. He takes it out on me. You hurt the one you love. H: because he trusts you Jane: you know, all his anger. He'd come home from school, and it'd be at me. He had nothing to do with my husband really and that's his dad. He thought very much like the doctors: "oh, he's a spoiled brat". So their relationship was awful until he got the diagnosis, and it's as if somebody's turned a light on. H: can we come back to that a little bit later on. It would be interesting to hear about the relationship with Richard and you and his dad. Jane: yes. H: so the crisis team picked up on some difficulties… Jane: I think they did a test and thought he might be on the spectrum, so that's how it came about. H: so he was referred here	Mum doesn't pry Mum doesn't want to cause meltdown by prying Son takes upset out on her When at school, son directed anger at mum Son had little to do with dad Dad thought spoiled brat Son and dad relationship awful until he got diagnosis – like someone turning light on	Making sense of behaviour pre-diagnosis – father negative perception Diagnosis changing father-son relationship

268 269 270 271 272 273 274 275 276 277 278 279 280 281 282 283 284 285 286 287 288 289 290 291 292 293 294 295 296 297	Jane: yes, and they had to apply for funding, so he had to wait quite a while for funding to come through. H: what did Richard think about that referral? Jane: I think at first, he was quite happy that someone was doing something and somebody was listening to him. I think he thought it was going to make things better. He thought he was going to get help. H: you said he also experiences anxiety and depression, when were they recognised or diagnosed? Jane: I would say round about the age of 14. The depression and anxiety went hand in hand as far as I was concerned. H: and was it you that picked up on those things? Jane: Yes. We took him to the doctors, but they wouldn't do anything for him. Even when he self-harmed, that was when he was 16, they never offered him anything. They never put him on anything. H: that was another situation where you were left to… Jane: we knew he was self-harming from the age of 14. I used to check his room for pen-knives 'cos he	Son had to wait for funding for referral Son happy with referral Son thought he was going to get help Son anxiety and depression since 14 Son offered little mental health help	

298	was a so and so for going and buying them. I've got a		
299	drawer full of them in my bedroom!		
300			
301	H: so the mental health was around from…		
302			Recognition of difference – self
303	Jane: I think from puberty. As they went to secondary		
304	school, he suddenly realised he hadn't got any	Son realised at	
305	friends. The boys had noticed Richard was different,	secondary school he had	Recognition of differences – peers
306	so I think that was his lonely world. They were	no friends	
307	horrible to him.	Boys at school noticed	
308		he was different and	
309	H: I'm really sorry to hear that….i think you said you	were horrible	
310	were surprised, or I don't know how you put it, when		
311	he was referred here for an assessment. What was		
312	your response to that?		
313			
314	Jane: I wasn't surprised, I'm going to contradict		Reaction to referral – relief/vindication
315	myself, but I was, you know what I mean. But it was		
316	like a relief that it wasn't me, that perhaps there was	Relief at referral –	
317	something and I was right all along.	perhaps I was right all	
318		along	
319	H: and you said you hadn't really been familiar with		
320	ASD and AS before?		
321			Awareness of ASD – limited
322	Jane: I'd never read up on it. I've got a friend whose		
323	got 2 little boys, a 10-year-old and a 6-year-old, and	Never read up on AS	
324	they're both autistic, but they're very bad, so I never	before	
325	knew there were different spectrums of it. I always	Understanding of autism	
326	thought they were like her children, not able to	from friend's kids	
327	function in a normal society.		Awareness of ASD – limited

328		Never knew there were	
329	H: we've kind of covered what your understanding of	different spectrums	
330	autism was. Had you heard of AS?	Thought people with	
331		autism couldn't function	
332	JANE: oh, I'd heard of it	in normal society	
333	H: just not really anything beyond…		
334			Awareness of ASD – media
335	Jane: the hearing of it. I'd never read up on it. And I		influence
336	think what…Richard had already been for his		
337	appointment here, and it was Chris Packham. This	Had heard of AS but not	
338	programme came on and I hadn't watched it, cos I	read up	
339	was down in Dorset, and my mum ringing up and	Chris Packham	
340	saying "you've got to watch that. You really must go	programme key moment	
341	and watch it." Now, I think with my mum, I shocked		
342	that she never picked up on it because she worked		
343	for Dr Barnado's, she worked with children with		
344	autism, but I mean really bad, but she didn't see it.		
345			
346	H: it was only with the Chris Packham documentary…		
347			
348	Jane: Richard is chris Packham! (laughing) apart		
349	from Chris can look after his self and Richard can't.		
350		Richard is Chris	
351	H: when you watched that documentary, what were	Packham!	
352	your thoughts?		
353			
354	Jane: I thought "oh my, perhaps they're right!"		
355	(laughing) but I wouldn't have been surprised if		
356	Richard had sat in the meeting and bluffed his way		
357			

358 359 360 361 362 363 364 365 366 367 368 369 370 371 372 373 374 375 376 377 378 379 380 381 382 383 384 385 386 387	through it, nothing would have surprised me ‘cos he’s clever like that. H: you almost said he had this ability to cover things up. Jane: yeah, like people think he’s looking at them when they’re talking to him ‘cos I’ve always said “look at the person when they’re talking to you”, he looks over their shoulder. He finds a poster to look at. And I suppose he’s well trained. H: what was your response when your mum said “watch this documentary” Jane: I suppose for my mum to say something, it had got to be pretty good. H: did you come to the diagnostic appointment with Richard? Jane: yeah H: what were expectations of diagnosis for you? Jane: I thought we might have had a bit of help for me and my husband, and we thought Richard would get help. But talking personally about me and husband, I thought we would have got help, we would have got some support, ‘cos we haven’t got a clue	Wouldn’t have been surprised if son had bluffed way through meeting Mum helped son learn strategies to cover up difficulties Thought we would have got help	Disappointment at lack of post-diagnostic support for parents Post-diagnosis feelings - clueless

388 389 390 391 392 393 394 395 396 397 398 399 400 401 402 403 404 405 406 407 408 409 410 411 412 413 414 415 416 417	what we're doing. We thought we would have got something. H: what would that have looked like for you in an ideal world? Jane: perhaps meeting other parents, discussing what other people are going through. I've joined several support groups just to see that I'm not on my own and how other people are handling it. We've not had a holiday for years and years because we daren't leave him. Well we did, we went away at Christmas but we ended up with the crisis team and the police. H: when you're not around… Jane: he goes into a depression. He doesn't want you in a room with him, but he wants to know you're in the house with him, just wants to know there's somebody there. H: that's what I was wondering. Is he on his own when you go away? Does anyone step into the breach? Jane: no, I was talking this over with my mother. My mother's elderly, she's in her 80's. she said "well, go away and I'll go and stop with him, so that's what we tried to put in place. I looked up there's a place where you can get respite, but I don't think Richard would	We haven't got a clue what we're doing What like to meet with other parents and discuss what going through Joined online support groups (but not suitable)	Post-diagnostic support – would like to meet other parents Post-diagnostic support – lack of suitable online groups

418 419 420 421 422 423 424 425 426 427 428 429 430 431 432 433 434 435 436 437 438 439 440 441 442 443 444 445 446 447	want that, he's not stupid, he's just lonely. And he gets his self into this, it's a circle isn't it, and he can't get out and he drags his self down and down and down and my worry is he won't get up and go to work. H: that's a very real worry I suppose Jane: if I can see he's having a bit of a meltdown, I'll move his car keys. H: is that a pre-emptive measure? Jane: it does worry me…well we had a to-do on Saturday 'cos suddenly at 10pm, he disappeared. The car went down the street at speed and then the one friend he has got is on the phone to me saying "where's Richard? he's just put a picture on facebook saying goodbye" so we ended up with the police, cos we couldn't find him, he wouldn't answer his phone, and he'd stabbed his self and he was in hospital. H: gosh Jane: but we don't know why. The fear is, what if he goes down the street and kills somebody else, not himself. And that's my worry. Not only have I got to look after Richard, I've got the guilt…I can usually tell. He has a glazed look, but I didn't see him before he went.	Son's mental health needs	Son's mental health needs

448			
449	H: that sounds really difficult…on a slightly different		
450	tangent, did you expect the diagnosis to change the		
451	way you think of yourself?		
452			
453	Jane: no, no, no. the only thing I got from it was I		Diagnosis legitimising
454	could be more open with people. I hadn't got to hide.		concerns/difficulties – not
455	Because we didn't know there was something wrong,		having to hide anymore
456	we kept it within our 4 walls. As a little boy, I always	Diagnosis meant could	
457	said "as long as you're good when we're out, you do	be more open with	
458	as you're told, whatever you do in our 4 walls, it	people about struggles	
459	doesn't matter". And we kept it so under control, I	Hadn't got to hide.	
460	think just to be able to turn round to people and say	Didn't know anything was	
461	"this is what we're living with"	wrong so kept in 4 walls.	
462			
463	H: is and was Richard's behaviour very different at		
464	home to when he was outside of the home?		
465			
466	Jane: yeah, yeah. But we always made sure he had		
467	Gameboys, things to do and he was occupied. He		
468	was always very withdrawn, he wouldn't join in at		
469	family functions. He'd go and sit in a corner. But I	Kept son occupied at	
470	didn't mind, as long as he wasn't creating and having	social functions	
471	a meltdown.		
472			
473	H: did you expect the diagnosis to change the way		
474	you think of Richard?		
475			
476	Jane: no, Richard is Richard. like I say, I think it's		
477	brought him and his dad, they weren't close. It's		

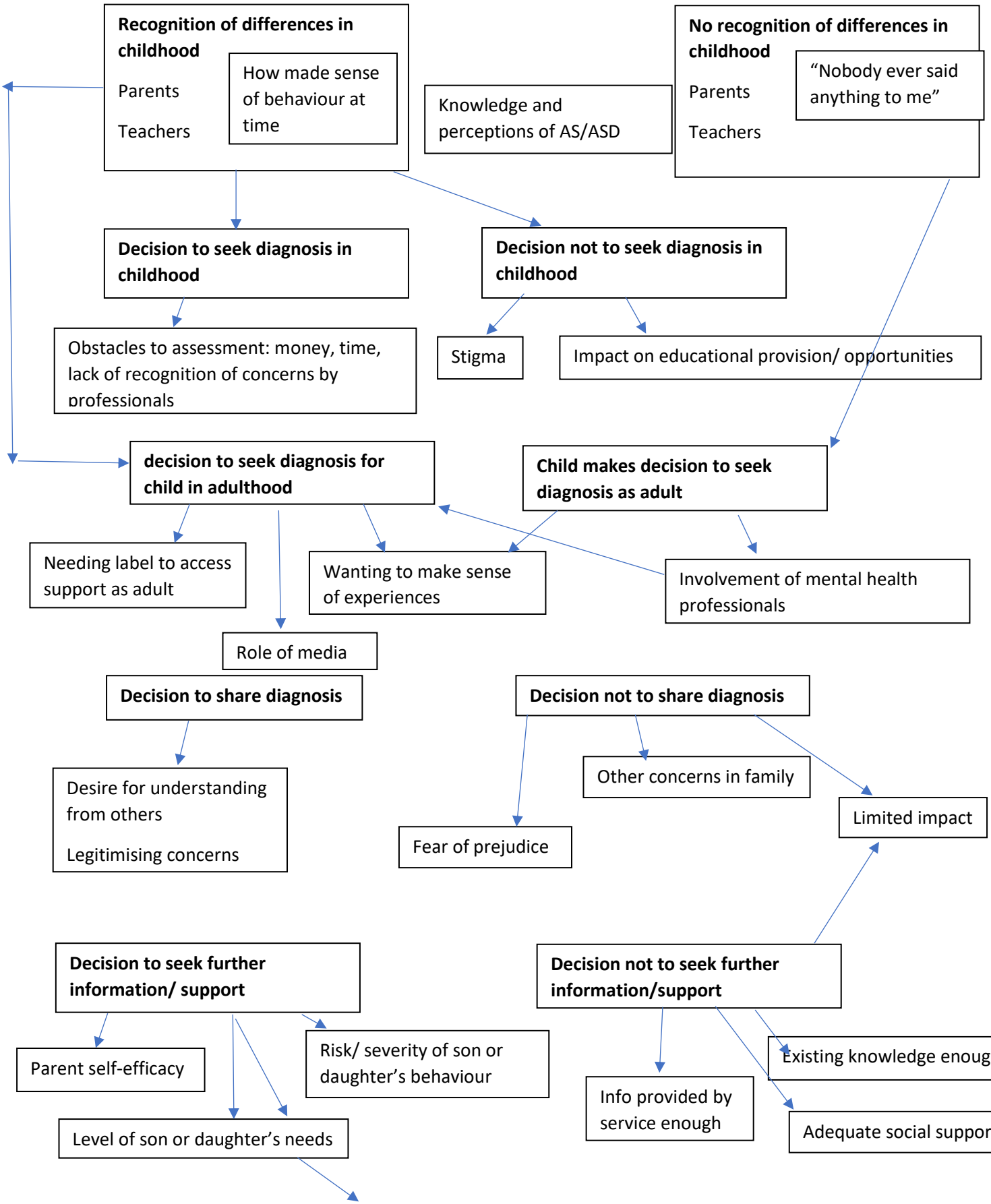
478 479 480 481 482 483 484 485 486 487 488 489 490 491 492 493 494 495 496 497 498 499 500 501 502 503 504 505 506 507	brought us together as a family the three of us, because now we understand why he does things, why he suddenly flips. We're all now working together whereas before it was just me and Richard. I couldn't talk to husband about it 'cos he'd say "he's just spoilt and naughty". H: how did you then explain Richard's behaviour, your partner had a different explanation. Jane: he'd got his head in the sand. He's a lot older than me, he's in his 70's and you don't talk about depression. I used to say Richard is down, he's depressed and he'd say "well, he needs to pull himself out of it, what's he got to be depressed about?". Well obviously he had a lot to be depressed about because he was muddled up. H: did you expect to have any emotional reaction when Richard came for the assessment and received the diagnosis? Jane: no, I find it emotional to talk about it, but I always have. I wasn't emotional that he was diagnosed. I think I was more relieved. H: did you think it would make any difference to your relationship with Richard?	Brought him and dad closer Brought together as family Better understanding of son All working together now whereas before just mum and son Mum couldn't talk to dad before Dad had head in sand Dad didn't understand Richard was muddled up Relief at diagnosis	Impact of diagnosis on relationships – improved father son rel Improved understanding Impact of diagnosis on relationships – closer as family Post-diagnosis feelings – relief

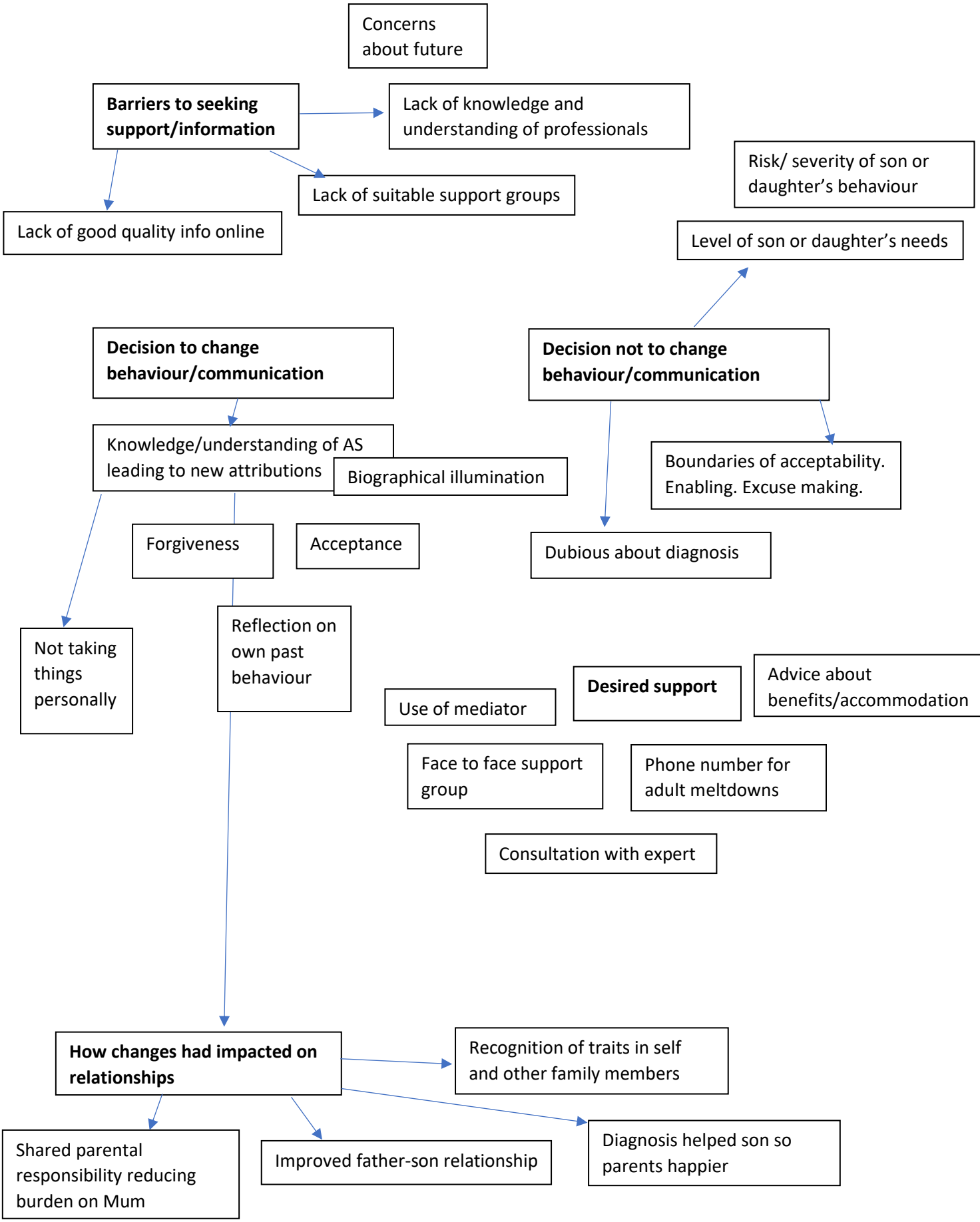
508 509 510 511 512 513 514 515 516 517 518 519 520 521 522 523 524 525 526 527 528 529 530 531 532 533 534 535 536 537	Jane: no, no, no. me and Richard have always been close. I suppose 'cos I've always been there watching his back, 'cos I've had to so we have got a very close relationship and I think that's what his partner didn't like. H: did you think that it would make any difference to your family? I think we've talked about this a little bit. What did you think? Did you think that it would make a difference? Jane: no, I suppose I hoped it would make a difference for my husband, for him to see that there was a problem, but I didn't expect it to change things as it has, that Richard and Dad have got a relationship now which they've never had. I never expected it to turn that round. H: the hope was there, but you didn't really think that it was going to Jane: I didn't really think that, but I think as husband has read up on it and got more understanding, he's become closer and closer to Richard. I noticed by the way he talks to him, and the way he suggests things. H: I see. You said that Richard and dad had never really had a relationship before because of his perceptions that Richard was naughty or spoiled, but that seems to have changed quite significantly.	Mum and son always close Mum always watched son's back Mum hoped diagnosis would make difference to dad but didn't expect change Dad and son have got relationship now Husband read up and got more understanding so become closer to son Dad talks to son differently now	Impact of diagnosis on relationships – improved father son rel Impact of diagnosis on relationships – improved father son rel

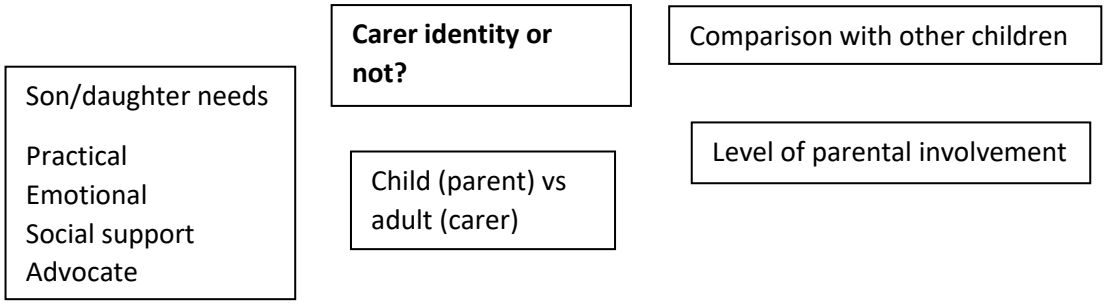
538			
539	Jane: oh, hugely.		
540			
541	H: apart from reading up on AS, do you think there's		
542	anything else that has allowed him to shift that view?		
543			
544	Jane: I suppose it's been on the news a lot recently,	Autism on news a lot –	Media impact on
545	different people and you say "oh they've got it", so	dad realised it's illness	understanding/awareness
546	you look at that person and then you look at Richard.	and lots of people have it	
547	I think that's his understanding. He's suddenly	Autism can't be hidden	
548	realising it is an illness and there's a lot of people got	away and brushed under	
549	it and it's not to be hidden away and brushed under	the carpet	
550	the carpet.		
551			
552	H: what changes would you say you've noticed in		
553	their relationship?		
554			
555	Jane: they talk to each other which they never did!	Son will go out with dad	Impact of diagnosis on
556	Richard will go out with his dad and if Richard wants	now	relationships – improved
557	to something, his dad will suddenly have the patience	Dad has patience to	father son rel
558	to show him how to do it. I don't know, they've	show son how to do	
559	suddenly turned into a father and a son, which	things	
560	they've never been, not since Richard was about 2 or	Suddenly turned into	Impact of diagnosis on
561	3, since he stopped reading stories at night, they had	father and son	relationships – improved
562	that close bond then, suddenly that close bond is	Close bond between	father son rel
563	back.	father and son back	
564			
565	H: how is that for you?		
566			
567			

568 569 570 571 572 573 574 575 576 577 578 579 580 581 582	Jane: it's a relief, it takes something off of me. I'm not the only one looking out for Richard. I work part-time, I leave for work at 8am, I know husband will get Richard up and Richard will go to work. Husand will help him, I know it's not just me running round after him. H: is that different from before then? Jane: yeah, yeah. I wouldn't have gone to work for 8 before, I would have waited to make sure Richard was up. And like the evening meals, if I'm going somewhere, husband will now cook for Richard, rather than saying "he's old enough to do it for his self".	Relief at change in relationship as takes something off her I'm not the only one looking out for Richard Dad more supportive of son now which has helped Mum	Impact of diagnosis – shared parental responsibility now

Appendix N: Provisional thematic map




Concerns about future
Barriers to seeking support/information
Lack of knowledge and understanding of professionals
Lack of suitable support groups
Lack of good quality info online
Risk/ severity of son or daughter's behaviour
Level of son or daughter's needs
Decision to change behaviour/communication
Decision not to change behaviour/communication
Knowledge/understanding of AS leading to new attributions
Biographical illumination
Boundaries of acceptability. Enabling. Excuse making.
Forgiveness
Acceptance
Dubious about diagnosis
Not taking things personally
Reflection on own past behaviour
Use of mediator
Desired support
Advice about benefits/accommodation
Face to face support group
Phone number for adult meltdowns
Consultation with expert
How changes had impacted on relationships
Recognition of traits in self and other family members
Shared parental responsibility reducing burden on Mum
Improved father-son relationship
Diagnosis helped son so parents happier


Carer identity or not?
Comparison with other children
Son/daughter needs
Practical
Emotional
Social support
Advocate
Level of parental involvement
Child (parent) vs adult (carer)

Appendix O: Final thematic map