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“I don't know what's the Asperger's and what's me”: an IPA exploration of young people and mothers' experiences of receiving and living with an autism spectrum condition diagnosis during adolescence. D Clin Psy thesis.

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***“I don’t know what’s the Asperger’s and what’s me” – An IPA  
Exploration of Young People and Mothers’ Experiences of  
Receiving and Living with an Autism Spectrum Condition  
Diagnosis during Adolescence  
And Clinical Research Portfolio***

Volume I

(Volume II bound separately)

Rona Ann Craig, MA SocSci (Hons.)

*Submitted in partial fulfilment of the requirements for the degree of  
Doctorate in Clinical Psychology*

Institute of Health and Wellbeing  
College of Medical, Veterinary and Life Sciences  
University of Glasgow

September 2015



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## **CHAPTER ONE: SYSTEMATIC REVIEW**

### **Experiences of Parenting an Adolescent with an Autism Spectrum Condition – A Synthesis using Meta-ethnography**

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Prepared in accordance with the requirements for submission to the Journal of *Autism: The International Journal of Research and Practice* (See Appendix 1.0).

Chapter One Word Count: 12,841 (including references)

## ABSTRACT

**Introduction:** Although there is growing qualitative research into parents' experiences of having a child with an autism spectrum condition (ASC) there is limited knowledge of parents' experiences during adolescence and the findings have not been synthesised. The current review synthesises qualitative research of parents' experiences of parenting an adolescent with an ASC and considers the quality of the current literature.

**Method:** A systematic search was carried out in; Medline, EMBASE, CINAHL, PsycINFO, Psychology & Behavioural Sciences, Web of Science Core Collection and Google Scholar which identified four relevant papers. The quality of these studies was rated using an adapted version of an existing quality rating framework. Meta-ethnography was used to synthesise the findings of these studies and to develop a new interpretation.

**Results:** Five themes were identified which related to parents' experiences of parenting an adolescent with an ASC; 1. Seeking and Receiving a Diagnosis, 2. The Challenges of ASCs, 3. The Impact of ASCs on The Family and Family Life, 4. Coping with ASCs, 5. The Parental Role and Navigating Adolescence.

**Conclusions:** This review identifies key themes in the experiences of parents of adolescents with ASCs including themes specific to this developmental stage. The implications for professionals and services are discussed along with directions for further research.



## INTRODUCTION

Autism spectrum conditions (ASCs) are a range of pervasive developmental conditions characterised by difficulties in social communication, social interaction and restricted, stereotyped and repetitive patterns of behaviour, interests and activities (ICD 10: WHO 1992, 1996; DSM-5: APA, 2013). UK prevalence studies suggest that around 1% of children and 1.1% of adults may have an ASC (Baron-Cohen et al., 2009; Brugha et al., 2012). The most recent version of the Diagnostic and Statistical Manual (DSM-5, APA 2013) replaced a range of diagnostic terms (e.g. 'childhood autism' and 'Asperger's disorder') with the broad diagnosis of 'autism spectrum disorder'. The current study uses the term 'autism spectrum conditions' to refer to all conditions on the autism spectrum in reference to the changes in diagnostic criteria and the growing literature that emphasises the importance of viewing the characteristics of ASCs as 'difference' rather than 'disorder' (Baron-Cohen, 2000).

The difficulties or traits associated with ASCs can have a major impact on the whole family system as well as the individual (Cridland et al., 2014c). For example, parents can report lower marital satisfaction, family cohesion and family adaptability (Higgins et al., 2005). Having a child with an ASC in the family may also have various positive or negative consequences for siblings (Ferraioli & Harris, 2010; Macks & Reeve, 2007) and may alter the roles of extended family such as grandparents (Margetts et al., 2006). Studies suggest that parents of children with ASCs experience higher levels of stress than parents of children with no disability and parents of children with Down's syndrome (Sanders & Morgan, 1997). In addition, they report increased rates of depression compared to parents of children who have an intellectual disability (Olsson & Hwang, 2001). These findings suggest that there may be particular challenges associated with parenting a child with an ASC in addition to those of raising a child with another developmental condition or disability.

### *Parents' Experiences*

While the existing quantitative literature is helpful in highlighting the challenges that many families face, not all parents of children with ASCs report higher levels of stress or psychological difficulties (Davis & Carter, 2008). A number of factors may mediate parental stress, for example, social support may reduce parental stress (Bromley et al., 2004) while behavioural difficulties may exacerbate it (McStay et al., 2013). Furthermore, qualitative literature suggests that many families identify positive aspects to having a child with an ASC, for example, personal growth, becoming closer as a family and having a greater appreciation for life (Altiere & Von Kluge, 2009; Bayat, 2007). This is particularly important given that positive aspects of parenting a child with an ASC may buffer against parental stress, at least in mothers (Hastings et al., 2005). Qualitative research has an important role in increasing our understanding of the range of parent experiences that exist. This is particularly important in light of the recognised need for specialised support and

services for individuals with ASCs and their families for example, the Scottish Strategy for Autism (Scottish Government, 2011).

Recently, DePape & Lindsay (2015) conducted a meta-synthesis of qualitative research about the experiences of parents of individuals (primarily under 18 years old) with ASCs. They synthesised themes from 31 papers using a narrative synthesis approach and found six overall themes:

- *'Prediagnosis'*; parents described noticing that something was different about their child's development and searching for answers.
- *'Diagnosis'*; parents described mixed emotional responses following diagnosis including relief, devastation, guilt and blame.
- *'Family life adjustment'*; parents spoke about the impact of having a child with an ASC on daily life, changes in their finances and employment and the impact on themselves, their spouse and siblings.
- *'Navigating the system'*; parents described trying to access the best services including education and treatment for their children.
- *'Parental empowerment'*; parents described seeking information about ASCs and finding strategies that worked for their family.
- *'Moving forward'*; parents spoke about accepting their child's diagnosis, finding a 'new normal' for their family, finding positive aspects of having a child with an ASC and discussed their thoughts about the future.

The DePape & Lindsay (2015) synthesis identifies themes across a large range of studies however, the paper has a number of methodological limitations. The authors excluded papers in which the child's diagnosis included co-morbid symptoms despite studies suggesting that 70% of young people 10-14 years old with an ASC meet criteria for at least one comorbid disorder (Simonoff et al., 2008). The review included studies conducted across a wide range of cultures. The authors acknowledged the impact of cultural beliefs and norms on parents' expectations and roles and it is unclear whether parents in countries such as India, Saudi Arabia and Israel would have comparable experiences of having a child with an ASC to those in Western and individualistic cultures. Furthermore, although the authors included papers where the majority of children were less than 18 years, participants' children ranged from 2 to 31 years old. Although there may be aspects of parents' experiences that are intrinsic to ASCs across the age span, the role of parents and their expectations is likely to differ depending on their child's developmental stage and associated needs (Marcus et al., 2005) such as during adolescence.

### *Adolescence and ASCs*

Research suggests that parents can experience adolescence as the most challenging stage of parenting (Buchanan et al., 1990). For the individual, adolescence is a unique time in development which includes a period of rapid brain development second only to infancy (Araín et al., 2013). This predisposes

adolescents to seek novelty, social engagement, to explore, think creatively and experience emotions intensely (Siegel, 2013). Adolescence is also associated with a range of contextual changes such as moving to secondary school, social and interpersonal transitions such as seeking more independence from parents, the peer group becoming more influential and an increased interest in romantic relationships (Brown, 2004; Smetana et al., 2006). Erikson suggested that the main developmental task of adolescence is to develop a sense of self-identity (Erikson, 1968). Newman and Newman (1976) suggest that this is the main feature of late adolescence (19-22 years) and that during early adolescence (12-18 years) the main drive is to develop a sense of group identity; to 'fit in'.

While adolescence can be a challenging time for any individual, young people with ASCs may face additional challenges compared to their peers (Cridland et al., 2014a). Attwood (1998) suggests that the emotional changes associated with adolescence are often "delayed and prolonged" for young people with ASCs and that an interest in romantic relationships and testing boundaries is not always a part of adolescence for young people with ASCs (Attwood, 1998, pg. 165). Smith & Anderson (2014) note that the stresses of parenting an individual with an ASC can be particularly high during adolescence. Similarly, parents of adults with ASCs in Portway & Johnson (2003) described the transition from childhood to adolescence as an especially stressful period for themselves and their family. Smith et al. (2009) found that parents of adolescents and adults (17-53 years olds) with ASCs spent significantly more time completing care-giving tasks and doing chores compared to mothers of individuals with no disability. They also described experiencing stressful events more frequently. In summary, it seems likely that the experiences and roles of parents of adolescents with ASCs differ from parents of neuro-typically developing adolescents (Cridland et al., 2014b; Fong et al., 1993).

#### *Rationale for the Current Review*

There are a small but growing number of qualitative studies exploring the experiences of parents who have a child with an ASC. The narrative synthesis conducted by DePape & Lindsay (2015) identifies themes common across these studies however, it is not possible to draw out themes associated with parenting at specific developmental stages. Given the challenges and stress associated with parenting adolescents and the additional challenges faced by adolescents with ASCs, there is a recognised need to understand the experiences of parents of young people with ASCs during adolescence (Cridland et al., 2014c). The findings from existing literature are likely to be more influential if their results can be synthesised. Consequently, this review aims to:

- i) Synthesise and consider the main findings from explorations of parents' experiences of parenting an adolescent with an ASC.
- ii) Discuss the quality of existing qualitative research exploring parents' experiences of parenting an adolescent with an ASC.

## METHOD

### *Systematic Search Strategy*

To identify relevant papers a systematic search was conducted of the following databases:

- Medline (Ovid)
- EMBASE (Ovid)
- CINAHL (EBSCO)
- PsycINFO (EBSCO)
- Psychology & Behavioural Sciences (EBSCO)
- Web of Science Core Collection (Web of Science)
- Google Scholar

Boolean operators 'AND' and 'OR' were used to combine search terms and '\*' was used to identify related words. Where possible, (in: Medline, EMBASE, CINAHL, PsycINFO), search terms were mapped to subject headings within the database.

Previous studies have reported difficulties using filter terms or subject headings within databases to identify qualitative literature (Atkins et al., 2008). Therefore, to increase the sensitivity of the search, terms that were mapped to subject headings were also entered as keywords. In addition, preliminary searches were completed on databases which include a 'clinical query' function for qualitative research. The number of results was compared with those from searches using keywords developed at McMaster University as a keyword search filter for qualitative research on Medline (McMaster University Health Information Research Unit, 2013). As the keyword searches produced more results overall the qualitative keyword search filter terms ('qualitative', interviews\*' and 'experience\*') were used in the final searches of all databases. An example of the full search conducted in Medline is detailed in appendix 1.1.

The search was limited to peer-reviewed studies published in English and those published between 1980 and 24.01.2015.

The following search terms were used:

1. autism\* OR kanner OR asperger\* OR "pervasive developmental disorder not otherwise specified" OR ASD OR ASC OR PDD NOS  
AND
2. adolescent\* OR youth OR teen\* OR young person OR young people  
AND
3. parent\* OR mother\* OR father\* OR carer\* OR caregiver\* OR guardian\* OR parenting OR child rearing  
AND
4. Qualitative OR interview\* OR experience\*

A search on Google Scholar using the full search strings yielded no results. As a result the key search terms were used consisting of: *autis\* OR asperger\* OR PDD NOS OR kanner AND parent\* OR mother\* OR father\* OR child rearing OR parenting*. Due to time constraints the first 100 results from this search were considered.

### *Inclusion / Exclusion Criteria*

Due to the specific focus on adolescence or 'early adolescence' (Newman & Newman, 1976), studies in which participants were parents of individuals under 11 years or over 19 years old were excluded unless they specified which findings were associated with particular developmental stages. Studies that explored parents' experiences of services or systems (e.g. schools) or that interviewed parents with the aim of understanding the experiences of young people were excluded. This was to allow a synthesis with a specific question and to limit the studies to a manageable number. This is consistent with the suggestion from Atkins et al. (2008) of an additional sub-stage of 'defining the focus of the synthesis' which involves balancing the desire for a broad review with a focus that would identify a manageable number of studies. The included studies were limited to research conducted in Western cultures in an attempt to minimise the impact of cultural differences. It has been noted that parents' cultural views can influence how they make sense of their child's autism spectrum condition, their expectations of parental roles and of their child's future (DePape & Lindsay, 2015). Societal awareness of ASCs may also vary across cultures. Studies relating to various ASC diagnoses were included. This is in reference to the move towards the broader conceptualisation of ASCs in DSM-5 as 'autism spectrum disorders' (APA, 2013) and concerns regarding the validity of the various diagnostic terms (Calzada et al., 2012). Papers were limited to those published after 1980 due to differences in terminology in the major diagnostic systems prior to 1980.

This review included research which:

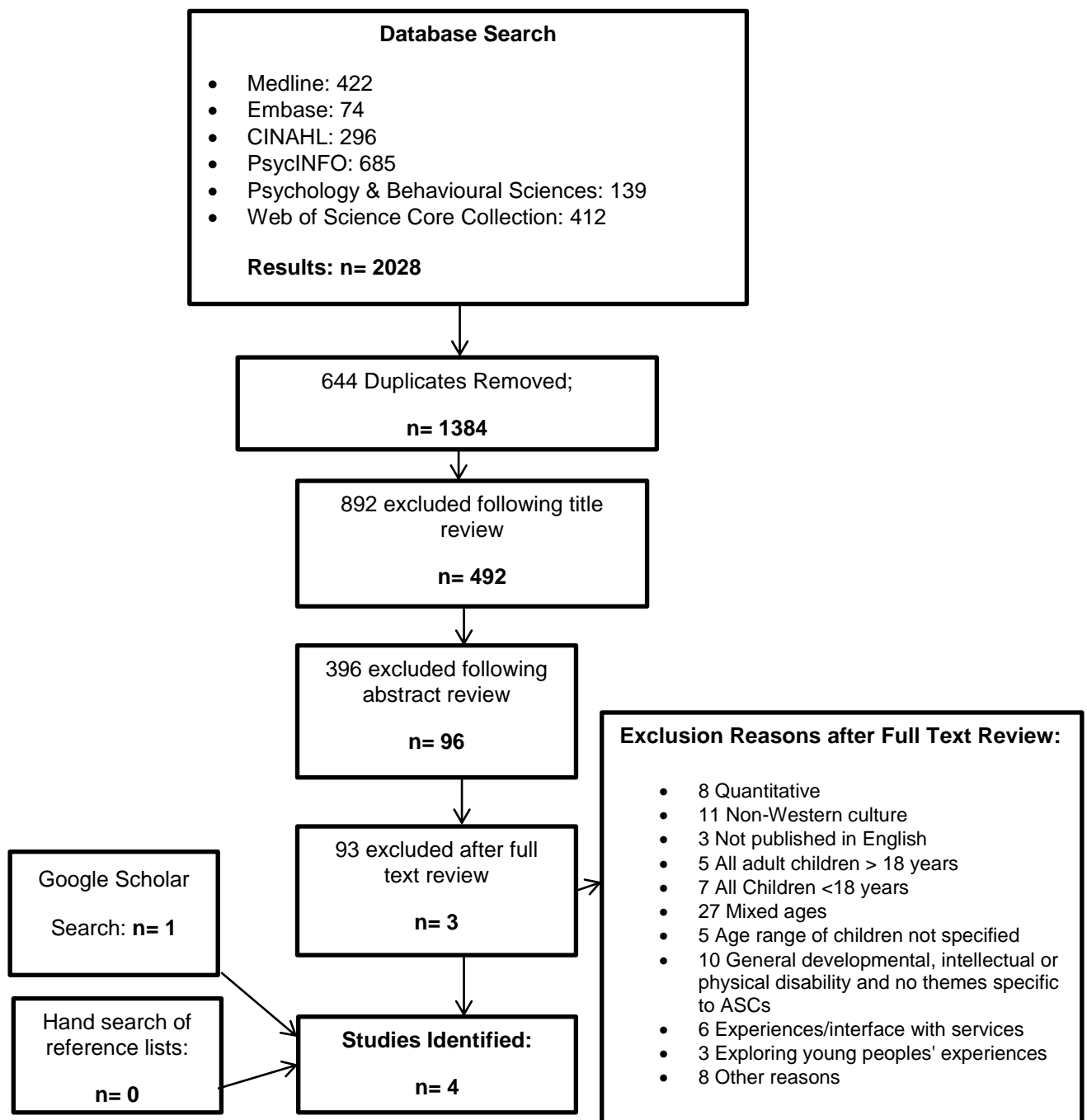
- Employed qualitative methodology and analysis or mixed methods with a referenced qualitative approach or model of analysis.
- Explored parents' experiences of parenting an adolescent (aged 11-19 years) with an ASC (not of services/systems or with the singular aim of understanding young people's experiences).
- Took place within a Western culture.
- Was published in English.
- Was peer-reviewed.
- Was published between 1980 and 24<sup>th</sup> January 2015.

### *Results of Search*

Endnote x7.2.1 for Windows & Macintosh was used to manage the results of the database searches. The database search produced a total of 2028 results; 1384 after duplicates were removed. Papers were then screened by title or title and

abstract according to the inclusion/exclusion criteria and 892 and 396 respectively were removed at these stages. The full text was reviewed for 96 papers resulting in 93 being excluded and identifying three suitable papers. The Google Scholar search identified one additional paper which met the inclusion criteria. The reference lists of these four papers were hand searched but no additional papers were identified. This resulted in a final list of four papers which were included in the review. This process is depicted below in figure 1.

**Figure 1: Flow Chart Detailing the Identification of Papers**



### *Quality Assessment*

Over one hundred methods for assessing quality of qualitative research have been identified, with few of these reviewed (Dixon-Woods et al., 2004). There is no consensus about how, or even whether, this should be carried out (Dixon-Woods et al., 2004). Walsh & Downe (2006) developed a summary framework for the appraisal of qualitative research based on a synthesis of eight existing frameworks. This summary framework was used as the basis for the rating framework in the current study (see appendix 1.2) with the addition of a further category of 'demographic context'. This was included to consider the level of demographic data included in the studies (e.g., the age and gender of participants and, in this instance, participants' children). This allows for a greater understanding of the context of the research and the sample which may allow judgements of specificity and typicality. The inclusion of participants' demographic information allows the findings of qualitative research to be synthesised in relation to specific questions such as particular developmental stages, as in the current study.

Due to the lack of consensus around assessing the quality of qualitative studies and the limited qualitative research in this area, an a priori decision was made not to exclude studies on the basis of quality. In the current study, papers were rated according to the framework in appendix 1.2. Total scores were used to consider the quality of included studies broadly and areas of relative strengths and weaknesses across the papers. Papers were rated according to 13 'essential criteria'. For the 12 criteria developed by Walsh & Downe (2006) the 'further prompts' they describe were considered for each paper to assign a score (see appendix 1.2). Papers were given scores 0, 1, 2 or 3 to indicate; 'not met', 'partially met', 'mostly met' or 'fully met' respectively for each of these aspects. To categorise the quality of papers overall, it was decided that those obtaining a total score of <50%, would be considered '*Poor*', scores of 50-75%: '*Acceptable*' and scores >75%: '*Good*'. The author rated all papers initially. A second researcher independent to the study also rated the papers and any discrepancies in ratings were resolved through discussion, resulting in 100% agreement between raters.

### *Meta Ethnography*

At present there is no standard method to synthesise qualitative research and a recent review by Barnett-Page & Thomas (2009) identified nine distinct methodologies. Of these, meta-ethnography (Noblit and Hare, 1988) is the most commonly used method for the synthesis of qualitative research within health research (Campbell et al., 2011). In addition, Atkins et al. (2008) suggested that meta-ethnography is best suited to generate models or higher order theories of experiences across studies. Consequently, meta-ethnography was considered best suited to meet the aims of the current study. Although recently meta-ethnography has been undertaken with larger numbers of studies, e.g. Pound et al. (2005), Noblit and Hare (1988) originally demonstrated the methodology by synthesising sets of between two and six papers. Therefore after the included papers were identified, meta-ethnography remained a suitable methodology for the current review.

The seven stages of meta-ethnography described by Noblit and Hare (1988) were used to guide the process along with additional prompts suggested by Atkins et al. (2008) as detailed in appendix 1.3. Meta-ethnography was used to synthesise the themes and concepts across the identified papers by 'translating' the studies into one another. A 'line of argument synthesis' or higher level interpretation was then developed. Atkins et al. (2008) note that the process involved in translating the studies into one another and synthesising these translations is not well defined as it may not be possible to reduce this into a series of specific tasks. As such the author took guidance from descriptions of Britten et al. (2002) and Atkins et al. (2008) in addition to the original methods by Noblit and Hare (1988). Consistent with the steps suggested by Noblit & Hare (1988) the researcher firstly familiarised themselves with the identified studies by reading them a number of times and noting down the themes and details of themes identified by the authors. The current author chose to include theme titles, participant quotations and author descriptions. The concepts from each study were then compared in chronological order; those from study one with those from study two and common themes that emerged across papers were noted along with any discordant themes identified. The synthesis of concepts from study one and two was then compared with study three and this further synthesis with study four. As suggested by Atkins et al. (2008) a table was used to chart whether and how each concept was described in each paper. The translated concepts from the papers were noted and relevant verbatim quotes and descriptions from the papers were organised under these headings. A new framework of themes was developed that could be applied to all the synthesised papers and explain the emergent concepts. One additional theme that was apparent across papers was considered and this added to the development of a new interpretation.



## RESULTS

### ***i) Synthesis of the main findings from explorations of parents' experiences of parenting an adolescent with an ASC.***

The identified papers are displayed in chronological order in table 1.1 along with the themes from each paper, demographic and contextual information about participants and details of study methodology. The four studies explored the experiences of 35 parents from 25 families overall. In the current review, adolescents are referred to as the “children” of their parents as some parents discussed experiences earlier in the children’s lives as well as during adolescence.

The process of meta-ethnography led to the development of five central and interlinked themes relevant to parents’ experiences of parenting an adolescent with an ASC listed below. These are discussed in more detail along with verbatim excerpts from the studies.

1. Seeking and Receiving a Diagnosis
2. The Challenges of ASCs
3. The Impact of ASCs on Family and Family Life
4. Coping with ASCs
5. The Parental Role and Navigating Adolescence

Table 1.1 Details of Included Papers and Quality Ratings

Author, Year & Country	Demographic Information		Study Aims	Data Collection Method	Method of Analysis	Themes	Quality Rating
	Parent Characteristics	Characteristics of Adolescent Children					
Fong, Wilgosh & Sobsey (1993)  Canada	<p>N= 8 parents (6 families)</p> <p>6 mothers 2 fathers</p> <p>Age: 39 – 47 years (mean = 43)</p> <p><i>Education/Employment:</i> All had Grade 12 + education, “several” had post-secondary/ professional education.</p> <p>6/6 mothers employed (3 full-time, 3 part-time) 2/2 fathers employed</p>	<p>6 adolescents (5 boys, 1 girl)</p> <p>Age: 13-15 years (mean = 14 years, 2 months)</p> <p><i>Education:</i> 1/6 vocational programme 2/6 in mainstream class with support 1/6 specialised programme in mainstream school 2/6 special education classes within mainstream school</p> <p><i>Diagnoses:</i> Not specified</p> <p><i>Siblings:</i> 2/6 none 2/6 one 2/6 two</p>	To understand the meaning of the experience of living with an adolescence with autism and to identify needs of adolescents and families.	<p>Parents were interviewed twice.</p> <p>All families took part in a follow up interview 3-4 months later to validate themes and for further clarification.</p> <p>Mothers and fathers interviewed together.</p>	Phenomenological approach (Colaizzi, 1978)	<ul style="list-style-type: none"> <li>• Behavioural concerns</li> <li>• Social and communicative concerns</li> <li>• Family-related concerns</li> <li>• Education and related services</li> <li>• Relationships with professionals</li> <li>• Independence and future concerns</li> </ul>	<p>26/39 (67%)</p> <p>‘Acceptable’</p>
Cridland, Jones, Caputi & Magee (2014b)  Australia	<p>N=5 parents (5 families)</p> <p>5 mothers 0 fathers</p> <p>Age: 47 – 54 years (mean = 50.4)</p> <p><i>Education/Employment:</i> Not specified Annual household income = \$20,000-200,000 (mean = \$84,000)</p>	<p>5 adolescent girls</p> <p>Age: 12-17 years (mean = 15)</p> <p><i>Education:</i> 2/5 mainstream with ASD support unit 1/5 specialised ASD unit 1/5 supported employment 1/5 mainstream</p> <p><i>Diagnosis:</i> 1/5 Autistic Disorder 3/5 Asperger’s syndrome 1/5 PDD-NOS Diagnosed y at age 6-14 years old. Diagnosis received between 3-6 years prior to the study.</p> <p><i>Siblings:</i> 1/5 none 1/5 one (had an ASC diagnosis) 3/5 two</p>	To investigate the experiences of girls with ASD during adolescence and conduct an in-depth investigation of the mother-daughter relationship during adolescence.	Mothers and 3/5 adolescents were interviewed once in face-to-face interviews.	Interpretative phenomenological analysis (Smith, 1996; Smith et al., 1999)	<ul style="list-style-type: none"> <li>• Diagnostic Issues</li> <li>• Being Surrounded by Boys</li> <li>• Experiences of High School</li> <li>• Complexity of Adolescent Female Relationships</li> <li>• Puberty and Its Related Issues</li> <li>• Sexual Relationships and Concerns</li> <li>• Impact of Having an Adolescent Daughter with ASD</li> </ul>	<p>30/39 (77%)</p> <p>‘Good’</p>

Author, Year & Country	Demographic Information		Study Aims	Data Collection Method	Method of Analysis	Themes	Quality Rating
	Parent Characteristics	Characteristics of Adolescent Children					
Robinson, York, Rothenberg & Bissell (2014)  Canada	N= 13 parents (8 families) 8 mothers 5 fathers Age: Mean = 46.6 years Education/Employment: 6/8 mothers and 3/5 fathers had college education + 5/8 mothers employed. 4/8 families had annual income of \$50,000+	8 adolescents (6 boys, 2 girls) Age: Mean = 14.17 years for boys, 16.5 for girls Recruitment criteria: 11-19 years Education: not specified Diagnosis: 8/8 Asperger's Syndrome Mean age at diagnosis = 10.75 years. Time since diagnosis = 3.87 years Siblings: 6/8 one 2/8 two	To investigate parents' experiences of raising a child with Asperger Syndrome.	Parents were interviewed on two occasions (one family was interviewed on 3 occasions).  Mothers and fathers interviewed together for some/all interviews.	Interpretative description (Thorne, 2008)	Core construct: 'a balancing act' Comprised of themes: • Losing Our Footing • Regaining Our Balance 1. Balancing expectations 2. Balancing parental roles and responsibilities	28/39 (72%)  'Acceptable'
Mount & Dillon (2014)  England	N= 9 parents (6 families) 5 mothers 4 fathers Age: 30-51 years (mean = 41) Education/Employment: 9/9 in full or part time employment	6 adolescents (5 boys, 1 girl) Age: 11-16 years, (mean = 13) Education: 6/6 attending one mainstream secondary school. Diagnosis: At age 4-12 years (median = 10.5) Siblings: 6/6 one (none with an ASC)	To explore parents' experiences of parenting adolescents with autism and the psychological impact that this had.	Parents were interviewed once in a face-to-face interview.	Thematic Analysis (Braun & Clarke, 2006)	• Difficulties faced by parents • Effects on relationships • Impact upon self • Diagnosis and support • Coping strategies • School issues • The future	25/39 (64%)  'Acceptable'
<b>Overall</b>	35 parents (25 families) 24 mothers, 11 fathers	25 adolescents; 16 boys, 9 girls					

## **1. Seeking and Receiving a Diagnosis**

Parents in all papers described their experiences of seeking and finally receiving their child's diagnosis. Most parents described a long and challenging process of searching for explanations for their child's difficulties or difference. Some parents described receiving unhelpful advice or interventions prior to diagnosis and felt that the wider community had perceived them and their child in a negative way. Parents in Robinson et al. described losing confidence in their parenting ability, blaming themselves for their child's difficulties and experiencing blame from partners, professionals and the wider community. All studies reflected parents' difficult experiences with professionals, for example, feeling that their concerns were dismissed or not acknowledged. As a result many parents described having to persevere or "battle" for their child to receive a diagnosis.

*"That's the very first reaction is that this is a parenting skills issue or an environment issue at home, so it's yours to deal with, or you need to get this child under control"* (Robinson et al., 2014 pg.6).

*"I always knew there was a problem but nobody wanted to put a diagnosis on it... no one was willing to put their name down and say that she had it. It was only when I really started pushing that there was a problem... that we got the diagnosis"* (Cridland et al., 2014b, pg. 1264).

All papers highlighted parents' mixed and complex reactions to the diagnosis which included feelings of shock, regret, anger, sadness and anxiety along with confirmation, relief and celebration. Many described a grieving process which seemingly led to acceptance, for the majority of parents. Some parents described the diagnosis as a positive turning point in their lives and others discussed the negative consequences of not having received a diagnosis sooner. After the adolescent received their diagnosis many parents described difficulties with services. Some parents had a sense of being abandoned by services, others found it overwhelming to navigate and access services.

*"When I first found out about Daniel, I knew what he'd got, I knew. But when they tell you it's a bit 'Oh' you go through that kind of like a grieving stage that you think 'Oh, what's going to happen to him in the future?' 'What's going to happen with things he's not going to do?'"* (Mount & Dillon, 2014 pg.77).

*"The diagnosis helps because you stop blaming other people, you accept that this is the way he was born, and that is okay. And it's nobody's fault anymore. And no parent is perfect, and we've done the very best that we can, and it's okay. That's huge"* (Robinson et al., 2014 pg.7).

*"It was like, 'Well there's your diagnosis, see ya later.' We were left on our own to work through all this information and because you're going through that grieving process you can't think clearly. You don't know where to start... You can't process it on your own because your brain is so scrambled with dealing with what you have just been diagnosed... it was overwhelming"* (Cridland et al., 2014b pg. 1265)

## **2. The Challenges of ASCs**

All studies highlighted challenges that parents faced in relation to their child's ASC. Three papers discussed challenging behaviours such as temper tantrums, crying, shouting and physical aggression. In Fong et al., parents also described obsessive, ritualistic and self-stimulatory behaviours. Some parents in Fong et al. described an increase in challenging behaviours associated with the onset of adolescence whereas some observed an improvement. Parents suggested that their child often displayed challenging behaviours in response to unexpected changes or new situations and noted that sometimes behaviours would occur long after the 'trigger'. In two papers, parents described the difficulties associated with their child's sensory preferences such as towards food, textures and noise levels (Mount & Dillon, 2014 & Robinson et al., 2014). Although observable challenging behaviours appeared to dominate parents' descriptions of the challenging aspects of ASCs, some also spoke about their child's less obvious difficulties, such as with change or the need to carefully consider how to communicate something to them effectively. The social and communication difficulties parents described are discussed further within the final theme.

*"So then you have to go, "Ok, I need to think how 'Hannah' needs to hear this"* (Cridland et al., 2014b pg.1268)

## **3. The Impact of ASCs on The Family and Family Life**

All of the studies highlighted the impact of ASCs on the family system and family life. Some parents found the demands of ASCs pervasive and described feeling stressed, tired and frustrated and worrying what to do for the best. Some parents described the emotional impact of their child's differences on them for example, their child disliking physical contact or having to witness their child's struggles. The needs of the young person with an ASC were a priority and for some parents their child's needs appeared all encompassing. Parents discussed how the demands of parenting their child impacted on their time with their partner and could leave them feeling isolated from their extended family and the wider community.

*"Everything is a struggle, so even from getting up in the morning to getting him to do things, to even going to bed, going out. He has to be coerced into [pause] everything, you can't just say 'I'm going out we're going out and we'll do this today"* (Mount & Dillon, 2014 pg. 76)

*"We are thinking about her all the time... virtually our whole lives have revolved around her..."* (Cridland et al., 2014b pg. 1269).

*"It's such hard yakka just keeping things going so I've had to step back. I can't put any more time into her, I have done 150 % but if I did 300 % it still wouldn't be enough for her"* (Cridland et al., 2014b pg. 1270).

The impact of their child's ASC on other siblings in the family was discussed in all studies with the exception of Cridland et al. Parents strove to ensure that their time, attention and money were shared fairly however, often they felt that this was not possible and that siblings had to make sacrifices for their sibling with an ASC.

*"Fair for us will never be [that typically developing child] will get equal time. She won't. That's just a reality. It's a reality that we've had to accept as parents, which is hard because you want that, I want to be able to give her as much time as I give [Child with AS] every day but I can't, I don't have that many hours in my day"* (Robinson et al., 2014 pg.9)

Two papers described that the young person's ASC influenced family activities such as going on day trips or holidays and decisions such as where the family chose to live. The negative impact for some parents' employment, career opportunities and finances was reflected in three studies. Despite these challenges, parents described their child's positive qualities in two papers. Furthermore, in all papers except, Fong et al., parents reflected on the positive aspects of parenting a child with an ASC e.g. becoming more accepting and tolerant, having a strong relationship with their child and connecting with other families living with ASCs.

*"Appreciate your child because they're wonderful.... Some people would call [AS] a disability, other people call it a gift".* (Robinson et al., 2014 pg.7).

#### **4. Coping with ASCs**

All papers described a range of ways in which parents coped with the challenges of their child's ASC. Some parents described a process of understanding and accepting the ASC as part of their child and adjusting the expectations they previously held.

*"You go quite negative at first but then you have to get round to the idea and you have to be positive. You have to try and think of all the things that they are good at, they can do. All the good qualities about that child because they've not changed, that's who they are"* (Mount & Dillon, 2014 pg.77).

Parents also described practical strategies such as behaviour management techniques, altering communication, having routines, being pro-active such as planning ahead and avoiding possible 'triggers'. Parents described being flexible about how they managed behaviours, for example, accepting and tolerating behaviours associated with ASCs that were not problematic. In this sense, parents had to be both flexible in how they responded and the strategies they used and somewhat inflexible in terms of providing routine and structure for the child.

*"A lot of his idiosyncrasies, once we found out he had Asperger's, immediately we let it go....That's the way he is, leave it be....Like he'd be flicking his fingers....Didn't matter"* (Robinson et al., 2014 pg.8).

In order to manage their own emotions parents described using humour, taking time out for themselves, engaging in personal interests or employment. In all studies with the exception of Robinson et al., parents described the importance of social support including from their partner, family and friends and from other parents.

*“I make time to myself and I sit down and read a book... I also talk to other parents of kids on the spectrum; I make time to do it... You need people that you can trust with your information. I think I’m lucky that I have people like that both on the spectrum and off the spectrum”* (Cridland et al., 2014b pg. 1270).

Receiving input and support from services was also important for parents’ coping, however, many parents found it difficult initially to find or access services. Many described the need to advocate and push for appropriate services for them and their child. When parents had identified services for their children they discussed services that they had found helpful such as support groups. Parents in Fong et al. valued input from professionals who had expertise in ASCs or who were in frequent contact with their child. Others described the limitations of services, e.g. for girls with ASCs and those they wished to have access to such as respite services.

*“...now that we are getting more connected with the services and we are not feeling so isolated like it is just us, I’m a lot more confident and the positives are coming out a lot more... it’s like we’ve come through the fog and are coming out through the other end...”* (Cridland et al., 2014b pg.1270).

*“So much of it comes back to the one core thing...a few days of respite, where we could’ve...had that one on one that you need with your [typical] children.... Just so that they could breathe, so...they know what it feels like to be normal. I think that would’ve been huge”* (Robinson et al., 2014 pg.9).

The young person’s experience of school had a significant impact on parents and this was discussed in all papers, except Robinson et al. Parents described concerns about whether their child should be in a mainstream or specialist placement and the extent of teachers’ knowledge of ASCs and the impact this had. Parents also described the transition to secondary school as challenging but reflected on positive aspects of the new school experience as well as the negative impact that the demands of school could have on their child.

*“...So if someone’s not quite got the understanding, don’t understand his needs it frustrates him and he may not show that again to that teacher or in that class he’ll bring it home with him and obviously we’ll get the backlash of it. That’s how it’s always been... You can tell as soon as he walks through the door, if he’s had a good day or a bad day”* (Mount and Dillon, 2014 pg.78)

## **5. The Parental Role and Navigating Adolescence**

Although this was not identified as a theme in any of the included papers, parents in all four studies reflected on their role as a parent and some discussed how this appeared to differ from parents of adolescents without ASCs. Parents' roles were described as being 'hands on' and they provided a high level of support in the adolescents' day-to-day activities. For some parents, this meant that they were more involved in helping their child to negotiate physical changes associated with adolescence such as the need for hygiene routines. Puberty itself was only discussed by Cridland et al. where the primary concern of mothers was their daughter managing menstruation. Some parents reflected on their realisation that their child might always require a higher level of parental support.

*"I always felt like at some point I would get my life back... Then I realised that that wasn't going to happen... It is like a loss..."* (Cridland et al., 2014b pg.1270).

Furthermore, some parents described an intense involvement in their child's experiences and a close relationship between parent and child was explicitly noted by Cridland et al. and Mount & Dillon. Some parents described seeing the world through their child's eyes to anticipate and negotiate potential challenges and to interpret events for their child. It appeared difficult for parents to separate their experiences from their child's.

*"It's almost like a second sight into his world.... I'm with him so much that I start to see things like he does...and what he's thinking without even asking a lot of the times"* (Robinson et al., 2014 pg7).

Parents were also aware of the relational demands of adolescence and discussed the young person's motivation to have friendships and to "fit in". For many, their child's social and communication difficulties had become more apparent as they got older and relationships became increasingly complex. Some parents described their child being teased or bullied by peers. In Cridland et al. mothers discussed the specific challenges for adolescent girls with ASCs, e.g. how their daughters' limited interest in fashion could be a barrier to fitting in with female peers.

*"I think girls have such high expectations within their own little social groups... Like, you know how they all kiss and cuddle and that? Hannah can't do those things, like she would know when she is supposed to... So if you don't know the rules, how are you going to survive in a little pod like that?"* (Cridland et al., 2014b pg.1267)

*"He really wants to be sociable, to talk to people. He just has no idea whether something is appropriate or not."* (Fong et al., 1993 pg. 108).

In Cridland et al. and Fong et al., parents discussed concerns about how their child would navigate romantic or intimate relationships as a result of their ASC. Some parents worried about their child being exploited by others and how they would approach issues around the young person's sexuality.



*"...it is a worry that she may meet someone who is NTD<sup>1</sup> and knows that she is not NTD and takes advantage of her, so there is always that worry. And the fact that she is very trustworthy, like if somebody says something she believes that to be true... But that worry will become bigger when she gets older and leaves school and starts working and starts going out of a night... because there are people out there that would take advantage of her and to fit in she would probably do things to fit in" (Cridland et al., 2014b pg.1269).*

*"[Sexual relationships] There isn't enough information on what to expect or how to handle it " (Fong et al., 1993 pg. 111).*

Some parents reflected on their own experiences of adolescence and their desire, therefore, for their children to be accepted by their peers. Others compared their child's interest in friendships and romantic or sexual relationships to those they associated with "typical" adolescence.

*"I think it's heart breaking for the Mums, and it probably is for the Mums of boys (with ASD) as well but I think for the girls it's different because you're a girl and you know what it is like going through school and how it was to be popular and look nice and be accepted and to be involved in things and to be invited to things. I think when they are not invited to parties and outings with kids their own age, I think it hurts you more than it hurts them. I think they deal with it in their own way but I think the parents take it on board themselves and it is just heart-breaking to see" (Cridland et al., 2014b pg. 1269)*

*"I've noticed that other teenage girls are a lot more social than she is. She tends to be more of a loner, so that whole thing of being a teenager and being off with your friends all the time hasn't happened yet" (Cridland et al., 2014b pg. 1267).*

Although this was not discussed at length in the studies (and in Mount & Dillon this theme was not discussed due to wordage), all papers reflected parents' hopes and concerns about their child's future. Parents worried about the extent to which their child could live independently and who would care for them if they could not continue to. Some parents described adjusting their expectations or holding flexible and individualistic hopes such as their child reaching their own potential and leading a happy and productive life.

## **ii) Quality of existing qualitative research exploring parents' experiences of parenting an adolescent with an ASC.**

The scores awarded to each paper for the 13 criteria are displayed in Table 1.2, appendix 1.4. In summary, three of the four papers were considered of "acceptable" quality (Fong et al., 1993; Mount & Dillon, 2014; Robinson et al., 2014) and one, (Cridland et al., 2014b), of "good" quality. The overall scores of the four papers were relatively homogenous; however, the papers had variable areas of strengths and weaknesses. Some broad trends across papers will be discussed briefly. A

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<sup>1</sup> Neurotypically developing

fuller consideration of the trends across papers in relation to each criterion is included in appendix 1.5.

Overall, the criterion yielding highest scores related to providing a 'clear statement of and rationale for the research question'. This was stated by all four papers, as was the link between the study aims and the existing literature. The papers gave sufficient detail of the research processes and decisions and scored highly on this criterion. Another area of relative strength across the papers related to the use of data to support interpretations. With the exception of Fong et al., all papers used extensive verbatim quotes in the description of themes which was a strength. Fong et al. described themes primarily in a narrative form which made it more difficult to get a sense of how participants' experiences related to the identified themes. All studies clearly presented how their interpretation had led to their conclusions.

Conversely, the area in which the papers scored lowest overall related to the demonstration of researcher reflexivity. One exception to this was Fong et al. which demonstrated the relevant criteria well. Most of the other papers did not discuss the relationship between researcher and participants, the researcher's influence on the research process or how any problems were dealt with. Only Fong et al. and Robinson et al. provided evidence of the researcher's self-awareness and none of the papers discussed the impact that the research had on the researcher. In addition, the sample and sampling method was not well described across the studies with the exception of Robinson et al. Most of the remaining papers gave no justification for their sampling strategy and none of the authors specified their planned sample and whether this was met. Fong et al. and Mount & Dillon recruited all participants from a parent support group which may be less representative of the range of parental experiences. Other areas of relative weakness across the papers related to contextualising the study in existing literature, the degree of demographic information included, discussion of the analytic approach employed and consideration of ethical concerns. It is possible that, in some instances, low scores might indicate omitted information or detail. As such, scores may relate to the quality of the written account of the study or word restrictions rather than the quality of the study itself.

## DISCUSSION

The aims of this review were to i) synthesise and consider the main findings from explorations of parents' experiences of parenting an adolescent with an ASC and ii) discuss the quality of existing qualitative research exploring parents' experiences of parenting an adolescent with an ASC. The findings are discussed in the context of existing literature along with suggestions for further research.

### ***i) Synthesis of the main findings from explorations of parents' experiences of parenting an adolescent with an ASC.***

It is clear that parents' experiences are influenced by many individual factors, however, this review has demonstrated that there are common themes in parents' experiences at this stage in family life. Five common themes were identified from relevant qualitative studies. With the exception of the final theme, these were broadly similar to those described in the DePape & Lindsay (2015) synthesis suggesting that there may be aspects of parenting an individual with an ASC that are relevant across different developmental stages. Notably, participants' children received their diagnosis at various ages and parents reflected on their experiences throughout their children's lives which could also explain some of the similarities with parental experiences described in DePape & Lindsay (2015).

#### *Seeking and Receiving a Diagnosis*

Parents' journey to receiving a diagnosis appeared to be an important and central part of their experiences overall, even although for many participants this was not a recent event. This is perhaps unsurprising given that these experiences might influence how parents adjust to or accept their child's diagnosis. Studies in the chronic illness literature suggest that the route to diagnosis, such as whether the diagnosis is suspected or unexpected, can be as important as the diagnosis itself (Peel et al., 2004). Parents' relationships with services are also likely to be influential throughout their child's life and therefore negative experiences of seeking or receiving a diagnosis might influence parents' use or experience of services later. Studies have suggested that many parents experience a high level of stress during the diagnostic period (Crane et al., 2015) and this may be understood in the context of parents' experiences of this process. Parents described a long process to diagnosis during which time many lost confidence in their parenting skills, blamed themselves or were blamed by others and had negative and undermining interactions with professionals. Neely-Barnes et al. (2011) also highlighted the issue of parental blame from extended family and the wider community. A recent UK study found that families wait on average 4.6 years between parents' initial concerns to receiving a diagnosis and that, prior to diagnosis, the majority of parents attend multiple professionals and services and are often told that there is no problem, to monitor difficulties or receive different diagnoses (Crane et al., 2015).

Around the time of receiving their child's diagnosis parents described a wide range of complex and conflicting emotional reactions. Other studies have discussed similar experiences including DePape & Lindsay (2015). Some parents described a process similar to grief. This is consistent with suggestions that the concept of 'ambiguous loss' may help to understand the experiences of parents of children with ASCs (Cridland et al. 2014c; O'Brien, 2007). Siegel (1997) suggested that parents may experience the loss of their 'idealised' or 'hoped-for' child when their child is diagnosed with an ASC. Furthermore, mothers appear to make diverse and complex attributions about the meaning of their child's ASC diagnosis (Dale et al., 2006) which may help to understand some of their emotional reactions.

### *The Challenges of ASCs & The Impact on The Family and Family Life*

Consistent with findings from DePape & Lindsay (2015) parents described a range of challenges associated with ASCs. Primarily these consisted of behaviours that could be difficult to manage including aggressive, self-stimulatory and obsessive or ritualistic behaviours. The contradictory effects of adolescence on the frequency of challenging behaviours was also noted by Gray (2002). Findings from Seltzer et al. (2011) suggest that a high level of challenging behaviours continue during adolescence and adulthood for individuals with ASCs. Parents in the current study also noted the less visible challenges of ASCs such as rigidity of thought and different social communication styles.

The demands of parenting a child with an ASC impacted on parents' wellbeing, social life, recreation and employment. Aspects of wider family life were influenced such as family activities and holidays as well as finances. Furthermore, the young person's ASC was described as having consequences for siblings. Balancing the needs of their children appeared to be a significant source of stress and guilt for parents. The day-to-day challenges for parents and the impact of ASCs on family life were also discussed by parents in DePape & Lindsay (2015). The wide-ranging impact of ASCs lends support to the argument of Cridland et al. (2014c) that research into ASCs should utilise family systems approaches. Studies suggest that parents of children with ASCs experience higher rates of stress and mental health problems than other parents (Bromley et al., 2004; Sanders & Morgan, 1997). There is some suggestion that increased parental stress may be associated with increased ASC symptoms (Bromley et al., 2004; Davis and Carter, 2008). However, findings are mixed (McStay et al., 2013) and it is possible that the complex interaction of multiple stressors such as guilt about siblings and social isolation may help to explain these disparate findings. It would appear that the challenges of ASCs for parents interact with wider systemic and contextual factors and that these factors are crucial in understanding parents' experiences. Much of the existing quantitative research would therefore appear to present a simplistic understanding of aspects of parental experiences such as stress and quality of life in isolation. Instead the need for researchers and services to consider ASCs in the context of the family system is apparent (Cridland et al., 2014c).

A further aspect of parents' experiences which emerged in the current review and similarly in DePape & Lindsay (2015) was the appreciation of their child's strengths and the positive aspects of parenting a child with an ASC. This is consistent with Cridland et al. (2014c) who suggest that the concept of traumatic growth is useful in understanding the experiences of parents and families living with ASCs. They suggest that families may experience both distress and personal growth from their experiences of living with ASCs. Similarly, there is growing evidence of traumatic growth in literature about parents' experiences of having a child with an ASC (Altiere & Von Kluge, 2009; Bayat, 2007) and having a child with a chronic illness (Hungerbuehler et al., 2011).

### *Coping with ASCs*

Parents described a wide range of strategies that they had developed to manage the challenges of their child's ASC. These included accepting the ASC and their child and adjusting their expectations. Interestingly, Weiss et al., (2012) suggested that parents' psychological acceptance might be an important factor in reducing the risk of mental health problems related to the chronic and demanding parenting challenges associated with ASCs. In the current review, parents described practical and pro-active strategies to manage their child's behaviours and the environment around them. In addition, they described using a range of strategies to cope with the emotional impact of their experiences such as using social supports, taking time out and engaging in activities and employment. Parents' use of both practical and emotional coping strategies is echoed in existing literature (Gray, 2003). It appears that mothers and fathers may differ in the coping strategies they utilise (Gray, 2003). However, the studies included in this synthesis did not discuss this and the preponderance of female participants across the four studies could limit their findings in relation to fathers.

Formal support from services was another source of support for parents in the studies and, again, this is recognised within other literature (Gray, 1994). Gray (2012) noted that families received less support as their child got older and suggested this might relate to shortages in services for adolescents and adults with ASCs rather than necessarily a reduction in need. Similar to the current synthesis, parents' mixed experiences of services and their sense of having to advocate for services was discussed in DePape & Lindsay (2015). Parents highlighted the importance of finding a suitable school placement and some discussed the impact that school had on their child, and therefore on them. This is, perhaps, unsurprising given the challenges and stress associated with school for many adolescents with ASCs and parents' suggestion that this stress is often expressed at home (Carrington & Graham, 2001; Mount & Dillon, 2014). In the current synthesis parents also described concerns about teachers' knowledge of ASCs, often as a result of previous adverse experiences with the school system.

## *The Parental Role and Navigating Adolescence*

The final theme appeared most distinctive to those identified in the DePape & Lindsay synthesis (2015) and this reflects parents' experiences specific to the stage of adolescence. Parents described an intense and 'hands on' role in their adolescent child's day-to-day life and some reflected on how this might differ to the roles of other parents during adolescence. Some parents spoke of their realisation that they might continue to be involved in their child's life in this way. It is possible that the support parents provided to their children in childhood may have been more comparable with other parents. Whereas, unlike other parents, parents of individuals with ASCs may remain actively involved in their child's life through adolescence and it may become more obvious at this point that their role differs from other parents. Van Bourgondien et al. (2014) note that the tendency for parents to become less involved in their child's life as they move into adolescence and adulthood may not occur for parents of children with disabilities. In addition, parents of adolescents and adults with ASCs report that they devote more of their time carrying out caregiving tasks than parents of individuals with no disability (Smith et al., 2009).

Parents described very close relationships with their adolescent child and at times it appeared difficult for them to disentangle their own experiences from those of their child. It is possible that adolescents with ASCs rely on their parents to make sense of their experiences as a result of the difficulties associated with ASCs. O'Brien (2007) discussed the concept of 'identity ambiguity' in relation to parents who, as a result of being preoccupied with their child's diagnosis, struggle to see their own life as independent from their child's experiences. Notably, O'Brien (2007) found that higher levels of identity ambiguity were associated with increased symptoms of stress and depression for mothers. The comparatively intense relationships described in the current review may also have consequences for young people with ASCs as the developmental tasks of adolescence include individuation, developing a sense of self identity and of group identity (Erikson, 1968; Newman & Newman, 1976). Difficulties with these developmental tasks may have negative consequences for individuals' future psychosocial functioning and as such, further research is required to explore this. In addition, it would be helpful to understand whether the intense and involved relationship between young people with ASCs and their parents is a consequence of the developmental demands of adolescence for young people with ASCs or is suggestive of a longer-term pattern. Further research should also consider whether adolescents with ASCs navigate developmental tasks of individuation and the development of group identity and self-identity at a later stage, or by different means, for example, with more scaffolding and support from parents.

Parents also discussed their child's desire for friendships and peer approval and many appeared to consider this from the perspective of their own experiences of adolescence and their expectations of 'typical' adolescence. Parents' awareness and desire for their child's social engagement is important as studies suggest that parental involvement in social and recreational activities is associated with increased participation in these activities for adolescents with ASCs (Orsmond et

al., 2004). Typically during adolescence young people move towards their peer group instinctively however, it may be that young people with ASCs require more support from their parents to facilitate this shift. Parents described concerns about their adolescent child being able to navigate sexual relationships as a result of their ASC, particularly that they might be more vulnerable to being victimised by others. Similar concerns about how to manage issues of sexuality and concerns about their child's vulnerability have been recognised in the literature (Nichols & Blakely-Smith, 2009). Parents discussed hopes and worries about their adolescent child's ability to live independently in the future. Interestingly, participants in DePape & Lindsay (2015), the majority of whom were parents of younger children, described similar concerns about their child's ability to live independently, form relationships and gain employment. The inclusion of parents of adolescents and adults in DePape & Lindsay (2015) mean that it is difficult to ascertain if parents of individuals with ASCs worry about the future regardless of their child's age or whether this is a unique feature of their experiences during adolescence or adulthood.

***ii) Quality of existing qualitative research exploring parents' experiences of parenting an adolescent with an ASC.***

The studies included in the present study were of 'average' quality with one categorised as 'good'. The four studies scored highly on providing a clear rationale for their research question and explanation of their research processes. Consideration of researcher reflexivity and the sample and sampling methods were less well developed in the included papers and both are crucial areas for development in future qualitative research. Importantly, in many instances, low scores could be due to missing information. Therefore, rather than reflecting methodological weaknesses of the studies, low scores might reflect the quality of the write up and the limited wordage associated with peer reviewed journals. The limited use of verbatim quotations by Fong et al. (1993) and the decision by Mount & Dillon (2014) not to discuss one of their seven themes made the synthesis of themes more challenging. The limitations of wordage have been discussed by qualitative researchers (Walsh & Downe, 2004) and editors of peer-reviewed journals might consider this to gain the maximum benefit from future qualitative research. The paucity of demographic information in many studies identified in the systematic search suggests that this is another area for development in future qualitative research.

**Researcher Reflexivity**

This review relies on an interpretation and synthesis of themes by a researcher and it is therefore important to acknowledge the possible influence of the researcher on the resulting themes. The researcher is a trainee clinical psychologist who is familiar with psychological models of behaviour, emotions and distress and has provided psychological therapy for young people with ASCs and their families. The researcher also conducted qualitative research into the experiences of young people with ASCs and their parents concurrently with performing this review. A

number of factors influence the interpretations individuals make (Sandelowski & Barroso, 2002) and, as with all qualitative research, it is possible that others might identify different themes to those discussed in this review. However, the concurrence of themes across the present study and DePape & Lindsay (2015) suggests that the present interpretations are relatively robust. Jones (2004) suggested that having a team of researchers conducting a meta-synthesis could allow for additional insights in the interpretations, however, this was out with the scope of the current study. As discussed, the quality ratings given to papers were verified by an independent rater.

## **Limitations**

Although there were some areas of weakness in terms of the quality of included studies these were of acceptable quality overall, particularly given the limited literature on this subject area. This is especially true when taking into account the uncertainty about the methods of quality assessment of qualitative literature and the extent to which ratings accurately represent the quality of the study per se. Evans (2002) noted that the systematic identification of qualitative literature through searches is challenging as many papers do not specify that they employed qualitative methods in the title or abstract, the keywords assigned to the paper may be inaccurate and the methods of indexing differs between databases. To ensure that high quality papers were identified, only those published in peer reviewed journals were included in the present review. This may have excluded relevant findings published in book chapters or theses (Walsh & Downe, 2004) however, as these have often not been subject to peer review it is difficult to determine the quality of the research.

As only four papers were identified as meeting the inclusion criteria this resulted in limited data to be synthesised. Arguably this could reduce the robustness of the findings and certainly the results should be interpreted with some caution. However, most studies using meta-ethnography are conducted with a small number of papers and this may allow for a more thorough understanding and synthesis of the original concepts. Many studies identified through the systematic search did not specify the age of participants' children or gave only an average age. These papers were excluded as it would not be possible to determine which themes related to adolescence, however, it is possible that some studies may have related to this period in development. Furthermore, only Cridland et al. specified both the age at diagnosis and the time since diagnosis for each participant. Yet, both of these factors could potentially influence parents' experiences. Similarly, Atkins et al. (2008) note that qualitative studies often include little contextual information. The focus on studies carried out in Western cultures may limit the applicability of the findings to other cultures. The current findings may also relate to parents of relatively highly functioning adolescents with ASCs which could limit the application to other families. However, this is difficult to determine from the limited information in the studies regarding this. Furthermore, it has been noted that research into ASCs tends to be predominated by mothers. Although fathers were included in all but one of the synthesised papers, they made up only one third of the overall



participants. Although the findings of the synthesis have been discussed in terms of parents' experiences, further research is required to determine to what extent the existing literature predominately exploring mothers' experiences does in fact represent the experiences of fathers.

## CONCLUSION & IMPLICATIONS

The current review identified five key themes relating to parents' experiences of parenting an adolescent with an ASC. These included parents' experiences of seeking and receiving a diagnosis, the challenges associated with ASCs and the impact of this on the family along with parents' methods of coping. These themes appeared broadly similar to the existing literature about parenting a younger child with an ASC. The final theme described parents' role in adolescence and the unique challenges associated with this developmental stage. The current findings have important implications for professionals and services working with families living with ASCs.

The long-term impact of parents' experiences of seeking and receiving their child's diagnosis highlights the need for services to improve both practical and emotional aspects of this process. This might include better recognition of more subtle presentations of ASCs, quicker access to assessment and consideration of parents' concerns in a non-judgemental manner. Professionals should also be aware of the often complex range of emotions parents experience following an ASC diagnosis and the need for families' to receive support to access appropriate services. Parents described a range of challenges associated with raising an adolescent with an ASC and discussed these within a wider context of their family and other systems. In relation to adolescence, parents described concerns about their child's difficulties with social relationships, potential sexual relationships and their ability to live independently in the future. Many parents described having a "hands on" role and an intense emotional relationship with their adolescent child. It is unclear how this may impact on the developmental tasks associated with adolescence and the transition to adulthood. This requires careful consideration in further research and in clinical practice to facilitate positive family transitions. As suggested by Cridland et al. (2014c) it would appear that family systems theory and concepts may be helpful in understanding the experiences of families living with ASCs.

In summary, it is important that services do not underestimate parents' abilities to cope effectively and to take positives from their experiences. As such they should aim to support parents to strengthen their own abilities in addition to offering assistance with the more challenging aspects of parenting. Services should be aware that parents and families living with ASCs may benefit from support at various stages. It is crucial that any support offered is sensitive to the family's wider systemic context as well as the particular developmental demands and tasks associated with the individuals' developmental stage.

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## CHAPTER TWO: MAJOR RESEARCH PROJECT

*“I don’t know what’s the Asperger’s and what’s me” –*  
**An IPA Exploration of Young People and Mothers’ Experiences  
of Receiving and Living with an Autism Spectrum Condition  
Diagnosis during Adolescence**

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## PLAIN ENGLISH SUMMARY

**Background:** Autism spectrum conditions (ASCs) are associated with difficulties in social communication, social interaction and social imagination. Research suggests that having an assessment and receiving an ASC diagnosis are important and often stressful events for an individual and their family. This study explored what it is like for young people and their mothers to have an assessment, receive and live with an ASC diagnosis during adolescence.

**Methods:** Four young people (14-16 years old) with an ASC and their mothers were interviewed. The interviews were audio recorded then transcribed and analysed using interpretative phenomenological analysis (IPA). IPA allows the researcher to draw out important themes from the interviews.

**Results:** Four main themes emerged from the interviews:

*Theme 1:* Participants described the experiences or 'journey' that led to the ASC diagnosis. Young people found the assessment a difficult or confusing experience. Many factors influenced how individuals reacted to and accepted the diagnosis e.g. whether or not they thought that the young person might have an ASC, the experiences they had before assessment and their beliefs about ASCs.

*Theme 2:* Following the diagnosis participants tried to understand ASCs and what the diagnosis meant for them or for their adolescent child. Over time, all participants accepted the diagnosis. For some this happened quickly and relatively easily, whereas for others this was a more difficult and lengthy process. Young people and mothers described accepting the ASC as part of themselves or their adolescent child while also trying to separate the young person from the ASC. The young people were still trying to understand who they were and working out how their ASC fitted into this.

*Theme 3:* Participants discussed positive aspects of having the ASC diagnosis. They said that the diagnosis gave them a new way to understand themselves or their adolescent child and their difficulties as well as access to support and services. Participants talked about negative aspects of the ASC diagnosis and for most people this related to negative beliefs that society holds about ASCs.

*Theme 4:* Participants spoke about day-to-day life with an ASC during adolescence. Mothers were very involved in the young people's lives and gave support to assist with their development. Young people wanted to 'fit in' with their peers and spoke about their difficulties related to this. Young people and mothers spoke about the positive aspects of ASCs and their hopes and worries for the future.

**Conclusion:** Participants described a range of experiences related to assessment, receiving and living with a diagnosis of an ASC and what it was like to live with the condition during adolescence. Young people and their mothers had different experiences of some or all parts of the process. It is hoped that these findings can inform developments in services that work with families living with ASCs.

## ABSTRACT

**Background:** Autism spectrum conditions (ASCs) are characterised by difficulties in social communication and social interaction. The experience of receiving a diagnosis of an ASC and the process of accepting this are recognised as potentially stressful events for individuals and their families. Individuals' experiences of assessment and receiving an ASC diagnosis during adolescence have not been explored in the literature. This is important as adolescence may be a particularly challenging time for individuals with ASCs and the diagnosis of an ASC could make the developmental tasks associated with adolescence more difficult. Furthermore, young peoples' experiences of the diagnostic process have yet to be explored alongside the experiences of their parents, however, parents may be able to support young people to develop a coherent narrative about stressful events.

**Aims:** To explore the lived experiences of young people with ASCs and their parents/carers of the process of assessment, receiving and living with a diagnosis of an ASC during adolescence. To consider the similarities and differences in young people and their parents' experiences.

**Methods:** Four dyads of young people (14-16 years) who had received a diagnosis of an ASC 6 months - 4 years previously, and their mothers, were recruited. Semi-structured interviews were used to explore their experiences. Interpretative phenomenological analysis (IPA) was used to identify emerging themes.

**Results:** Four super-ordinate themes emerged that related to the research question. The first three themes depicted a chronological process comprising of: 1. The Journey to Diagnosis, 2. Accepting and Incorporating ASCs into our Understanding and 3. Living with a Label. The final theme: 4: Living with an ASC in Adolescence depicted young peoples' and mothers' experiences of day-to-day life with an ASC in adolescence.

**Conclusion:** This study provides an insight into the experiences of young people and their parents of assessment, receiving and living with a diagnosis of an ASC during adolescence. Participants had varied experiences and a number of factors appeared to influence their reactions to and acceptance of the diagnosis. Notably, young people described difficult experiences of assessment. Young people and their mothers' experiences differed across some or all stages of the process. Participants also discussed what it was like to live with an ASC during adolescence. The experiences of young people and mothers were broadly similar to the existing literature, however, some aspects may be specific or particularly relevant to the stage of adolescence. The findings have implications for services that carry out assessments for ASCs and work with families living with ASCs and highlight areas where further research is required.

## INTRODUCTION

Autism spectrum conditions are pervasive developmental conditions characterised by difficulties in social communication and social interaction along with restricted, stereotyped and repetitive patterns of behaviour, interests and activities (ICD 10, WHO, 1992, 1996; DSM-5, APA 2013). The most recent version of the Diagnostic and Statistical Manual (DSM-5, APA 2013) replaced a range of diagnostic terms (e.g. Asperger's syndrome and childhood autism) with the broad diagnosis of 'autism spectrum disorder'. The term 'autism spectrum conditions' (ASCs) is used in the current study in reference to these changes in diagnostic criteria and the growing literature that emphasises the importance of viewing the characteristics of ASCs as 'difference' rather than 'disorder' (Baron-Cohen, 2000).

Receiving an ASC diagnosis can be challenging for young people and their parents as it implies a pattern of development that will impact throughout their lives (Abbott et al., 2013). Consequently, Siegel (1997) conceptualises an ASC diagnosis as both an acute and long-term stressor. The diagnostic process itself can be time consuming, stressful and frustrating for parents (Howlin and Moore, 1997). Crane et al. (2015) found that the majority of parents of individuals with ASCs were dissatisfied with the diagnostic process overall and 84% described it as 'very' or 'quite' stressful. Conversely, Hackett et al. (2009) report higher levels of parent satisfaction. Jones et al. (2014) found that individuals with ASCs aged 18-76 years old had heterogeneous experiences of the diagnostic process and expressed varied levels of satisfaction with the process.

Although such quantitative studies provide a helpful overview of parents' and individuals' experiences of the diagnostic process, there is a need for deeper understanding of individuals' lived experiences and the potentially complex emotional processes involved in receiving an ASC diagnosis. Qualitative methods are well placed to offer such insights yet the growing qualitative literature relating to ASCs is limited in a number of ways. Firstly, the majority of research involves parents, most commonly mothers and few studies involve individuals with ASCs (Cridland et al., 2014c). Many existing studies relate to individuals across a wide age range and those who have received the diagnosis at various stages in their lives. There is a need to understand the experiences of individuals and their families at particular developmental stages (Cridland et al., 2014c) as the developmental tasks (Erikson, 1968; Newman & Newman, 1976) and parental roles (Marcus et al., 2005) associated with these stages differ. One developmental stage that requires further consideration is adolescence (Cridland et al., 2014c).

### *Adolescence and ASCs*

Despite increasing numbers of adolescents and adults living with ASC diagnoses over the last few decades, there has not been a corresponding increase in research specific to this stage (Volkmar et al. 2014). Adolescence can be a challenging time for individuals generally (Siegel, 2013) and their parents (Buchanan et al., 1990) and young people with ASCs may face additional challenges compared to their

peers (Cridland et al., 2014a). Parents of young adults with ASCs describe the transition from childhood to adolescence as a highly stressful period for themselves and their family (Portway and Johnson, 2003). Erikson (1968) suggested that the main developmental task of adolescence involves developing a sense of self-identity. Newman and Newman (1976) conceptualise adolescence in two stages whereby the task of early adolescence (12-18 years) is to develop a sense of group identity and the development of self-identity relates to late adolescence (19-22 years). The impact of receiving a diagnosis of an ASC in adolescence for individuals and their families is largely unknown. Yet both receiving an ASC diagnosis and the stage of adolescence itself have been conceptualised as family transitions (Cridland et al., 2014c), which are recognised as times of vulnerability for family functioning (Phelps et al., 2009).

### *Diagnostic Experiences of Parents of Adolescents with ASCs*

The diagnostic process has been highlighted as an important part of parents' experiences in many qualitative studies. Consequently, a thematic synthesis of 31 studies of parents' of individuals with ASCs (primarily those under 18 years old) identified themes of 'pre-diagnosis' and 'diagnosis' (DePape & Lindsay, 2015). The diagnostic process also appears to be a significant aspect in the experiences of parents of adolescents with ASCs (Cridland et al., 2014b; Fong et al., 1993; Mount & Dillon, 2014; Robinson et al., 2014). Many parents of adolescents describe this as a lengthy and challenging process (Cridland et al., 2014b; Robinson et al., 2014) whereby they had recognised differences in the young person's development early in their lives. Yet, their concerns were often dismissed by professionals requiring them to persevere and actively seek out a diagnosis (Cridland et al., 2014b; Fong et al., 1993; Mount & Dillon, 2014; Robinson et al., 2014). Parents of individuals with ASCs (DePape & Lindsay, 2015) and of adolescents specifically (Fong et al., 1993; Mount & Dillon, 2014; Robinson et al., 2014), describe a wide range of emotional reactions to the diagnosis. Many describe a process akin to grief that ended in a sense of acceptance for the majority of parents (Fong et al., 1993; Robinson et al., 2014). Siegel (1997) suggested that parents experience stages of 'outcry', 'denial', 'intrusion' and 'working through' before they achieve a state of 'stasis'. 'Stasis' involves accepting the ASC as part of their child and the potential impact of this for the child's future. Siegel suggests that during 'stasis' some sadness may remain, however, parents who are unable to work through the process may experience intensified emotional reactions. Notably, the extent to which parents have accepted or adjusted to their child's diagnosis can influence their style of interaction with their child, at least in early childhood, (Wachtel and Carter, 2008). Parents of adolescents describe difficulties receiving support following diagnosis (Cridland et al., 2014b; Mount & Dillon, 2014). It is difficult to determine the extent to which the similarity in the experiences of parents of adolescents and parents generally (e.g. DePape & Lindsay, 2015) is due to the varied ages at which individuals received their diagnosis in the literature e.g., 6-14 years old in Cridland et al. (2014b).

### *Diagnostic Experiences of Individuals with ASCs*

Two studies describe aspects of the diagnostic experiences of individuals with an ASC. Punshon et al. (2009) employed interpretative phenomenological analysis (IPA) to explore the experiences of adults (22-45 years) who had received an ASC diagnosis in adulthood (at age 21-44 years). Huws & Jones (2008) explored 16-21 year olds experiences of being told about their ASC diagnosis. Notably, many of these individuals had been given a diagnosis in childhood but were only informed about this later in their lives. A number of themes and experiences are consistent across these studies. Firstly, participants discussed the negative impact of receiving (Punshon et al., 2009) or being told about their diagnosis later in life (Huws & Jones, 2008). They described how the diagnosis allowed a new understanding of their experiences and difficulties for themselves and others. Participants in both studies described a range of emotional reactions to their diagnosis, however, participants in the study by Huws & Jones (2008) varied in their ability to accept or adjust to this. Participants in both studies discussed the impact of societal views about ASCs. These studies provide a valuable insight, however, further exploration of individuals' experiences of receiving an ASC diagnosis is required (Huws & Jones, 2008). Given the developmental tasks of adolescence and the potential for an ASC diagnosis to promote a new understanding of oneself (Huws & Jones, 2008; Punshon et al., 2009) and to imply 'difference' from others, an understanding of individuals' experiences of receiving an ASC diagnosis during adolescence is particularly important.

### *Young People and Parents' Diagnostic Experiences*

To our knowledge, there is no literature that specifically explores adolescents' experiences of assessment, receiving and living with an ASC. Furthermore, there are no studies that consider adolescents' experiences of each aspect of this process specifically, alongside those of their parents. Only three explorations of young people with ASCs and their parents' experiences include aspects of the diagnostic process. Cridland et al. (2014b) explored the general lived experiences of mothers and adolescent daughters with ASCs. They identified a theme of 'diagnostic issues', however, this was discussed in relation to the mothers' experiences and it is unclear whether the young people described similar experiences. Calzada et al. (2012) specifically explored the utility of 'high functioning autism' and 'Asperger's disorder' diagnoses for young people (9-16 years) and their parents. Participants discussed the benefits of having a diagnosis as it provided greater understanding, practical support and empowering parents as well as negative consequences such as stigma from society and concerns over validity of the diagnostic terms. Molloy and Vasil (2004) used a narrative research approach with young people (12-18 years) with ASCs and their parents. They discussed six themes relating to their general experiences. These include 'diagnosis as a sense making narrative' in which families described the diagnosis as providing an explanation for the young person's experiences along with their varied emotional reactions to the diagnosis. In 'labelling and identity' young people discussed the extent to which they identified with their ASC diagnosis and defined

themselves in relation to this. They also discussed whether they conceptualised ASC as a 'disability' and the impact of other peoples' assumptions about ASCs. Notably, Molloy and Vasil's (2004) work is not peer-reviewed and they did not specify their recruitment methods. In addition, their participants had diverse cultural backgrounds, which the authors noted appeared to influence their experiences. A further limitation of all three explorations is that they include young people who received their diagnosis at varying developmental stages e.g., between 4 and 15 years in Calzada et al. (2012) and at varied times e.g., between 1 and 11 years prior to interviews in Molloy and Vasil (2004). In some cases, young people were informed of their diagnosis years after it had been disclosed to their parents.

The limitations in the current research relating to adolescents with ASCs and their parents is notable as taking part in an assessment and receiving a diagnosis of an ASC could potentially constitute a stressful or emotional experience for individuals' and their families (Crane et al., 2015; DePape & Lindsay, 2015; Huws & Jones, 2008; Punshon et al., 2009). The ability to make sense of and form a narrative about stressful events is related to psychological well-being in adults and children (Baerger and McAdams, 1999; Fivush et al., 2004) and research suggests that parents may be able to support children to develop a coherent narrative before they are able to do so themselves (Fivush and Sales, 2003). Furthermore, the way in which families form narratives of emotional events has been linked with self-esteem, self-efficacy and social competence in young adolescents (Bohanek et al., 2006; Marin et al., 2008). Whitaker (2006) notes that parents must cope with their own reactions to a child's ASC diagnosis in addition to helping their child understand themselves and their diagnosis. From the studies of parents' and individuals' experiences discussed previously it would appear that although some experiences might be similar, e.g., varied emotional reactions to diagnosis, other aspects may differ, e.g., the personal meaning of the diagnosis for individuals. Consequently, there is a need to understand young peoples' narratives about the diagnostic process alongside those of their parents.

### *Aims of the Current Study*

Overall, the few qualitative studies that include the experiences of individuals with ASCs and their parents of receiving or living with this diagnosis have a number of limitations. Most relate to their experiences of ASCs generally or a specific aspect of the diagnostic process e.g. the diagnostic feedback session (Abbott et al., 2012). This does not allow for thorough consideration of the full process or the potential impact of these experiences. As discussed, studies tend not to separate out findings by developmental stage or the time since diagnosis. No peer-reviewed studies have explored the impact of receiving an ASC diagnosis during adolescence when the development of group and self-identity are fundamental. A greater understanding of individuals' experiences alongside those of their parents is indicated given parents' role in supporting the development of a coherent narrative of stressful events (Fivush and Sales, 2003). To address these limitations, the present study aimed to explore the lived experiences of assessment, receiving and living with a diagnosis of an ASC in a specific subset of young people and

parents/carers. The study focused on the experience of receiving an ASC diagnosis during adolescence or 'early adolescence'; between 12 and 18 years (Newman & Newman, 1976), for families attending Child and Adolescent Mental Health Services and at a specific point in time; between 6 months and 4 years after diagnosis.

*Research Question:*

How do young people and their parents/carers experience the process of assessment, receiving and living with a diagnosis of an ASC?

*Aims:*

- i) To describe the key features of young people and their parent/carers' experiences of assessment, receiving and living with an ASC diagnosis.
- ii) To explore similarities and differences in young people and their parent/carers' experiences of assessment, receiving and living with an ASC diagnosis.



## METHOD

### *Recruitment*

Prior to recruitment ethical approval for the study was obtained from the West of Scotland Research Ethics Committee and NHS Greater Glasgow and Clyde Research and Development Team (see appendices 2.0 and 2.1). Recruitment took place between November 2014 and March 2015. It was intended that 3 or 4 dyads would participate and that recruitment would conclude at this point. This is consistent with IPA methodology that aims to examine the experiences of a small number of individuals in detail (Smith et al., 2009). Smith et al. (2009) also note that 4-10 interviews are most commonly conducted for professional doctorate research.

There is some debate about the age associated with 'adolescence' and recent literature suggests that the changes in the brain related to adolescence continue beyond teenage years until around 25 years of age (Blum et al., 2012). The age range of 12-18 years was selected as this is suggested to relate to particular developmental tasks (Newman & Newman, 1976). Furthermore, young people under 18 years who participate in an ASC assessment in the UK are likely to receive this from children's services (e.g. CAMHS). As such their parents or carers are likely to be involved in the process of assessment and feedback while this may not always be the case in adult services.

To participate, families had to meet the following criteria:

### *Inclusion*

- i) Young people aged 12-18 who had received a diagnosis of an ASC and their parent/carer (both of whom wished to participate).
- ii) The diagnosis was received at 11+ years old and between 6 months - 4<sup>1</sup> years prior to participation in the study<sup>2</sup>.
- iii) The young person was aware of the purpose of their assessment when it was carried out.
- iv) The young person and parent/carer were able to recall the process of assessment and diagnosis.
- v) The young person and parent/carer were able to communicate their experiences verbally and in English<sup>3</sup>.
- vi) The parent/carer, young person and clinician subjectively believed that the young person was likely to cope with an interview situation.

### *Exclusion*

- i) Any active risk identified by CAMHS clinician, e.g., suicidality.
- ii) If one member of a dyad did not consent to participate.

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<sup>1</sup> Initially a period of 1-4 years was specified however, this was altered due to recruitment difficulties.

<sup>2</sup> With reference to the time elapsed since diagnosis for young people interviewed by Cridland et al. (2014b) and Molloy & Vasil (2004), a time period of 6 months - 4 years previously appeared reasonable.

<sup>3</sup> Due to the financial constraints of the study it was not possible to use translators.

### *Recruitment Procedures*

Clinicians in two NHS CAMHS teams were invited to identify families on their caseload who met the inclusion criteria. A poster was displayed in the waiting rooms of the CAMH services to inform families about the study (appendix 2.2). Clinicians provided families with participant information sheets (appendices 2.3 and 2.4), which requested them to contact the main researcher if they wished to find out more about the study. The researcher discussed the study with interested families by telephone or email. At this point the CAMHS case manager was contacted to clarify whether any 12-15 year old participants had capacity to give informed consent. Consistent with research recommendations, (e.g., Cridland et al., 2015; Harrington et al., 2013), an initial meeting was conducted in recognition that individuals with ASCs can find unfamiliar or social situations anxiety provoking (Attwood, 2006). This meeting aimed to put participants at ease (e.g., by finding out about their interests) and allow discussion about how to support the young person during the interview. CAMHS case managers were informed in writing (see appendix 2.5) that the family intended to participate in the study. Participants were given consent forms and participant information sheets in advance. These were discussed at the initial meeting and again prior to commencing interviews. Written and verbal consent was sought from all parents (along with parental assent where indicated) and from young people aged 16-18 years. For participants aged 12-15 years consent was sought (where capacity to do so was indicated by their CAMHS clinician) along with parental assent. Examples of participant consent forms are included in appendices 2.7 and 2.8.

### *Sample*

Eight participants; four dyads of young people and parents were recruited. Participants were not selected on the basis of sex and the final sample consisted of three adolescent boys and one adolescent girl. This is relatively reflective of the male: female ratio of those diagnosed with ASCs (Baird et al., 2006). Participating young people were aged 14-16 years old (mean: 15.25, sd: 0.96 years) and received their diagnosis between 10 months and 2 years, 9 months prior to participation in the study (mean: 21.8, sd: 9.95 months). All parents who participated were female so in the discussion of results 'parents' are referred to as 'mothers' for clarity. Mothers' ages ranged from 42-49 (mean: 45.75, sd: 2.99 years). Participants' formal diagnoses were not requested due to the move towards the broader conceptualisation of ASCs in DSM-5 as 'autism spectrum disorders' (APA, 2013) and concerns regarding the validity of the various diagnostic terms (Calzada et al., 2012). Sample demographic and contextual information including pseudonyms are detailed in table 2.0 below. For the purpose of clarity relating to their developmental stage, young people are referred to as their parents' 'adolescent child' throughout the current study.

Table 2.0: Demographic Information

<b>Young Person's Pseudonym &amp; Age</b>	<b>Time since Diagnosis</b>	<b>Current Education</b>	<b>Mother's pseudonym &amp; age</b>	<b>Family Structure</b>
Jack, 14	2 years, 2 months	Mainstream school with support from support unit	Marie, 45	1 older brother 1 older sister (1 sibling with ASC diagnosis) Lives with mother
Max, 16	2 years, 9 months	Mainstream school	Beth, 42	1 younger brother Lives with mother
Tom, 15	10 months	Mainstream school with some support	Jo, 47	1 older brother 1 older sister (1 sibling with ASC diagnosis) Lives with mother and father
Sophie, 16	1 year, 6 months	Mainstream school with limited timetable	Charlotte, 49	1 younger sister 2 older step-sisters Lives with mother

### *Procedure*

All interviews were conducted with young people and mothers separately at their request and in their preferred location (CAMHS, the young person's school or a local carers' centre). The duration of interviews ranged from 34 to 77 minutes; on average 69 minutes (sd: 9.9) with mothers and 44 minutes (sd: 7.3) with young people. The researcher was able to develop good rapport with all participants aided by the pre-interview meeting with families. Semi-structured interview schedules were developed (see appendix 2.6) consistent with guidance for IPA studies (Smith et al., 2009). The schedules were informed by existing literature relating to individuals with ASCs and their parents. The schedules were piloted with one dyad of young person and parent. These transcripts were included in the final analysis because there were minimal subsequent alterations to the interview protocols. As described by Smith et al. (2009) interviews were conducted flexibly with the aim of following participants' narratives. Open-ended questions were utilised where possible and spontaneous follow-up questions were used to encourage participants to elaborate on their experiences. Interviews were audio recorded digitally and transcribed verbatim on an encrypted laptop for analysis. To ensure anonymity, participants were given a pseudonym and any references to a specific location or person that might compromise anonymity were removed from the interview transcripts.

Recommendations from good practice guidelines for involving individuals with ASCs in research were considered in the development of the research protocol (Brown, 2011, Harrington et al., 2013). Interviews were conducted with the difficulties associated with ASCs in mind. For example, participants were given sufficient time to process and respond to questions, had the opportunity to use written communication aides (all chose to describe their experiences verbally without other supports) and were provided with “tangle toys” for sensory stimulation (3 of 4 young people used these throughout the interview). As the study was interview based and individuals with ASCs may find unfamiliar and social situations anxiety provoking young people were given a £10 book voucher and certificate to acknowledge their efforts.

### *Data Analysis*

The study employed interpretative phenomenological analysis (IPA; Smith et al., 2009) to explore the experiences of young people with ASCs and their mothers. IPA was considered best placed to offer insight into participants’ experiences as it allows a detailed and flexible examination of individuals’ lived experiences within their wider context (Smith et al., 2009). IPA has been used in previous research with young people with ASCs and parents to good effect (e.g. Cridland et al., 2014b; Huws and Jones, 2008). Interview transcripts were analysed using a six stage IPA process as documented by Smith et al. (2009). Initially this involved immersion in the data by reading and listening to the transcripts multiple times. The researcher commented on the transcripts in increasing depth, including consideration of descriptive, linguistic and conceptual content. Samples of analysed transcripts are included in appendices 2.9 and 3.0. The researcher analysed each transcript individually identifying emergent themes and how these related to one another by developing sub-themes and super-ordinate themes for each participant. A second researcher read and identified emergent themes in the transcripts of two participants (one parent and one young person). These were comparable with those identified by the main researcher and any additional themes were discussed to reach agreement. Emergent themes within the group of mothers and of young people were then considered (an example is included in appendix 3.1). Finally, key themes were identified that incorporated the experiences of the mothers and young people overall. As suggested by Smith et al. (2009) a word document was created to record excerpts from the transcripts related to each emergent theme.

### **Researcher Reflexivity**

The role of the researcher in the process of analysis is explicitly recognised in IPA. Smith et al., (2009) state that, in IPA, the researcher attempts to make sense of the participant who is making sense of their experience. As a trainee clinical psychologist, the researcher is familiar with psychological models and has delivered psychological therapy to young people with ASCs and their families. The researcher also conducted a systematic review of literature related to parents’ experiences of parenting an adolescent with an ASC concurrently with this study. The researcher kept reflective notes throughout the study to help to recognise their

subjective views and emotional reactions to the interview content. This assisted the process of acknowledging and 'bracketing off' beliefs and expectations throughout the process of analysis and identification of themes, as is suggested by Smith et al. (2009). Reflective notes and discussions with research supervisors allowed consideration of the impact of the research on the researcher for example, in relation to the researcher's clinical practice. As recommended by Elliot et al. (1999), a second researcher identified emergent themes in two transcripts to verify the reliability of the analysis.

### **Context of Participants' Experiences**

IPA emphasises the importance of understanding the lived experiences of participants within their own individual context (Smith et al., 2009). The systemic context of participants' experiences was apparent, particularly in relation to the immediate family in addition to families' wider social network and the services that they interacted with. Of note was the impact of the young person's difficulties on the family system and at times, the family system on the young person and this is discussed in more detail in the subtheme 'ASCs and the Family Context'. One participant, Sophie, described a challenging process of accepting her diagnosis and her mother noted that this occurred around the time of a number of significant family life events which could have compounded her reaction. The influential nature of family experiences and narratives and the role of the diagnosis in interactions with services were also particularly apparent and are discussed further in relation to the identified themes.

## RESULTS

Four super-ordinate themes emerged from the analysis. The structure of sub-themes is detailed in table 2.1. The first three themes explored participants' experiences of assessment, receiving and living with an ASC diagnosis as a chronological process. The final theme depicted the realities of day-to-day life for young people with an ASC and their mothers during adolescence.

Quotations from participants have been used to illustrate the themes, and as theme titles, to ground these within participants' lived experiences. The interpretations of selected extracts have been discussed as per the description of IPA by Smith et al. (2009; Smith, 2010), however, due to word restrictions it was not possible to discuss all extracts in detail. Some sub-themes applied differently to participants and divergent experiences are discussed. Where the theme applied differently to mothers and young people separate headings have been noted in italics. Additional information to give context to extracts is given in square brackets and where extracts have been condensed this is shown as three dots within square brackets: [...]. Any non-verbal behaviour such as laughter or pauses is denoted within brackets and the researcher's speech is shown in bold.

Table 2.1: Super-ordinate and Sub-themes

<b>Super-ordinate Theme</b>	<b>Sub-Themes</b>
<i>1. The Journey to Diagnosis – “oh yeah, you’ve got it and kinda get on with your life”</i>	1: Different Starting Points and Paths to Assessment
	2: Being Assessed
	3: Receiving a Diagnosis
<i>2. Making Sense of ASCs - “I used to really hate myself for having it but now I’ve got used to it”</i>	1: Understanding and Accepting the Diagnosis
	2: Incorporating the ASC into an Understanding of Who They Are
<i>3. Living with a Label – “it’s funny isn’t it because it’s just one word”</i>	1: Diagnosis Providing Understanding and Access to Services
	2: The Challenges of Living with a Label - Societal Views of ASCs
<i>4. Living with an ASC in Adolescence – “[I’m] just trying to fit in”</i>	1: Adolescence and the Challenges of the Parental Role
	2: Fitting in – Social and Romantic Relationships
	3: Appreciating the Positives
	4: ASCs and the Family Context
	5: Thinking about the Future - Hopes and Worries

**Super-ordinate Theme 1: The Journey to Diagnosis – “oh yeah, you’ve got it and kinda get on with your life” (Sophie, line 301).**

The first theme encapsulates participants’ broad range of routes and experiences towards receiving a diagnosis of an ASC. This included becoming aware of ASCs, the assessment and receiving the diagnosis.

***Sub-theme 1: Different Starting Points and Paths to Assessment***

*Mothers - Varied Starting Points*

All of the mothers spontaneously described the route by which they and their adolescent child had reached the point of assessment indicating that this was an important aspect of their experiences generally. For all of the mothers this had been a long journey starting with the recognition or a ‘sense’ that the young person’s development differed from others as illustrated in the extract below. With the exception of Beth, all of the mothers had considered that the young person might have an ASC earlier in their development. Both Tom and Sophie had taken part in a previous assessment in primary school.

*“[...] There was always this sense of, always since she was, I would say four or five, **Ok**, a lot of things about the way that she would communicate, her level of, her literalism, her level of distress, sure, it’s always been hard, very hard, **mm**, so my sense of that being a possibility was around from really quite early on” (Charlotte, lines 80-92).*

Charlotte’s use and repetition of the word ‘sense’ has connotations of this being a feeling rather than fact and perhaps the idea of ‘mothers’ intuition’.

For all of the mothers, with the exception of Charlotte who requested the assessment, it was a CAMHS professional or teacher who suggested an assessment. For most of the mothers, the possibility that their adolescent child might have an ASC did not provoke any strong emotion. Conversely, Beth, who had not previously considered ASCs, described the shock she experienced when this was raised with her.

*“his teacher told me her suspicion, like Max may be autistic and when she, (pause) she said autistic, it, it was so alien to me although I knew he was different than his brother” (Beth, line 4).*

The mothers’ had varied experiences of life prior to diagnosis. One mother, Jo did not describe any difficulties prior to the diagnosis. The other three mothers described significant struggles to make sense of their adolescent child’s difficulties and to know how to support them best. As a result of their experiences, many mothers hoped that a diagnosis might give them a clearer direction. As illustrated in the excerpt below Charlotte hoped for something concrete in contrast to the vague ‘sense’ she described in the earlier excerpt.

*“I was hopeful that that would give us something a bit more, kind of concrete to work with [...] to provide us with guidance in terms of how to*

*support her [...] something, **sure**, maybe a bit more concrete to get my teeth into” (Charlotte, lines 174-178).*

### *Young People – A Late Starting Point*

Young people’s experiences differed from the majority of their mothers. Firstly, they had not considered that they might have an ASC until their parents or a professional suggested this. In this sense, the young peoples’ journey to diagnosis started much later and more abruptly than for most of the mothers at the point of being referred for assessment in adolescence. The young people’s reaction to this news varied; Max described this as a distressing experience whereas others described feeling unconcerned by this, as is illustrated in the excerpt below.

*“Sort of just, didn't really feel anything, sorta just thought whatever, it's not a big deal” (Tom, line 31).*

One young person, Jack discussed the impact of not being made aware sooner that he might have an ASC:

*“Since I was really, really young they’ve always been telling my mum. I wasn’t told that people thought I had autism which I thought was pretty, I, I thought that was a terrible thing to do. [...] ‘Cos if I knew, then it would be a lot easier to just, get on with things than if I was like having problems with something or if I didn’t manage to do something rather than blaming my own capabilities I could, not blame autism, but I mean, **sure**, kinda know why” (Jack, lines 121-125)*

Jack’s repetition in the phrase “really really young” highlights how long he felt that this was kept from him. He discusses how influential this knowledge could have been for him in terms of understanding and externalising his difficulties rather than blaming himself.

### **Sub-theme 2: Being Assessed**

#### *Mothers – The Experiences of the Young Person*

Mothers in the current study described limited involvement in the assessment process and instead they focussed on how they perceived their adolescent child had experienced this. Many mothers commented on their adolescent child’s anxiety during the assessment as illustrated below.

*“the problem that I did have was I knew that Jack was anxious, **mm hm**, and he, he obviously didn't know what was going to happen” (Marie, lines 106-108).*



## *Young People – Being Observed*

In contrast, most young people spoke of quite powerful experiences of their assessment. Many of the young people described attending the assessment due to a sense of obligation however, some described feelings of anxiety or curiosity. The assessment appeared to be a confusing process for all of the young people and some found it challenging to recall their experiences of this in detail. Sophie found the experience particularly confusing as she recalls only being fully aware of the purpose of the assessment during the appointment as described in the excerpt below. Despite this Sophie's description of her assessment overall was not especially negative.

*“(pause) I dunno, just (pause) I knew, I knew it was Asperger’s then like when I was in the room, **Ok**, and they were doing all that, nn, yeah, **and so did they explain to you that that’s why they were meeting with you? Yeah, yeah, ok, and what did you think at that point? Can’t really remember (laughs), Can’t remember? That’s alright. What did you feel like? just confused I guess (laughs)”*** (Sophie, lines 55-63).

Sophie's difficulty recalling the assessment perhaps conveys the confusion and mixed emotions she experienced during it and her laughter perhaps suggests that this is still a difficult memory for her to make sense of or think about.

Many of the young people described feeling unsure of the methods of assessment and there was a sense of mystery as to how the assessment tasks were used to reach a diagnosis. Some young people appeared to experience the assessment as a “test” and one young person described wishing he could have studied for it. Two of the young people described feeling patronised by the assessment tools or approach. There was also a sense from the young peoples' narratives that assessment was something done *to* them rather than a process that they felt part of.

*“[would have preferred] to be asked literal questions rather than, mm, (pause) being gave (pause) items and see what I done with them like I don’t, like some subject or something in a lab, I don’t know”* (Jack, line 44).

Jack's feeling of being observed and studied is emphasised by his use of simile 'like some subject or something in a lab'. He first compares himself to a 'subject' which allows us to sense his feeling of being powerless. Jack then suggests he felt like *something* suggesting he felt dehumanised, like an interesting specimen to be studied.

### ***Sub-theme 3: Receiving a diagnosis***

Overall, most participants were happy with the manner in which professionals delivered feedback about the diagnosis. All participants had very diverse reactions to hearing the diagnosis. Some mothers described positive emotional reactions such as relief however, Beth, who was aware of the possibility of an ASC much later than the other mothers, described strong feelings of shock and guilt.

*“(long pause) I think, I think it was a bit of a shock although I had a feeling he might be autistic [...] I may have felt at that time a wee bit maybe guilty, if I knew (pause), mm, he’s autistic maybe, if I had this help maybe I would have handled him better, it wouldn’t be so stressful, it wouldn’t be so hard” (Beth, line 144).*

Beth’s son Max and another young person, Sophie also described a strong negative emotional reaction to their diagnosis. Max’s reaction appeared to relate to the meaning he took from the diagnosis; that it implied he would never be ‘normal’ and others might bully him because of it. In contrast, Jo and Tom (a mother and young person dyad) and Jack described no emotional reaction to the diagnosis as described in the excerpts below. For Jack this related to his belief that the diagnosis would make little difference as he had always ‘had’ an ASC. For Jo and Tom this appeared to relate to a strong positive family attitude about ASCs.

*“Well he’s Tom beforehand and he’s Tom afterwards, that doesn’t change a thing about him” (Jo, line 180).*

*“I just thought ok, I’m autistic so that’s that. **Ok**, I didn’t really think about it again” (Tom, line 139).*

Jo noted that she and her husband had found it more challenging initially when their elder son was diagnosed with an ASC 16 years earlier. It is possible that when this was raised in relation to Tom they had already developed a family narrative about the meaning of an ASC diagnosis and an acceptance of this.

For some participants there was a sense of being abandoned by services following the diagnosis and an expectation that they would have received more information and support.

*“basically when he got diagnosed you were given a diagnosis and as far as I was concerned, that was it, “see you later” [...] You were given some leaflets, **mm** and (pause) I didn’t feel that was good enough, **mm**, because this has such a big impact on, **sure**, on not just Jack’s life but the full family round about hims’ life” (Marie, lines 469-475).*

*“I was kinda left in the lurch a wee bit (laughs) [...] it was kinda like “oh yeah, you’ve got it and kinda get on with your life kinda thing” rather than, **right**, “this is what it is and that kinda thing” (Sophie, lines 297-303).*

Both Marie and Sophie give the impression that they experienced services as somewhat heartless and unsupportive. Sophie felt she was expected to simply “get on with” her life implying a potentially unrealistic expectation which minimised the impact the diagnosis had for her.

**Super-ordinate Theme 2: Making Sense of ASCs - “I used to really hate myself for having it but now I’ve got used to it” (Max, line 46).**

This theme illustrates participants’ experiences of understanding and accepting the diagnosis and incorporating this into their understanding of themselves or their adolescent child. The two sub-themes describe aspects of a process following diagnosis however, these are closely interrelated, perhaps occurring simultaneously and as such, they are discussed in this manner.

***Sub-theme 1: Understanding and Accepting the Diagnosis***

Participants described varied experiences following diagnosis. Four participants described the diagnosis as having little impact and felt that life continued on as it had before. Most mothers gained information about ASCs, attended courses and started to seek out services or support. Conversely, young people gained information about ASCs in a more ad-hoc manner through family members, teachers and the media. In coming to terms with the diagnosis, young people and mothers tried to make sense of what ASCs were. Some young people struggled to conceptualise this as illustrated below:

*“It’s not really an illness and it’s not really a disability but it’s kind of just there (laughs) [...] it’s a (pause), mental thing, I don’t know, it’s something that changes the way that you do things. You won’t react normally to certain things than normal people would”. (Jack, lines 177-179).*

Some young people and mothers described their attempts to gauge the young person’s difficulties and abilities on the autism ‘spectrum’. Here Jo describes that a ‘benchmark’ as part of the diagnosis would have been helpful.

*“... maybe getting a benchmark woulda helped out, woulda helped, not necessarily change the perception of Tom but for my own mind-set “right am I getting this, am I ok with this so that I’m doing the best”, sure, Am I underestimating? Because that would be a concern for me [...] or giving them a less level of support than I should be” (Jo, lines 442-448).*

Conversely, Sophie and Charlotte were told that Sophie had “mild” Asperger’s syndrome yet this appeared to undermine the extent to which she struggled at times and led to confusion and doubt about whether or where to seek support.

All participants described reaching a point of acceptance in relation to the diagnosis. Three mothers and two young people described accepting the diagnosis quickly and without difficulty. Two of these mothers had described relief at the point of diagnosis. One mother and the two young people described a personal or family narrative that the diagnosis did not change anything. Conversely, Beth, Max (a mother and young person dyad) and Sophie experienced a challenging and distressing time following the diagnosis. They described acceptance as a longer process. They also described more intense emotional reactions at the time of receiving the diagnosis. Notably, of all participants Beth and Sophie had been

aware of the possibility for shortest length of time. Max's feelings of hatred and shame about his diagnosis come across clearly in the extract below. Although he describes getting used to it, he shares that he still does not tend to talk about his diagnosis suggesting that, to some extent, he is still accepting his diagnosis.

*"That's why I just, I don't know, I don't talk about it [...] I used to really hate myself for having it but now I've got used to it" (Max, lines 46-48).*

Both Max and his Mum, Beth, described a process of acceptance that occurred with the help of time and, in Beth's case, meeting other parents living with ASCs.

*"For me it's been time (pause), I've tried, I've searched online, I read a lot but it didn't mean, you know, I still had a mixture of feelings, **mm**, I think time, just time, when you are ready [...] and I think what, what helped me was to be around people [...] you know just talking to people who've been through the same" (Beth, lines 328-334).*

Here Beth emphasises the importance of time above her many other attempts to make sense of Max's diagnosis. We also see the value she found in spending time with other parents living with ASCs. Beth also discussed the particular challenges of accepting Max's diagnosis in adolescence due to the number of other changes and transitions at that time.

Sophie spoke about how her diagnosis initially felt all-encompassing as illustrated below. She discussed the particular benefit of professional input to understand which aspects of ASCs related more or less to her individually.

*"Maybe for the first six months it was completely, but now it's ok, **sure and what happened in that first six months, what did you feel about it then?** I dunno, just that, eh, it kinda overtook my life and (pause) that I was getting a label and that kinda thing" (Sophie, lines 411-413).*

## ***Sub-theme 2: Incorporating the ASC into an Understanding of Who They Are***

### *Mothers – A Holistic Understanding*

Part of the experience of accepting the diagnosis involved mothers incorporating this into their understanding of their adolescent child. All of the mothers appeared to have done so however, at the same time they endeavoured to separate the diagnosis from 'who' their adolescent child is.

*"having the diagnosis doesn't change who they are because they are who they are, **mm hm**, and they'll never be any different from who they are" (Marie, lines 574-576).*

Charlotte spoke about her difficulty raising the possibility that Sophie may have an ASC with her daughter due to the unique nature of the difficulties associated with ASCs:

*"it's kind of existential about who she is, **yeah**, so how do you explain that to someone?, **yeah**, who has enough awareness to (pause) without it*

*sounding really (pause) you know, well this is about who you are.”*  
(Charlotte, lines 316-320)

For mothers, understanding the diagnosis involved developing a holistic understanding of the individual which included the young person’s mental health difficulties and sensory sensitivities.

#### *Young People – Diagnosis and the Developing Sense of Self*

All of the young people struggled to describe ‘who’ they were and varied in how they understood ASCs in relation to their sense of self. For many young people the way in which they discussed this appeared contradictory at points throughout the interview perhaps suggesting that this was still an evolving process. Receiving a diagnosis had a particularly significant impact on Sophie’s developing sense of self which she describes below:

*“It’s probably harder because you’re, I was already in stuff like, I was half way through high school and eh that and I’d got used to life and (pause) then it all kind of changed with that kinda half way through it and (pause) that’s where things I think started to go downhill for me after getting that [...] I was just kind of accepting who I was and that and then it came”* (Sophie, lines 513-519).

Max and Sophie described feeling unsure about what was ‘them’ and what related to their ASC. For Sophie, this struggle was compounded with a sense that other people overlooked ‘her’ because of her diagnosis. Max and Tom described that their diagnosis did not fundamentally change who ‘they’ were, suggesting a broader sense of self out with their diagnosis.

*“cos there’s stuff like, there’s autistic traits within me but there’s also stuff that’s just Tom”* (Tom, line 377).

For Max and Jack there was a suggestion that they were more able to be their true ‘self’ at home. However, for Max, his attempts to present himself in a certain way in public left him unsure about who his ‘real’ self was, as illustrated below:

*“who do you think your ‘real’ self is? That’s a question I ask myself, (laughs), I really don’t know (pause) myself (laughs), hmm, I don’t know, hmm, I’ll have to think about it”* (Max, lines 356-363).

Part of the process of making sense of the diagnosis as a part of their adolescent child or themselves involved using the diagnosis as a new framework for understanding their experiences. This is described in more detail in the following super-ordinate theme.

### **Super-ordinate Theme 3: Living with a Label – “it’s funny isn’t it because it’s just one word” (Charlotte, line 338)**

This theme encapsulated the positive and negative consequences of having an ASC diagnosis.

#### **Sub-theme 1: Diagnosis Providing Understanding and Access to Services**

All participants spoke about positive and negative consequences of having a diagnosis of an ASC. Something that came across very strongly in their narratives was how the diagnosis served as a way of making sense of their past and current experiences for the young people, their families and others. This new framework allowed young people to separate themselves from their difficulties whereas previously Sophie and Jack had internalised their difficulties leading to a negative self-image.

*“[...] it made a lot of sense (laughs) [...] ‘cos, yeah, just because I’d never been able to fit in and I just never knew why I guess, **Ok, ok, aye, and what did you think beforehand, before people mentioned Asperger’s?**, I just thought I was weird (laughs)”* (Sophie, lines 179-185).

Similarly some mothers found that the diagnosis helped to externalise the young person’s difficulties and allow discussion of these. With the exception of Tom, all of the young people felt that they had become more socially able since receiving their diagnosis although they did not know why this might be. Notably, for some, the diagnosis appeared to serve as a short-hand explanation for the young people’s behaviour or difficulties.

*“it just makes it a lot easier now that I’ve been diagnosed I can tell people, like sorry if I am socially awkward or sorry if I say something inappropriate, this, this is the reason for it”* (Jack, line 243).

Having a diagnosis also gave families access to support and services. In particular almost all participants spoke about the benefits of diagnosis in terms of support and their experiences of school. Some mothers described benefits of attending parent support groups or CAMH services and in the extract below Beth recalls attending a carers’ centre.

*“I felt like (pause), I’ve got a place where people will help me, you know, **hmm**, they will look after me. They will make sure I, I’ve got places to go to, to learn about autism and other stuff. It’s just, just (pause), I felt at that time, I’m not alone any longer”* (Beth, lines 114-116).

Within this extract we get a sense of the powerful emotional experience that Beth had attending the Carers’ centre. The phrases “people will help me” and “they will make sure” gives us a sense of the centre as having a nurturing, almost parental role, for her.

Two mothers discussed how the diagnosis of an ASC had been helpful in adjusting their expectations and guiding their adolescent child towards future activities that might suit them.

*“it has helped me manage expectations of what she may be able to do. [...] it also helps actually for her going into adulthood is it helps her to kind of tailor those expectations a bit more, **sure**, so that she doesn’t open herself to endless disappointment which is my fear for her”* (Charlotte, lines 1003-1009).

### **Sub-theme 2: The Challenges of Living with a Label - Societal Views of ASCs**

Although two mothers described no negative consequences of diagnosis, two mothers and all of the young people discussed the impact of societal views about ASCs. This included the perception of ASCs being a “fashionable” label which is used liberally and the impact of society’s negative beliefs and stereotypes of ASCs. Some participants suggested that individuals with ASCs themselves should be involved in educating others about their experiences to increase awareness and challenge societal perceptions. In the extract below Tom describes the extreme stereotypes of ASCs that he feels other people hold.

*“one stereotype where just like you’re Einstein constantly, **right**, also the other ones where you’re just really like introverted and not talking”* (Tom, lines 413-415).

As a result some young people and parents were careful about who they disclosed the diagnosis to. Almost all young people discussed experiences of being excluded or bullied which they perceived to be a consequence of their diagnosis.

*“I did not want people knowing, I wanted it hidden, **mm**, Yeah I was scared, [...] people would judge me, make fun of me (pause) just laugh in my face, **mm**, which happened, a few times”* (Max, lines 309-315).

As discussed in sub-theme 2, Sophie felt that other people struggled to see beyond her diagnosis and this included the support she received from CAMHS. Jo and Tom offered a divergent perspective as, unlike the other participants, they felt that Tom’s diagnosis had limited impact on their lives

*“now that I understand that it’s the Asperger’s, the pedantry, it’s not him just being a belligerent teenager [...] it’s altered how we now deal with him [...] it has altered slightly.”* (Jo, lines 456-458).

*“it’s a bit helpful but even if I didn’t get it, it still wouldn’t of really have changed that much stuff, **mm**, [...] like I’d still be doing the exact same stuff and getting the exact, similar help”* (Tom, lines 303-305).

#### **Superordinate Theme 4: Living with an ASC in Adolescence – “[I’m] just trying to fit in” (Max, lines 230)**

In addition to their experiences of having the diagnosis of an ASC, participants spoke about what it was like to live with the underlying traits associated with the condition itself during adolescence.

##### ***Subtheme 1: Adolescence and the Challenges of the Parental Role***

Mothers spoke about aspects of their child’s adolescence that they felt were typical for this stage such as more intense emotional reactions. They also spoke about differences between their child and other adolescents for example, their difficulty with the increased need for personal hygiene routines or lack of interest in fashionable clothing. One mother noted that unlike many adolescents who move towards their peers, their adolescent child continued to keep a close bond the family instead. The mothers described offering a high level of support in their adolescent child’s day to day life. For example, maintaining a careful family routine, developing the young person’s skills and helping them to navigate situations.

*“I mean, not every day but every second day there’s normally a conversation that I’m trying to teach him something and he’s, **ok**, he’s not happy with me, **ok**, so he’ll go in and close his door, **ok**, bang about” (Marie, lines 616-622).*

Many of the mothers appeared to facilitate their adolescent child’s development rather than the young person leading this as illustrated in the excerpt below:

*“Tom’s shown no interest in relationships like that [Romantic relationships] yet, he says he’s too young so I’m aware that I’m gonna have to, mm, watch that [...] to make sure that he’s going out and experiencing social situations” (Jo, lines 582-584).*

Jo felt that some of Tom’s ASC traits could make parenting easier in adolescence because he is very rule-bound and therefore would not smoke or drink alcohol despite his peers being interested in these activities. In the following extract Jo’s flexible parenting style that promotes Tom’s development is illustrated in relation to Tom receiving a console game that was certified for over 18 year olds. Here she describes the dilemma between what is legally ‘right’ and what is right for Tom in terms of his development.

*“that was him actually entering into something that a load of teenagers are doing, **sure**, that was outside that legal room so he was actually pushing himself, **sure**, So I had to let it go [...] to me that’s a positive even though by the rules and laws it’s not right. But he’s done that and he’s bent himself a bit so that’s a positive” (Jo, lines 622-630).*

Almost all of the mothers spoke about the impact of their parenting role on themselves. Some acknowledged that their role could be stressful or tiring at times. Marie described a greater impact of her role on her physical health and her son Jack, also suggested that his mother found his ASC stressful.



## **Subtheme 2: Fitting in – Social and Romantic Relationships**

The young people's desire or drive to 'fit in' socially came across clearly in interviews with all participants. All of the young people spoke of the challenges they experienced socially as illustrated below:

*"it's slow and it takes a lot of effort where for most people it's just, it's normal and easy and, **hmm**, just to have a normal chat with someone, for me it's, my, my hands start to sweat, it's stupid, and my heart starts to beat faster like I can't get myself to talk"* (Max, lines 403-405).

Here Max emphasises how effortful social interactions are for him and the intense physical symptoms of anxiety he experiences contrasting this with the simplicity of a "normal" chat.

Two young people spoke explicitly about their experiences of bullying and another spoke about being excluded by peers. Some of the young people were aware that some of their tendencies in social situations could be detrimental and conveyed a sense of having to monitor themselves or 'learn' to 'fit in'.

*"I sorta get nervous, anxious and sorta just do everything you shouldn't do in a social situation [...] which is always quite bad which I have to restrain myself from now"* (Tom, lines 561-565).

Young people and mothers spoke about the impact that the young person's difficulties 'fitting in' had for them as illustrated by the excerpts below.

*"I think for her where I see that with the Asperger's is that (long pause) is her awareness of her social awkwardness and that's, sometimes it breaks your heart"*. (Charlotte, line 749).

*"It was difficult and, mm, heartbreaking and, **mm**, and disappointing (pause) I felt really angry too, **mm hm**, like about, I was there but I could not, could not speak"* (Max, lines 276-280).

Both Charlotte and Max refer to these experiences as 'heartbreaking' giving a sense of the raw emotion that both young people and their mothers experience as a result of the young people's social difficulties.

Many mothers discussed fears about their child's vulnerability in relationships at present or in the future as illustrated below.

*"I know he's so naïve, **ok**, when it comes to, mm, socialising, he, **sure**, I fear he would be used, put in danger, fear he doesn't read the body language of people you know, mm, **sure**, I think I'm more overprotective when it comes to Max at teenage age"* (Beth, lines 356-362).

Two of the young people were described as being in a romantic relationship and current or future relationships were discussed by three of the mothers and by Max. For Max, the positive impact of having a girlfriend was clear in terms of his self-esteem and in the excerpt below there is a sense of his excitement about this new part of his life.

*“now I have more confidence, I have got better subjects and friends and my girlfriend (laughs), mm, I feel better, I feel, I look forward to going to school, I look forward to it, I don't look forward to waking up but I (laughs) (laughs) I will even get dressed earlier, go to school just to see her” (Max, lines 519-523).*

Two mothers discussed that their adolescent children did not feel or seem ready for romantic relationships however, both were aware that they might need to support them with this. For Charlotte this included the potential challenges for Sophie of navigating sexual relationships.

### ***Subtheme 3: Appreciating the Positives***

Both young people and mothers spoke of positive aspects of ASCs such as having intense areas of interest and knowledge, refreshing honesty and a different perspective.

*“I think that (pause) thinking differently is exactly what the community needs, not really just a community, I guess what the world (laughs) needs. I don't know. Mm. (laughs) [...] Mm (pause) I think that we'd be further on in research” (Jack, lines 339-341).*

Initially in this excerpt Jack appears enthusiastic about the potential benefits of his different perspective. However, there is also a sense that he feels embarrassed suggesting that the ‘world’ might benefit from this, perhaps reflecting his uncertainty about challenging societal beliefs about ASCs.

Three of the mothers also discussed their appreciation of their adolescent child's unique way of seeing or connecting with the world as illustrated below:

*“there is a beauty in them, how they connect in different ways with the world, mm, for example, Max's got, mm, a real, a real passion, for animals, he loves animals, ok, [...] and he's sixteen but the way he cuddles and talks to them, it's, it's unusual, mm hmm, it's so beautiful, so innocent, so honest.” (Beth, lines 344 -348).*

One mother described that she felt her experiences of living with her adolescent child's ASC had made her less judgmental and more accepting of others. Three of the young people discussed how they could use their experiences of living with an ASC to help others. For example, taking part in the present research project, helping others to understand ASCs or supporting other young people with ASCs. This is illustrated by Sophie who talked about her role as a youth leader.

*“so say there was aye, a kid that came with Asperger's and some of the other leaders who don't have as much experience in it, don't really know like how to kind of connect with him and that, it would help” (Sophie, line 547).*

#### ***Subtheme 4: ASCs and the Family Context***

The reciprocal interaction between the young people with ASCs and their family context emerged as a common theme. The role of the family in terms of understanding and accepting ASCs has been discussed previously as has the impact of the parental role on mothers. In addition, three mothers discussed the impact that having a brother or sister with an ASC could have for siblings.

*“I think it has affected my bond with [Jack’s sister] without a doubt [...] they’re [siblings without an ASC] always put last and it doesn’t give them a very good self-image [...] I think it’s made her feel less worthy”* (Marie, lines 180-184).

Two young people also discussed sibling relationships and some of the tensions in these relationships are explored in Sophie’s quote below:

*“I really don’t know about my sister though so, **ok**, ‘cos I feel like I’m quite like overprotective of her in a way, **ok**, I kind of always want to be there but she doesn’t want that and then I don’t like that and all that kind of stuff”* (Sophie, lines 461-465).

In addition, Charlotte felt that Sophie compared herself to her sister and discussed the emotional impact of this for Sophie.

*“her major struggle is with her little sister, **mm**, who she perceives as being sociable and energetic and for her all it does is highlight what she can’t do, **ok**, and that’s very very painful”* (Charlotte, lines 767-771).

Two mothers described the impact of family life events that had served as a barrier to accessing services or seeking an assessment. This highlighted the wider context within which the young people and their mothers’ lives took place.

#### ***Subtheme 5: Thinking about the Future - Hopes and Worries***

All mothers discussed worries about their adolescent child’s future to greater or lesser degrees including the concerns about their social vulnerability discussed in subtheme 2. Two mothers described concerns about how their adolescent child would cope with any disappointments they might encounter and one mother worried about how her son would cope without her. Some mothers expected that their adolescent child might remain in the family home for some time. However, overall the mothers appeared hopeful about the young people’s futures, particularly that they would find an occupation that suited them.

*“she moves towards structure [...] and I think that’s what she’ll find in due course is she’ll find a niche”* (Charlotte, lines 989-991).

Conversely, the young people did not talk explicitly about any worries about their future. Although Jack described an expectation that having an ASC would be viewed negatively in terms of employment he sought to challenge this expectation by becoming a physicist. Tom felt that having an ASC would not affect his

aspirations to become an actor or an animator. Both Max and Sophie described uncertainly about what they wanted to do in the future and Sophie felt that her ASC may influence her choice of career. In the excerpt below Max described the tension between other people's expectations and his desire to enjoy the present moment.

*"I don't like people "oh go and do that, you'll be smart" or "go to college, go to university", right now I'm here, I'm happy, that's, I want to just stay happy [...] it just makes me stressed out 'cause, I dunno what I want to be [...] I dunno what will happen **mm**, can't speculate and can't imagine, it's just. I just enjoy where, where I am."* (Max, lines 461-471).

## DISCUSSION

The aims of the current study were to: *i)* Describe the key features of young people and their parent/carers' experiences of assessment, receiving and living with an ASC diagnosis and *ii)* Explore the similarities and differences in young people and their parent/carers' experiences of assessment, receiving and living with an ASC diagnosis. The findings relating to these aims are discussed in the context of existing literature. The implications of these findings for professionals and services are discussed along with suggestions for future research.

### ***i) Young people and their mothers' experiences of assessment, receiving and living with an ASC diagnosis***

The first three themes described a chronological process from participants first becoming aware of the possibility of an ASC through to receiving and accepting the diagnosis including the positive and negative consequences of having the ASC 'label'. Overall, these stages in participants' experiences are comparable with the suggestion by Mansel & Morris (2004) that the diagnostic process, for parents at least, involves four stages: 1. pre-diagnosis, 2. diagnosis, 3. post-diagnosis and 4. acceptance and adaptation and the process described by parents of 9-12 year olds in Midence & O'Neil (1999). Although this was not the original focus of the study, participants also discussed their experiences of living with the underlying traits of ASCs during adolescence separately from their experiences of living with the diagnosis per se. These experiences are depicted in the final superordinate theme Living with an ASC in Adolescence - "[I'm] just trying to fit in".

*Super-ordinate Theme 1: The Journey to Diagnosis –“oh yeah, you've got it and kinda get on with your life”*

#### *Sub-theme 1: Different Starting Points and Paths to Assessment*

The significance of diagnostic experiences identified in this study is mirrored in existing literature relating to parents (Cridland et al., 2014b; DePape et al., 2015; Fong et al., 1993; Mount & Dillon, 2014; Robinson et al., 2014) and individuals with ASCs (Punshon et al., 2009). Consistent with existing research, most of the mothers' 'journeys' started early in their child's life when they recognised differences in their development (DePape & Lindsay, 2015; Robinson et al., 2014) and the majority had explicitly considered that their child may have an ASC. For the four young people and one mother the 'journey' to diagnosis started later, and more abruptly, during adolescence when a professional or parent suggested that they might have an ASC. Whether or not these participants found this possibility distressing appeared to relate to the beliefs that they and their family held about ASCs. Notably, participants' experiences and emotional responses at each stage of the process appeared to be influenced by their journey towards diagnosis as well as the narratives and beliefs that they or their family held about ASCs. It is possible that these factors, in addition to the developmental stage of adolescence, may

explain some of the discrepancies between the existing literature and current findings.

#### *Sub-theme 2: Being Assessed*

The assessment experiences of individuals with ASCs are not documented in the current qualitative literature. In the present study, young people described this as a confusing and somewhat mysterious or patronising process. Notably, the majority appeared to feel observed and studied during assessment rather than it being something they felt able to collaborate with. This is an important finding for services and highlights a crucial area for further research to promote individuals' active participation in the process particularly as an individual's level of engagement could potentially influence the validity of the assessment.

#### *Sub-theme 3: Receiving a diagnosis*

Participants described a wide range of emotional reactions at the point of receiving the diagnosis. Some described strong emotions (positive and negative) and this is consistent with studies of parents (Fong et al., 1993; Mount & Dillon, 2014; Robinson et al., 2014) and individuals with ASCs (Huws & Jones, 2008; Molloy & Vasil, 2004; Punshon et al., 2009). In contrast to these studies, not all participants in the present study described experiencing an intense, or any, emotional reaction to the diagnosis. This appeared to relate to already having a child or sibling with an ASC in the family and holding neutral or positive beliefs about ASCs. Participants who described negative emotional reactions to diagnosis had not previously considered the possibility of an ASC and, for young people, held negative beliefs about ASCs. Similarly in a study relating to type-2 diabetes Peel et al. (2004) suggested that whether or not individuals had suspected that they might have type 2 diabetes or had family members with this diagnosis influenced their emotional reaction to the diagnosis. Adolescence itself is associated with increased emotional intensity and Whitaker (2006) notes the possibility for more intense reactions to an ASC diagnosis during this period. Consistent with existing qualitative (Cridland et al., 2014b; Mount & Dillon, 2014) and quantitative research (Crane et al., 2015; Jones et al., 2014) many mothers and one young person in the current study had hoped for more support from services following diagnosis.

### *Super-ordinate Theme 2: Making Sense of ASCs - "I used to really hate myself for having it but now I've got used to it"*

#### *Sub-theme 1: Understanding and Accepting the Diagnosis*

Participants in the current study described a range of responses and experiences following diagnosis. Part of the process of understanding and accepting the diagnosis involved making sense of this for the individual e.g. where the young person's abilities were on the 'spectrum' and what aspects of ASCs were more or less apparent for them. Mothers also tended to make links between their adolescent child's sensory and mental health difficulties and their ASC. Volkmar & Klin (2005) argue that a diagnosis is only one part of the 'diagnostic process' and

this should include a rich formulation including the individual's strengths and weaknesses. Since ASCs are associated with particular sensory needs (Kern et al., 2006) and high levels of co-morbid mental health difficulties and other neuro-developmental conditions (Simonoff et al., 2008), arguably these should also be incorporated into the narrative that is provided to families. A psychological formulation could help to describe how the ASC presents for that individual person and possible links with other difficulties or diagnoses. A formulation can also consider the personal meaning and impact of the condition for the individual along with systemic and contextual factors (DCP, 2011) which were found to be influential in the current study. Furthermore, parents appear to appreciate diagnostic feedback that includes their child's strengths and difficulties in a holistic and hopeful manner (Abbott et al., 2013).

All participants described reaching a point of acceptance regarding their diagnosis, however, they had very varied experiences of this process. Some participants described accepting this immediately and without difficulty. Others described a more challenging and emotional process leading to acceptance. This appeared to relate to the possibility of an ASC as being more unexpected and perceiving the diagnosis to have negative implications. Interestingly, much of the existing literature about parents of individuals, including adolescents, with ASCs describes an emotional process similar to grief which leads to acceptance (DePape & Lindsay, 2015; Fong et al., 1993; Mount & Dillon, 2014; Robinson et al., 2014; Siegel, 1997). This was true for only one mother in the current study, perhaps as many of the mothers had come to terms with the young person's difference many years earlier. This may also relate to their pre-diagnosis experiences and beliefs about ASCs. It is also possible that families who had reached a point of acceptance might have been more likely to participate in the study.

Conversely, two young people in the current study described experiences comparable to grief or loss. These young people and their mothers said that the number of transitions associated with adolescence made this a particularly difficult time to accept the diagnosis. Huws & Jones (2008) described a theme of 'acceptance and avoidance' in which some adolescents and young adults found their diagnosis difficult to acknowledge at first and, contrary to the current findings, some remained unable to accept this. A wide range of factors have been proposed to influence adjustment following diagnosis in the chronic health literature including relationships, personality attributes, coping processes and cognitive appraisals (Stanton et al., 2007). The role of beliefs and cognitive processes was highlighted in the current study and to some extent cognitive appraisal models of adjustment may be applicable. For example, Lazarus (1991) suggested that how an individual perceives the 'illness' to impact upon their life goals and the personal meaning of the illness are central to adjustment. Many young people in the current study described goals of 'fitting in' or 'being normal' and those who perceived a diagnosis of ASC as a barrier to this described more difficulty accepting their diagnosis. There are, however, a number of limitations in applying these findings to ASCs due to the intrinsic differences between ASCs and physical health diagnoses (Punshon et al., 2009; Whitaker, 2006).

### *Sub-theme 2: Incorporating the ASC into an Understanding of Who They Are*

Participants described both incorporating the ASC diagnosis into their understanding of their adolescent child and trying to separate the diagnosis from 'who' their adolescent child was. This was mirrored by parents in Molloy and Vasil (2004) and Robinson et al. (2014). Conversely, in Siegel's (1997) theoretical model part of 'healthy' coping with a child's diagnosis involves the parent integrating the ASC into their view of the 'whole' child. The role of their ASC in their sense of self varied among the young people in the current study and for many it appeared that this was still evolving. Similarly, Huws & Jones (2008) and Molloy and Vasil (2004) noted that young people tended to adjust their sense of identity in relation to their ASC diagnosis and for some this became an integral part of their identity. Similar to adolescents in Molloy and Vasil (2004) and adults in Punshon et al. (2009), young people spoke about aspects of themselves as separate to their ASC.

Interestingly, Punshon et al. (2009) identified 'identity formation' as a super-ordinate theme in the experiences of individuals receiving a diagnosis of an ASC in adulthood (at 21-44 years old). This may suggest that regardless of developmental stage, individuals appear to readjust their sense of self in relation to the diagnosis of an ASC. The impact of receiving an ASC diagnosis in adolescence may be particularly significant as the developmental tasks associated with adolescence relate to developing a sense of group identity and a sense of self (Erikson, 1968; Newman & Newman, 1976). Yet a diagnosis of an ASC suggests difference from the majority and relates to differences in how the individual interacts and connects with others. Cridland et al. (2014a) suggest that young people with ASCs might find the process of identity formation especially challenging and it is possible that receiving an ASC diagnosis during adolescence could exacerbate these difficulties. Consistent with the experiences of some participants in the current study, Punshon et al. (2009) suggest that it takes individuals time to integrate the diagnosis into a coherent view of themselves and to process what the diagnosis means for them. Punshon et al. (2009) suggested that some people may benefit from professional help to do so and this was true for some of the young people and mothers in the present study.

### *Super-ordinate Theme 3: Living with a Label – "it's funny isn't it because it's just one word"*

#### *Sub-theme 1: Diagnosis Providing Understanding and Access to Services*

Participants discussed both benefits and costs of the diagnosis consistent with findings in Calzada et al. (2012) however, contrary to their findings, all of the young people in the present study perceived there to be some benefits to having their diagnosis. Primarily this related to the diagnosis providing a new narrative about current and past experiences and difficulties. This new narrative appeared helpful in enhancing understanding for the young person, their family and the wider system consistent with existing literature (Calzada et al., 2012; Molloy & Vasil, 2004; Punshon et al., 2009; Robinson et al., 2014). Similar to participants in Punshon et al. (2009) some young people in the current study felt that the understanding



provided by their diagnosis externalised difficulties that they had previously blamed themselves for. Consistent with existing literature, the diagnosis also provided access to support in school and access to services for young people and parents (Calzada et al., 2012; Fong et al., 1993; Huws & Jones, 2008; Punshon et al., 2009; Robinson et al., 2014). Some mothers also described the diagnosis as helping to adjust their expectations for the young person's future and this is consistent with parents in Robinson et al. (2014).

#### *Sub-theme 2: The Challenges of Living with a Label - Societal Views of ASCs*

All of the young people and some mothers discussed negative aspects of having an ASC diagnosis which almost exclusively related to negative beliefs and stereotypes held in society. Young people discussed the impact of societal views more than their mothers, including experiences of bullying or exclusion from peers. Similarly, individuals with ASCs in Huws & Jones (2008), Jones et al. (2013) and Punshon et al. (2009) discussed the impact of society's lack of understanding about ASCs. In the current study, some mothers described caution about whom they disclosed the diagnosis to, however, they did not describe experiences of social isolation or stigma as described in the existing literature (Cridland et al., 2014b; Fong et al., 1993; Gray, 2002; Robinson et al., 2014). Consistent with the current study, participants in Davidson & Henderson (2010) emphasised the need for individuals with ASCs to educate society about ASCs to promote understanding and acceptance.

#### *Superordinate Theme 4: Living with an ASC in Adolescence – “[I’m] just trying to fit in” (Max, lines 230-232)*

##### *Sub-theme 1: Adolescence and the Challenges of the Parental Role*

Mothers described how the traits of ASCs could make their parental role easier or more challenging during adolescence and described aspects of their adolescent child's development that were similar to their expectations of 'typical' adolescence and those that differed. Notably, the mothers appeared to retain an intense and highly involved role in their adolescent child's lives as described in existing literature (Cridland et al. 2014b; Fong et al., 1993; Mount & Dillon, 2014). Similarly, Van Bourgondien et al. (2014) discuss that parents of individuals with disabilities may not become increasingly less involved in their child's life through adolescence and adulthood as might be expected. The mothers in the present study appeared to facilitate and encourage their adolescent child's development rather than the young person leading this. Given the seemingly important role that mothers or parents may have in guiding their adolescent child's development, parents of young people with ASCs might benefit from information or support to be aware of 'typical' developmental processes. Although some mothers felt their role had a significant impact on their health as suggested in the literature relating to parental stress (Sanders & Morgan, 1997) most mothers reported that their role had a very limited impact on them and their lives.

### *Sub-theme 2: Fitting in – Social and Romantic Relationships*

All of the young people in the current study expressed a strong motivation to 'fit in' with their peers which is in keeping with the relevant developmental tasks of developing a sense of group identity and self-identity (Erikson, 1968; Newman & Newman, 1976). The young people spoke of the difficulties they had socialising and some described attempts to 'learn' to 'fit in' or monitor their behaviour which reflects existing literature with adults (Punshon et al., 2009) and young people (Huws & Jones, 2013). Both young people and their mothers described the negative emotional impact of the young person's struggle to 'fit in'. Although it is not possible to determine whether this was also a concern for them earlier in their lives it may be that this is exacerbated by the pressures and expectations of adolescence. Mothers described concerns about their adolescent child's potential vulnerability in social, romantic or sexual relationships and anticipated that they would need support with this. Similar concerns regarding sexual relationships were reflected by parents in Cridland et al. (2014b) and Fong et al. (1993).

### *Sub-theme 3: Appreciating the Positives*

Both mothers and young people described positive traits associated with the young person's ASC as is reflected in some existing literature with parents (Robinson et al., 2014) and young people (Humphrey & Lewis, 2008). One mother described a sense of personal growth as a result of her experiences and this is described in the literature (Cridland et al., 2014b; DePape & Lindsay, 2014; Robinson et al., 2014). Consequently, Cridland et al. (2014c) suggest that the concept of traumatic growth may be relevant in understanding the experiences of some parents of young people with ASCs. Three young people in the current study discussed how they could use their lived experiences of having an ASC to help others and this appears to be a unique finding within the existing literature.

### *Sub-theme 4: ASCs and the Family Context*

There appeared to be a reciprocal interaction between the young people's ASCs and the wider family context. As discussed previously this included family beliefs about ASCs and the influence of having another child with an ASC diagnosis within the family. As in the current study, the potential challenges for siblings who do not have ASCs were also described in existing parent literature (Fong et al., 1993; Mount & Dillon, 2014; Robinson et al., 2014). One family in the present study noted that siblings without an ASC could be a painful social comparison for the young person with an ASC. The wider context of family stressors and life events was discussed in relation to seeking assessment, adjusting to the diagnosis and accessing services. Unlike parents in the existing literature mothers in the current study did not discuss the wider impact of having an adolescent with an ASC such as on their relationships, career or family activities and finances (Cridland et al., 2014b; Fong et al., 1993; Mount & Dillon, 2014; Robinson et al., 2014). The interaction between the family context and ASCs would support the suggestion from Cridland et al. (2014c) that family systems approaches may be a useful

framework for understanding and researching the experiences of families living with ASCs.

#### *Sub-theme 5: Thinking about the Future - Hopes and Worries*

Similar to parents in the existing literature (Fong et al., 1993; Mount & Dillon, 2014), mothers in the current study described a number of worries about the future in relation to their adolescent child. However, overall, mothers were hopeful about their adolescent child's future, particularly in relation to the young person finding employment that would suit them. In the existing literature relating to parents of adolescents, parents have tended to focus on hopes relating to their child's ability to live independently (Fong et al., 1993; Robinson et al., 2014). The discussion about employment may reflect the young people's relatively high level of academic functioning in the current study. Most of the young people were considering their future career options. A minority of young people discussed the potential for their ASC diagnosis to influence their future career plans as discussed by participants in Huws & Jones (2008) however, others felt this would have little or no influence or could be helpful for them in some ways.

#### ***ii) Similarities and differences in young people and their mothers' experiences of assessment, receiving and living with an ASC diagnosis.***

Overall, mothers and young people had differing experiences at various points in the diagnostic process particularly in relation to their experience of first hearing about ASCs, assessment and the impact of societal views. The potential impact of receiving a diagnosis in adolescence was also experienced differently by some young people and mothers. Given these differing perspectives it was challenging to identify themes that could incorporate both perspectives. The researcher attempted to manage this by identifying broad overall themes and offering different titles for how this theme applied to young people and mothers separately. Young people and mothers within two dyads described relatively similar experiences. In one case this appeared to relate, at least in part, to a positive family narrative about ASCs and they accepted the diagnosis quickly. For the other dyad, the possibility of an ASC was unexpected and both had difficult experiences of coming to terms with this. Mothers and young people in the other two families differed in their reactions to diagnosis and the ease in which they accepted the diagnosis. Some aspects of the diagnostic process will invariably be different for young people and parents. Furthermore, it would be expected that young people and parents might react and adjust differently to the diagnosis given their different experiences prior to assessment, their developmental stage and the meaning or implications of ASCs for individuals and parents. In addition, research suggests that a range of individual differences may influence reactions to stressful life events (Carr, 2006). Given that it may be common for young people and their parents to develop different narratives about stressful events, the way in which families respond to one another's experiences may be more important. For example, Gil-Rivas et al. (2007) found that symptoms of post-traumatic stress disorder in adolescents were

influenced by parental distress, parents' availability to discuss the traumatic events and the level of coping advice they provided. There is a need for greater understanding of parents' ability to support their young person through the diagnostic process and to develop a coherent narrative and the potential impact of this support. For example, where young people and parents have different experiences or where one or both individuals are struggling to come to terms with the diagnosis.

### **Implications for Services**

The current findings highlight the need for careful consideration in clinical practice regarding the disclosure of difficulties associated with ASCs as this could offer a more helpful narrative of an individual's difficulties. Consistent with Osborne & Reed (2008), one mother emphasised the need for quicker access to diagnosis. It is important that professionals working with children and young people are aware of the more subtle presentations of ASCs to allow this to be raised as early as possible. Furthermore, the additional diagnostic challenges for young females with ASCs discussed in Cridland et al. (2014b) mirror the experiences of the female participant in the current study. The present study highlighted the need for professionals to be routinely involved in discussions with young people to explain ASCs and the assessment in a developmentally appropriate manner to ensure fully informed consent. There is a need for services to consider how young people could become active partners in the assessment process. Fostering young people's curiosity about their difference or difficulties may help however, services should also consider how the assessment process could be more transparent for young people and their families. Wider questions were raised about the suitability of the methods and approaches used for assessing ASCs in adolescents and this requires consideration. It would appear beneficial for a diagnosis to be given as part of an individualised formulation.

Findings from the current study suggest that families should be routinely informed about available post-diagnostic services at the point of diagnosis however, families themselves should be in control of when or whether they seek support. The need for accessible information about ASCs tailored to the needs of adolescents was indicated and this may be best delivered via family members. In terms of promoting acceptance, some mothers found it helpful to meet other parents of young people with ASCs. Some young people and mothers found help from professionals beneficial to consider how the ASC applied to them. Although individuals' beliefs about ASCs might appear a potential target for intervention in terms of acceptance and adjustment, it would seem that a shift in societal views about ASCs is required to allow a more balanced or positive view. Services should also be aware that many adolescents with ASCs are extremely motivated to socialise with peers and to 'fit in' and consequently their difficulties doing so could potentially cause them distress. It appears that mothers may retain a highly involved role in their adolescent child's life and some may need support or information in order to guide their adolescent child's development. Any support offered to families should be tailored to the specific developmental needs of the individual and family.

## **Limitations**

The current study explored the experiences of a particular group of young people with ASCs and their mothers at a specific point in time following diagnosis. The young people all attended mainstream school suggesting that they were functioning relatively highly in the academic sphere at least. All participants in the present study were Caucasian and the parents who participated were exclusively female which may limit the application of the results. Sample homogeneity is both a strength and limitation of the present study. Further research is required to explore whether the emergent themes are representative of other adolescents with ASCs and their mothers. All participants appeared to have reached a point of relative acceptance and it is possible that the families who volunteered to participate felt more able to discuss their experiences because they had reached this point of acceptance. Although all of the young people spontaneously raised aspects of their experiences, the researcher had to guide the interviews with young people more so than with the mothers. It is possible that they may have had other relevant experiences that were not discussed because the researcher did not enquire about them.

## **Future Research**

The study highlighted the need for further research of families' experiences at specific developmental stages such as adolescence. The finding that individuals' preparation for the possibility of the diagnosis may influence their post-diagnostic trajectory highlights the need for research to consider the impact of how and when young people are told that they might have traits associated with an ASC. The need for further understanding of adolescents' experiences of assessment is also indicated. As in the present study, current literature exploring parents' experiences of ASCs predominately involves mothers (O'Halloran et al., 2013). Given that there appear to be gender related differences in parents' roles and coping styles following an ASC diagnosis (Gray, 2003) there is a need for more research considering the perspectives of fathers. Further research is required to understand the impact of family members having different experiences of the same process for example, on their adjustment following diagnosis and ability to form a coherent narrative around this. Research is also required to explore families' experiences of the process of acceptance following a diagnosis of an ASC and whether some find this an on-going challenge. Given the variations in the process of acceptance for individuals, future studies should aim to recruit families at a specific point in time or specify when participants received their diagnosis to provide context for their findings.

## CONCLUSION

To our knowledge, this is the first qualitative study to explore the lived experiences of adolescents and their mothers of undergoing an assessment for an ASC along with receiving and living with this diagnosis. This afforded insights into individuals' experiences at different points in this process. A number of factors appeared to influence individuals' emotional responses throughout the process and their acceptance of the diagnosis. The study highlighted the similarities and differences between young people and mothers' experiences at the dyad and group level. Although some young people and mothers shared similar experiences of the process of receiving and accepting the diagnosis, many had divergent experiences. The potential consequences of this require further exploration. This study was also unique in that it explored how individuals with ASCs experience the assessment process. It appeared that this could be a difficult and confusing process for young people and further consideration of this is required in clinical practice and in future research. Participants also discussed what it was like to live with an ASC during adolescence. Notably, this included an exploration of mothers' roles during adolescence, young people's intense desire to 'fit in' and the impact of their difficulties doing so. Many experiences described by young people and their mothers in the current study were broadly similar to existing literature however, some aspects of their experiences may be unique to adolescence. In particular, the potential impact of receiving a diagnosis of this nature during adolescence where individuals are developing a sense of group identity and sense of self should not be underestimated.

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## CHAPTER THREE: ADVANCED CLINICAL PRACTICE 1

### **Reflective Account: Reflections on Developing a Professional 'Self'**

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*Submitted in partial fulfilment of the requirements for the degree of  
Doctorate in Clinical Psychology*

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Chapter Three Word Count: 256

## ABSTRACT

**Introduction:** Research emphasises the importance of developing and maintaining an effective therapeutic relationship when engaging in therapeutic work with individuals. It is suggested that factors such as the therapist being empathic and genuine and offering positive regard may foster the therapeutic relationship and facilitate effective therapy. Professional guidelines for clinical psychologists from the HCPC and BPS emphasise the importance of maintaining appropriate professional boundaries. As such, therapists must find a balance between being genuine with those they work with while maintaining appropriate boundaries.

**Reflections:** This account includes reflections on my on-going development throughout training in relation to developing a professional sense of 'self' while maintaining appropriate boundaries with the individuals I have worked with. I have reflected upon experiences across my three years of training drawing on Gibb (1988) and Kolb's (1984) models to aid my reflections. This allowed me to consider the impact of each learning experience in a process of development throughout my training.

**Conclusions:** Through writing this account, I am more aware of the developmental process that has taken place during my training leading to my increasing ability and confidence in being genuine in my therapeutic relationships in a safe and appropriate manner. This delicate balance continues to be a constant consideration in my clinical work; client-to-client and even session-to-session and I expect that this will be the case throughout my career. Consequently, I hope to remain aware of this balance and the value of reflecting on this in relation to the relationships I have with the individuals I am working with.

## CHAPTER FOUR: ADVANCED CLINICAL PRACTICE 2

### Reflective Account:

### Learning the Power of Process: Reflections on Using the Process of Therapy

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Chapter Four Word Count: 214

## ABSTRACT

**Introduction:** Awareness and use of the process of therapy is a vital therapeutic skill for therapists delivering psychological therapies. This is perhaps particularly true for clinical psychologists who are increasingly expected to work with individuals with more complex presentations.

**Reflections:** In this account I have reflected on my ability to use the process of therapy in my work and how this has developed through my training. I have considered the development of my practice during one placement in particular as well as considering my awareness of process issues at various points during my career. In reflecting on these experiences I have drawn on the models of Gibb (1988), Kolb (1984) and Stoltenberg & Delworth (1987).

**Conclusions:** In reflecting on these experiences I have become more aware of my own learning and development in relation to using process as well as my therapeutic skills generally. I have also considered the need to have confidence in my skills and role as a future qualified clinical psychologist and the importance of continuing to develop my own and others' awareness and ability to use process. Finally, I considered how I might use my own experiences of being introduced to process issues and supported to use the process of therapy in the future when I may supervise others.



## APPENDICES

### Appendix 1.0 - Manuscript Submission Guidelines

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*Autism* provides a major international forum for research of direct and practical relevance to improving the quality of life for individuals with autism or autism-related disorders.

#### 1. Peer review policy

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

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

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## 2. Article types

The Journal considers the following kinds of article for publication:

1. **Research Reports.** *Full papers* describing new empirical findings;

2. **Review Articles.**

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

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

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

3. **Short Reports.** Brief papers restricted to a maximum of 2,000 words with no more than two tables and 15 references. Short reports could include other approaches like discussions, new or controversial ideas, comments, perspectives, critiques, or preliminary findings. The title should begin with 'Short Report'.

4. **Letters to the Editors.** Readers' letters should address issues raised by published articles. The decision to publish is made by the Editors, in order to ensure a timely appearance in print. Letters should be no more than 800 words, with no tables and a maximum of 5 references.

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## 3. How to submit your manuscript

Before submitting your manuscript, please ensure you carefully read and adhere to all the guidelines and instructions to authors provided below. Manuscripts not conforming to these guidelines may be returned.

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IMPORTANT: Please check whether you already have an account in the system before trying to create a new one. If you have reviewed or authored for the journal in the past year it is likely that you will have had an account created. For further guidance on submitting your manuscript online please visit [ScholarOne Online Help](#).

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#### 6. Other conventions

We would prefer to use the term 'people with autism' or 'people with autism spectrum disorders or conditions'. We would also prefer the term 'typically developing' rather than 'normal'.

##### 6.1 Research ethics

All papers reporting animal and human studies must include whether written consent was obtained from the local Ethics Committee or Institutional Review Board. **Please ensure that you have provided the full name and institution of the review committee and an Ethics Committee reference number.**

We accept manuscripts that report human and/or animal studies for publication only if it is made clear that investigations were carried out to a high ethical standard. Studies in

humans which might be interpreted as experimental (e.g. controlled trials) should conform to the Declaration of Helsinki <http://www.wma.net/en/30publications/10policies/b3/index.html> and typescripts must include a statement that the research protocol was approved by the appropriate ethical committee. In line with the Declaration of Helsinki 1975, revised Hong Kong 1989, we encourage authors to register their clinical trials (at <http://clinicaltrials.gov> or other suitable databases identified by the ICMJE, [http://www.icmje.org/publishing\\_10register.html](http://www.icmje.org/publishing_10register.html)). If your trial has been registered, please state this on the Title Page. When reporting experiments on animals, indicate on the Title Page which guideline/law on the care and use of laboratory animals was followed.

## **6.2 Patient consent**

Authors are required to ensure the following guidelines are followed, as recommended by the International Committee of Medical Journal Editors, Uniform Requirements for Manuscripts Submitted to Biomedical Journals. Patients have a right to privacy that should not be infringed without informed consent. Identifying information, including patients' names, initials, or hospital numbers, should not be published in written descriptions, photographs, and pedigrees unless the information is essential for scientific purposes and the patient (or parent or guardian) gives written informed consent for publication. Informed consent for this purpose requires that a patient who is identifiable be shown the manuscript to be published.

Identifying details should be omitted if they are not essential. Complete anonymity is difficult to achieve, however, and informed consent should be obtained if there is any doubt. For example, masking the eye region in photographs of patients is inadequate protection of anonymity. If identifying characteristics are altered to protect anonymity, such as in genetic pedigrees, authors should provide assurance that alterations do not distort scientific meaning and editors should so note. When informed consent has been obtained it should be indicated in the submitted article.

## **6.3 Statistical analyses**

Where statistical analyses have been carried out please ensure that the methodology has been accurately described. In comparative studies power calculations are usually required. In research papers requiring complex statistics the advice of an expert statistician should be sought at the design/implementation stage of the study.

## **6.4 Randomized controlled trials**

All randomized controlled trials submitted for publication in *Autism* should include a completed Consolidated Standards of Reporting Trials (CONSORT) flow chart. Please refer to the CONSORT statement website at <http://www.consort-statement.org> for more information.

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## **7. Acknowledgements**

Any acknowledgements should appear first at the end of your article prior to your Declaration of Conflicting Interests (if applicable), any notes and your References.

All contributors who do not meet the criteria for authorship should be listed in an 'Acknowledgements' section. Examples of those who might be acknowledged include a person who provided purely technical help, writing assistance, or a department chair who provided only general support. Authors should disclose whether they had any writing assistance and identify the entity that paid for this assistance.

### **7.1 Funding Acknowledgement**

To comply with the guidance for Research Funders, Authors and Publishers issued by the [Research Information Network](#) (RIN), *Autism* additionally requires all Authors to acknowledge their funding in a consistent fashion under a separate heading. All research articles should have a funding acknowledgement in the form of a sentence as follows, with the funding agency written out in full, followed by the grant number in square brackets:

This work was supported by the Medical Research Council [grant number xxx].

Multiple grant numbers should be separated by comma and space. Where the research was supported by more than one agency, the different agencies should be separated by semi-colon, with "and" before the final funder. Thus:

This work was supported by the Wellcome Trust [grant numbers xxxx, yyyy]; the Natural Environment Research Council [grant number zzzz]; and the Economic and Social Research Council [grant number aaaa].

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This research received no specific grant from any funding agency in the public, commercial, or not-for-profit sectors.

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Only electronic files conforming to the journal's guidelines will be accepted. Preferred

formats for the text and tables of your manuscript are Word DOC, RTF, XLS. LaTeX files are also accepted. Please also refer to additional guideline on submitting artwork and supplemental files below.

## **9.2 Journal Style**

*Autism* conforms to the SAGE house style. [Click here](#) to review guidelines on SAGE UK House Style.

## **9.3 Reference Style**

*Autism* operates a Sage Harvard reference style. [Click here](#) to review the guidelines on SAGE Harvard to ensure your manuscript conforms to this reference style.

## **9.4. Manuscript Preparation**

The text should be double-spaced throughout and with a minimum of 3cm for left and right hand margins and 5cm at head and foot. Text should be standard 10 or 12 point. SI units should be used throughout the text.

### **9.4.1 Keywords and Abstracts: Helping readers find your article online**

The title, keywords and abstract are key to ensuring that readers find your article online through online search engines such as Google. Please refer to the information and guidance on how best to title your article, write your abstract and select your keywords by visiting SAGE's Journal Author Gateway Guidelines on [How to Help Readers Find Your Article Online](#).

### **9.4.2 Corresponding Author Contact details**

Provide full contact details for the corresponding author including email, mailing address and telephone numbers. Academic affiliations are required for all co-authors. These details should be presented separately to the main text of the article to facilitate anonymous peer review.

### **9.4.3 Guidelines for submitting artwork, figures and other graphics**

Artwork, figures and other graphics such as tables should be uploaded through SAGE's Online Submission System alongside the main body of the text, as a separate file to ensure best quality in production. For further guidance on the preparation of illustrations, pictures and graphs in electronic format, please visit SAGE's [Manuscript Submission Guidelines](#).

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This journal is able to host approved supplemental materials online, alongside the full-text of articles. Supplemental files will be subjected to peer-review alongside the article. For more information please refer to SAGE's [Guidelines for Authors on Supplemental Files](#).

### **9.4.5 English Language Editing**

Non-English speaking authors who would like to refine their use of language in their manuscripts might consider using a professional editing service. Visit [English Language Editing Services](#) for further information.

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## 10. After acceptance

### 10.1 Lay Abstracts

Upon acceptance of your article you will be required to submit a lay abstract of your article to the Social Media Editor, Laura Crane ([journalautism@gmail.com](mailto:journalautism@gmail.com)). Lay abstracts are brief (max 250 words) descriptions of the paper that are easily understandable. These abstracts will be made available to researchers and clinicians, as well as the general public (including individuals with autism spectrum disorders and their families).

These abstracts should avoid both technical terminology and the reporting of statistics. Examples of lay abstracts are provided in recent issues of the journal.

### 10.2 Proofs

We will email a PDF of the proofs to the corresponding author.

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## 11. Further information

Any correspondence, queries or additional requests for information on the Manuscript Submission process should be sent to the Editorial Office as follows:

### **Katie Maras**

Department of Psychology  
University of Bath  
Claverton Down  
Bath BA2 7AY  
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Email: [K.L.Maras@bath.ac.uk](mailto:K.L.Maras@bath.ac.uk)

## Appendix 1.1 – Example of Full Search Strategy in Medline

*Searched:*

**A.**

Autism (mapped to subject heading Autistic Disorder) OR Asperger (mapped to subject heading) OR pervasive developmental disorder (mapped to subject heading 'Child Development Disorders, Pervasive')  
OR (keywords): autis\* OR kanner OR asperger\* OR "pervasive developmental disorder not otherwise specified" OR ASD OR ASC OR PDD NOS

AND

**B.** Adolescent (mapped to subject heading) OR (keywords): adolescen\* OR youth OR teen\* OR young person OR young people

AND

**C.** Parent (mapped to subject heading) OR mother (mapped to subject heading) OR father (mapped to subject heading) OR parenting (mapped to subject heading) OR child rearing (mapped to subject heading) OR (keywords): parent\* OR mother\* OR father\* OR carer\* OR caregiver\* OR guardian\* OR parenting OR child rearing

AND

**D.** Qualitative (mapped to subject heading 'Qualitative Research') OR (keywords): interview\* OR experience\* OR qualitative

AND limit language to English



## Appendix 1.2 – Quality Rating Framework

### Scoring:

- *Not met* = 0
- *Partially* = 1
- *Mostly met* = 2
- *Fully met* = 3

<b>Aspect</b>	<b>Essential Criteria</b>	<b>Specific Prompts</b>	
<b>A. Scope and Purpose</b>	1. Clear statement of and rationale for research question/aims/purposes	<ul style="list-style-type: none"> <li>• <i>Clarity of focus demonstrated</i></li> <li>• <i>Explicit purpose given, such as descriptive/explanatory intent, theory building, hypothesis testing</i></li> <li>• <i>Link between research and existing knowledge demonstrated</i></li> </ul>	
	2. Study thoroughly contextualised by existing literature	<ul style="list-style-type: none"> <li>• <i>Evidence of systematic approach to literature review, location of literature to contextualise the findings, or both</i></li> </ul>	
<b>B. Design</b>	3. Method/design apparent consistent with research intent	<ul style="list-style-type: none"> <li>• <i>Rationale given for use of qualitative design</i></li> <li>• <i>Discussion of epistemological/ontological grounding</i></li> <li>• <i>Rationale explored for specific qualitative method (e.g. ethnography, grounded theory, phenomenology)</i></li> <li>• <i>Discussion of why particular method chosen is most appropriate/sensitive/relevant for research question/aims</i></li> <li>• <i>Setting appropriate</i></li> </ul>	
	4. Data collection strategy apparent and appropriate	<ul style="list-style-type: none"> <li>• <i>Were data collection methods appropriate for type of data required and for specific qualitative method?</i></li> <li>• <i>Were they likely to capture the complexity/diversity of experience and illuminate context in sufficient detail?</i></li> <li>• <i>Was triangulation of data sources used if appropriate?</i></li> </ul>	
<b>C. Sampling Strategy</b>	5. Sample and sampling method appropriate	<ul style="list-style-type: none"> <li>• <i>Selection criteria detailed, and description of how sampling was undertaken</i></li> <li>• <i>Justification for sampling strategy given</i></li> <li>• <i>Thickness of description likely to be achieved from sampling</i></li> <li>• <i>Any disparity between planned and actual sample explained</i></li> </ul>	

<p><b>D. Analysis</b></p>	<p>6. Analytic approach appropriate</p>	<ul style="list-style-type: none"> <li>• Approach made explicit (e.g. Thematic distillation, constant comparative method, grounded theory)</li> <li>• Was it appropriate for the qualitative method chosen?</li> <li>• Was data managed by software package or by hand and why?</li> <li>• Discussion of how coding systems/conceptual frameworks evolved</li> <li>• How was context of data retained during analysis</li> <li>• Evidence that the subjective meanings of participants were portrayed</li> <li>• Evidence of more than one researcher involved in stages if appropriate to epistemological/theoretical stance</li> <li>• Did research participants have any involvement in analysis (e.g. member checking)</li> <li>• Evidence provided that data reached saturation or discussion/rationale if it did not</li> <li>• Evidence that deviant data was sought, or discussion/rationale if it was not</li> </ul>	
<p><b>E. Interpretation</b></p>	<p>7. Context described and taken account of in interpretation</p>	<ul style="list-style-type: none"> <li>• Description of social/physical and interpersonal contexts of data collection</li> <li>• Evidence that researcher spent time 'dwelling with the data', interrogating it for competing/alternative explanations of phenomena</li> </ul>	
	<p>8. Clear audit trail given</p>	<ul style="list-style-type: none"> <li>• Sufficient discussion of research processes such that others can follow 'decision trail'</li> </ul>	
	<p>9. Data used to support interpretation</p>	<ul style="list-style-type: none"> <li>• Extensive use of field notes entries/verbatim interview quotes in discussion of findings</li> <li>• Clear exposition of how interpretation led to conclusions</li> </ul>	
<p><b>F. Reflexivity</b></p>	<p>10. Researcher reflexivity demonstrated</p>	<ul style="list-style-type: none"> <li>• Discussion of relationship between researcher and participants during fieldwork</li> <li>• Demonstration of researcher's influence on stages of research process</li> <li>• Evidence of self-awareness/insight</li> <li>• Documentation of effects of the research on researcher</li> <li>• Evidence of how problems/complications met were dealt with</li> </ul>	

<p><b>G. Ethical Dimensions</b></p>	<p>11. Demonstration of sensitivity to ethical concerns</p>	<ul style="list-style-type: none"> <li>• <i>Ethical committee approval granted</i></li> <li>• <i>Clear commitment to integrity, honesty, transparency, equality and mutual respect in relationships with participants</i></li> <li>• <i>Evidence of fair dealing with all research participants</i></li> <li>• <i>Recording of dilemmas met and how resolved in relation to ethical issues</i></li> <li>• <i>Documentation of how autonomy, consent, confidentiality, anonymity were managed</i></li> </ul>	
<p><b>H. Relevance &amp; Transferability</b></p>	<p>12. Relevance and transferability evident</p>	<ul style="list-style-type: none"> <li>• <i>Sufficient evidence for typicality specificity to be assessed</i></li> <li>• <i>Analysis interwoven with existing theories and other relevant explanatory literature drawn from similar settings and studies</i></li> <li>• <i>Discussion of how explanatory propositions/emergent theory may fit other contexts</i></li> <li>• <i>Limitations/weaknesses of study clearly outlined</i></li> <li>• <i>Clearly resonates with other knowledge and experience</i></li> <li>• <i>Results/conclusions obviously supported by evidence</i></li> <li>• <i>Interpretation plausible and 'makes sense'</i></li> <li>• <i>Provides new insights and increases understanding</i></li> <li>• <i>Significance for current policy and practice outlined</i></li> <li>• <i>Assessment of value/empowerment for participants</i></li> <li>• <i>Outlines further directions for investigation</i></li> <li>• <i>Comment on whether aims/purposes of research were achieved</i></li> </ul>	
<p><b>I. Demographic Context</b></p>	<p>13. Relevant demographic information included to describe research context &amp; to allow synthesis.</p>	<ul style="list-style-type: none"> <li>• <i>Demographic information about main researcher/interviewer included (e.g. gender, profession)</i></li> <li>• <i>Relevant demographic information about participants included (e.g. gender, age, age of participants child)</i></li> </ul>	
	<p><b>Total Score:</b></p>		

**Appendix 1.3 – Table 1.0: Process of Meta-Ethnography**

<b>Noblit &amp; Hare (1988) Stages</b>	<b>Description from Atkins et al. (2008)</b>
1. Getting started	<ul style="list-style-type: none"> <li>• Determine a research question that could be informed by qualitative research.</li> </ul>
2. Deciding what is relevant to the initial interest.	<ul style="list-style-type: none"> <li>• Define the focus of the synthesis.</li> <li>• Locate relevant studies.</li> <li>• Inclusion decisions.</li> <li>• Quality assessment of included studies.</li> </ul>
3. Reading studies	<ul style="list-style-type: none"> <li>• Become familiar with the content and detail of studies.</li> <li>• Begin to extract metaphors of emerging themes.</li> </ul>
4. Determining how studies are related.	<ul style="list-style-type: none"> <li>• Create a list/grid/table to display themes and metaphors across papers.</li> <li>• Determine how themes are related.</li> <li>• Revise and merge themes into relevant categories.</li> </ul>
5. Translating the studies into one another.	<ul style="list-style-type: none"> <li>• Arrange papers chronologically</li> <li>• Compare paper 1 with paper 2, and the synthesis of these papers with paper 3 and so on.</li> </ul>
6. Synthesising translations.	<ul style="list-style-type: none"> <li>• List translated themes and subthemes in a table along with secondary themes derived from author interpretations.</li> <li>• Third order interpretation of themes leads to a line of argument synthesis.</li> </ul>
7. Expressing the synthesis.	<ul style="list-style-type: none"> <li>• Present results.</li> <li>• Publish and communicate findings.</li> </ul>

**Appendix 1.4 - Table 1.2: Quality Rating Scores by Study**

<b>Essential Criteria</b>	<b>Fong et al. (1993)</b>	<b>Cridland et al. (2014b)</b>	<b>Robinson et al. (2014)</b>	<b>Mount &amp; Dillon (2014)</b>
1. Clear statement of and rationale for research question/aims/purposes	3	3	3	3
2. Study thoroughly contextualised by existing literature	1	2	2	2
3. Method/design apparent consistent with research intent	1	3	3	1
4. Data collection strategy apparent and appropriate	2	3	2	2
5. Sample and sampling method appropriate	1	1	3	1
6. Analytic approach appropriate	2	2	2	1
7. Context described and taken account of in interpretation	3	3	1	3
8. Clear audit trail given	3	3	3	2
9. Data used to support interpretation	1	3	3	3
10. Researcher reflexivity demonstrated	3	1	1	1
11. Demonstration of sensitivity to ethical concerns	2	2	2	1
12. Relevance and transferability evident	2	3	2	2
13. Relevant demographic information included	2	1	1	3
<b>Total Scores</b>	26/39 (67%)	30/39 (77%)	28/39 (72%)	25/39 (64%)
	'Acceptable'	'Good'	'Acceptable'	'Acceptable'

## **Appendix 1.5 – Discussion of Quality Ratings of Included Papers by Criteria**

### *1. Clear statement of and rationale for research question/aims/purposes*

This criterion yielded the maximum scores for all papers. All four papers stated the research question or aim clearly along with sufficient justification for this. The link between existing research and the studies was demonstrated by all papers.

### *2. Study thoroughly contextualised by existing literature*

Although three studies contextualised the research well within existing literature, Fong et al. (1993) gave only a brief overview drawing on a limited range of literature, however, notably the literature might have been more limited at that time. None of the studies stated whether they had conducted a systematic review of the literature.

### *3. Method/design apparent consistent with research intent*

The studies selected a methodology and design that were consistent with their aims and all specified the rationale for using a qualitative approach. All studies except Fong et al. discussed the rationale for the specific qualitative methodology utilised. Only Cridland et al. and Robinson et al. discussed the epistemological grounding of their chosen methodology.

### *4. Data collection strategy apparent and appropriate*

All studies conducted face-to-face semi-structured interviews using an interview guide. This appeared appropriate for their aims and methodologies and would appear likely to capture the complexity and diversity in parents' experiences and context. Although all of the studies conducted some interviews with more than one member of a family unit, only Cridland et al. specified that in doing so they hoped to gain a multifaceted understanding of families' experiences.

#### 5. *Sample and sampling method appropriate*

One of the criteria that resulted in the lowest ratings related to the sample and sampling method. Fong et al. gave a particularly limited explanation of this process. All four studies described their selection criteria and all, with the exception of Fong et al., described how sampling was undertaken. Given the focus on individual experience the studies' samples may have allowed a "thick" description of experiences however, Fong et al. and Mount & Dillon recruited all participants from a parent support group which could limit the variety of experiences within the sample. None of the authors specified what their planned sample was and whether this was met.

#### 6. *Analytic approach appropriate*

The studies varied in how much information they gave about their analytic approach. All four studies specified the approach they used and these appeared appropriate to the methodology. Two papers had used a software package to assist with data analysis but none of the studies specified why they had or had not done so. All studies gave a brief description of how the coding systems or conceptual frameworks had evolved. Only Robinson et al. made reference to retaining the context of the data during analysis through the use of the researchers' field notes however, all papers appeared to portray participants' subjective meanings. Only Fong et al. described that participants were involved in checking the identified themes. In two papers more than one researcher was involved in data analysis; in Robinson et al. two researchers analysed the data and in Cridland et al. the research team reviewed transcripts to check themes identified by the primary researcher. Only Robinson et al. specified that they had reached data saturation. This was also the only paper to specify that they had sought deviant data during analysis however, in the results of all four papers it would appear that they also sought this.

#### 7. *Context described and taken account of in interpretation*

All papers with the exception of Robinson et al. described the social/physical and interpersonal context of data collection e.g., where interviews took place and the stance taken by the researcher. Notably, Fong et al. mentioned conducting one interview in the researchers' home which seemed unusual. The papers gave sufficient

detail of the research processes and it appeared that those carrying out the analysis had spent time “dwelling with” the data and interrogating it.

8. *Clear audit trail given*

All four papers gave a sufficient discussion of research processes to allow others to follow their research decisions. As such, this was an area of strength across the papers.

9. *Data used to support interpretation*

All papers, with the exception of one, used extensive verbatim quotations in the discussion of their findings and this was an area of relative strength across the papers. Fong et al. described themes primarily in a narrative with limited use of verbatim extracts which was a relative weakness for that individual paper. All four studies conveyed clearly how their interpretation had led to their conclusions.

10. *Researcher reflexivity demonstrated*

Evidence of researcher reflexivity was a relative weakness for all included papers. Fong et al. discussed this most extensively, for example, in reflecting on the possible impact of the researcher being a parent of a child with autism. Mount & Dillon did not discuss the potential implications of the researcher being known to participants. With the exception of Fong et al, the papers made limited reference to researcher reflexivity and none of the papers discussed the impact that the research had on the researcher.

11. *Demonstration of sensitivity to ethical concerns*

In terms of ethical practice, only two papers specified that they had received approval from an ethical committee. All papers described gaining consent from participants, however, only Robinson et al. described gaining consent as being an on-going process rather than a singular event. All papers used pseudonyms or assigned numbers to families to protect anonymity. Fong et al. discussed how they managed the ethical dilemma of protecting the identity of the one female adolescent, however, aside from this no papers noted whether they had encountered any ethical difficulties.



12. *Relevance and transferability evident*

Overall the relevance and transferability of findings was relatively well documented. The findings were discussed in the context of other theories and research and all papers reflected on the implications for current practice and/or policy. Most authors reflected about the extent to which their findings may be typical of parents in other contexts. All authors, except Mount & Dillon, discussed possible limitations of their study. The results and conclusions of the studies were supported by evidence and the interpretations made appeared plausible. With the exception of Fong et al., all papers indicated areas for future research.

13. *Relevant demographic information included*

In terms of the demographic context, all papers gave basic information about participants and their children however, some gave additional information for example, the specific diagnoses the young people had been given (Cridland et al., Robinson et al.) and all except Fong et al. specified when the young people had received their diagnosis. The papers tended to specify little or no information about the demographic details of the research team with the exception of Fong et al., and, to a lesser extent, Cridland et al.

## WoSRES

*West of Scotland Research Ethics Service*

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Date 05 November 2014  
 Direct line 0141 211 2102  
 E-mail WoSREC5@ggc.scot.nhs.uk

Dear Miss Craig

**Study title:** Experiences of Receiving and Living with a Diagnosis of an Autism Spectrum Condition: Listening to Young People and their Families.  
**REC reference:** 14/WS/1104  
**IRAS project ID:** 158736

Thank you for your letter of 25 October 2014. I can confirm the REC has received the documents listed below and that these comply with the approval conditions detailed in our letter dated 21 October 2014.

### Documents received

The documents received were as follows:

<i>Document</i>	<i>Version</i>	<i>Date</i>
Participant consent form [Assent form Young person]	3	25 October 2014
Participant consent form [Assent form Parent for child]	3	25 October 2014
Participant consent form [Parent]	4	25 October 2014
Participant consent form [Parent for child]	2	25 October 2014
Participant consent form [Young person 12-15yrs]	2	25 October 2014
Participant consent form [Young person 16-18yrs]	3	25 October 2014
Participant information sheet (PIS) [1 Parent]	6	25 October 2014
Participant information sheet (PIS) [2 Young People]	6	25 October 2014
Response to Request for Further Information [Response to ethics]		25 October 2014

### Approved documents

The final list of approved documentation for the study is therefore as follows:

<i>Document</i>	<i>Version</i>	<i>Date</i>
Copies of advertisement materials for research participants [Recruitment Poster 14.07.14 v1]	v1	14 July 2014
Covering letter on headed paper [Cover letter to ethics 12.09.14]	v2	12 September 2014
GP/consultant information sheets or letters [Letter to CAMHS Clinician 31.08.14 v2]	v2	31 August 2014
Interview schedules or topic guides for participants [Interview Schedules 17.08.14 v3]	v3	17 August 2014
Other [Helpful Services for Young People 05.09.14 v1]	v1	31 August 2014
Other [Helpful Serviced for Parents v1 31.08.14]	v1	31 August 2014
Other [West CAMHS Letter 21.08.14 v1]	v1	21 August 2014
Other [Letter from South CAMHS 20.08.14 v1]	v1	20 August 2014
Participant consent form [Young person 16-18yrs]	3	25 October 2014
Participant consent form [Young person 12-15yrs]	2	25 October 2014
Participant consent form [Consent form Parent 31.08.14 v3]	v3	31 August 2014
Participant consent form [Parent for child]	2	25 October 2014
Participant consent form [Assent form Parent for child]	3	25 October 2014
Participant consent form [Parent]	4	25 October 2014
Participant consent form [Assent form Young person]	3	25 October 2014
Participant information sheet (PIS) [2 Young People]	6	25 October 2014
Participant information sheet (PIS) [1 Parent]	6	25 October 2014
REC Application Form [REC_Form_12092014]		12 September 2014
Referee's report or other scientific critique report [Letter from Glasgow University 25.08.14 v1]	v1	25 August 2014
Research protocol or project proposal [MRP Proposal 05.09.14 v11]	11	05 September 2014
Response to Request for Further Information [Response to ethics]		25 October 2014
Summary CV for Chief Investigator (CI) [SOC CV 05.09.14 v1]	v1	05 September 2014
Summary CV for student [RC CV 05.09.14 v1]	v1	05 September 2014
Summary, synopsis or diagram (flowchart) of protocol in non technical language [Plain English Summary 05.09.14 v1]	v1	05 September 2014


You should ensure that the sponsor has a copy of the final documentation for the study. It is the sponsor's responsibility to ensure that the documentation is made available to R&D offices at all participating sites.

**14/WS/1104**

**Please quote this number on all**

**correspondence**

Yours sincerely



**Mrs Sharon Macgregor  
REC Manager**

Copy to: Dr Suzy O'Connor, University of Glasgow  
Ms Emma-Jane Gault, University of Glasgow  
Ms Joanne McGarry, NHS GGC

## Appendix 2.1 - NHS Research and Development Approval

Administrator: Lorn Mackenzie  
Telephone Number: 0141 211 1743  
E-Mail: [Lorn.Mackenzie@ggc.scot.nhs.uk](mailto:Lorn.Mackenzie@ggc.scot.nhs.uk)  
Website: [www.nhsggc.org.uk/r&d](http://www.nhsggc.org.uk/r&d)

R&D Management Office  
Western Infirmary  
Tennent Institute  
1<sup>st</sup> Floor 38 Church Street  
Glasgow, G11 6NT



07/11/2014

Ms Rona Craig  
Institute of Mental Health  
and Wellbeing  
Administration Building,  
Gartnavel Royal Hospital  
1055 Great Western Road  
Glasgow, G12 0XN

### NHS GG&C Board Approval

Dear Ms Craig,

Study Title:	Experiences of Receiving and Living with a Diagnosis of an Autism Spectrum Condition: Listening to Young People and their Families.
Principal Investigator:	Ms Rona Craig
GG&C HB site	South & West Child & Adolescent Mental Health Services (CAMHS)
Sponsor	NHS GG&C
R&D reference:	GN14KH469
REC reference:	14/WS/1104
Protocol no: (including version and date)	v11.0 Date:05.09.14

I am pleased to confirm that Greater Glasgow & Clyde Health Board is now able to grant Approval for the above study.

#### Conditions of Approval

1. For Clinical Trials as defined by the Medicines for Human Use Clinical Trial Regulations, 2004
  - a. During the life span of the study GGHB requires the following information relating to this site
    - i. Notification of any potential serious breaches.
    - ii. Notification of any regulatory inspections.

It is your responsibility to ensure that all staff involved in the study at this site have the

appropriate GCP training according to the GGHB GCP policy ([www.nhsggc.org.uk/content/default.asp?page=s1411](http://www.nhsggc.org.uk/content/default.asp?page=s1411)), evidence of such training to be filed in the site file.

2. For all studies the following information is required during their lifespan.
  - a. Recruitment Numbers on a quarterly basis
  - b. Any change of staff named on the original SSI form
  - c. Any amendments – Substantial or Non Substantial
  - d. Notification of Trial/study end including final recruitment figures
  - e. Final Report & Copies of Publications/Abstracts

Please add this approval to your study file as this letter may be subject to audit and monitoring.

Your personal information will be held on a secure national web-based NHS database. I wish you every success with this research study

Yours sincerely,



Lorn Mackenzie  
Senior Research Administrator

## Appendix 2.2 - Recruitment Poster



### Research exploring the experiences of young people with autism spectrum conditions and their parents/carers.

We are carrying out a study to explore what it is like to receive a diagnosis of an autism spectrum condition and what life is like with this diagnosis for young people and their parent/carers.

We hope that the findings from the study might help to improve the experiences of other families in the future.

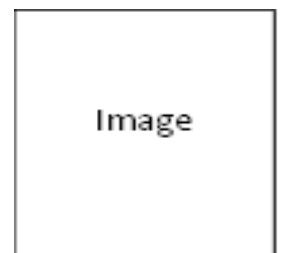
#### Who can take part?



Young people aged 12-18 years old who received a diagnosis of an autism spectrum condition between 6 months and 4 years ago (and when they were at least 11 years old) and one of their parent/carers. Young people or their parent/carer must be currently attending the Child & Adolescent Mental Health Service (CAMHS).

#### What does it involve?

- An informal meeting (30-45mins) with the researcher to get to know families to help them feel more comfortable.
- An interview with young people and parent/carers (separately) which will each take up to one hour.
- Young people will receive a £10 book voucher to say thank you for their time.



#### What do I do?

If you might like to take part in the study please ask a member of the CAMHS team who will give you more information. Alternatively you can contact our researcher, Rona Craig, by email: [r.craig.1@research.gla.ac.uk](mailto:r.craig.1@research.gla.ac.uk) or by telephone on 0141 201 0915.



**Thank you for your time!**

## Appendix 2.3 – Participant Information Sheet for Parents/Carers



### ***Participant Information Sheet 1 – For Parents/Carers***

#### ***Experiences of Receiving and Living with a Diagnosis of an Autism Spectrum Condition: Listening to Young People and their Families.***

This research project is looking at families' experiences of receiving and living with a diagnosis of an autism spectrum condition. There is some further information about the research study below for you to read before you and your child consider whether you would like to take part.

Thank you for reading this information.

#### **Who is carrying out the research?**

Rona Craig, (Trainee Clinical Psychologist) from the University of Glasgow is carrying out the study as part of her qualification for the Doctorate in Clinical Psychology. The project will be supervised by Dr Suzy O'Connor, University of Glasgow, Institute of Mental Health & Wellbeing and Dr Simon Smith, NHS Greater Glasgow & Clyde.

#### **What is the research about?**

The aim of the project is to explore the experiences of young people who have been diagnosed with an autism spectrum condition (ASC). We would like to find out what it was like for them to receive this diagnosis and what their lives have been like since. We are also interested in how the parents of these young people experienced this process. We hope that this research might help to improve the experience of assessment and receiving and living with a diagnosis of an ASC for parents and young people in the future.

#### **Do we have to take part?**

No, you and your child can decide whether or not you would like to take part. If you choose to take part you can withdraw at any time (without having to give a reason) with your care unaffected.

#### **Why have I been asked?**

You have been asked to take part in this study by the clinician you are working with because you have a child aged between 12-18 years old who received a diagnosis of an ASC between 6 months and 4 years ago (and after their 11<sup>th</sup> birthday). The diagnosis of an ASC can include diagnoses of; autism, Asperger's syndrome, atypical autism, high functioning autism or pervasive developmental disorder. To take part in the study, your child should have been aware of the purpose of their ASC assessment

at the time it was carried out. You and your child should also be able to remember and discuss the process of assessment and receiving a diagnosis verbally and in English.

### **What would happen if we took part in the research?**

We plan to interview young people and a parent/carer to get both view-points so it is important that both you and your child are interested in taking part. If you are interested in taking part, **please contact Rona Craig by phone or email** (contact details are at the end of this letter).

What happens next?

1. Rona will answer any questions that you (and/or your child) might have by speaking to you on the telephone when you call (or arranging a suitable time) or by email if you prefer.
2. If you and your child would like to take part, Rona will arrange to meet you both somewhere you are comfortable (e.g. a G.P. practice, CAMHS Service, a carer's centre or your child's school) for around 30-45 minutes.

At this meeting Rona will:

- Ask you and your child some questions to get to know you, to try and put your child at ease and reduce any anxiety you and/or your child may have about participating in the research.
  - Discuss and agree how she might recognise that your child is feeling anxious or uncomfortable and what might help them to feel more relaxed (e.g. having a break, speaking about something they are interested in).
  - Discuss with you and your child whether you both feel able to cope with an interview situation. If you think that your child or you might find an interview stressful you are able to withdraw from the study at any time.
  - Gain your consent or assent for your child to participate (this depends on their age and whether their CAMHS clinician thinks they are able to give informed consent themselves).
3. Rona will then arrange to meet with the young people and their parent/carers separately to carry out the research interview. If a young person would like their parent/carer to be present during their interview this can be discussed.

### **What will happen in the research interviews?**

Prior to the interview commencing, Rona will ensure that you would still like to participate in the interview and will ask you to sign a written consent form to give your own consent (your child will also be asked to give their own consent or assent prior to their interview).

The research interview will take up to one hour. Rona will ask questions about your experiences of your child being assessed for an ASC, receiving a diagnosis of an ASC and your experiences of living with your child's diagnosis. Rona will also ask the young person about their experiences of having an assessment, receiving and living with a diagnosis of an ASC.

Rona will have some specific questions to ask but she is most interested in hearing about your experiences from your point of view.

### **Where will the Research Interviews take place?**

Rona will meet with parents/carers and young people at a time and place that is convenient and in which they feel comfortable e.g. in a local G.P. practice, CAMHS Team, local carer's service or the child's school. This will be discussed and arranged



with you and your child. Unfortunately we cannot reimburse travel expenses and it is not possible to carry out interviews at home.

### **What happens to our information?**

Rona will record the interviews on a Dictaphone and then will type them out. This information will be kept securely on an encrypted laptop computer. Each participant will be given a pseudonym so that they cannot be identified (as will the names of any individuals mentioned during the interview).

Aside from the research report discussed below, everything that you and your child say will be kept confidential, this includes that information given by yourself or your child will not be routinely shared with the other or with CAMHS clinicians unless Rona is concerned that someone might be at risk of harm. In these circumstances Rona is obligated to pass on information to the relevant professionals however, she would try to discuss this with you first. Representatives of the study Sponsor, NHS GG&C, may look at your information to make sure the study is being conducted correctly.

The final report will include the overall themes from interviews with parents/carers and those with young people along with quotations from individual interviews. Only you and your child will be able to identify which quotations are yours. You may also be able to identify each other's quotations. Rona will ask whether you and your child would like a summary of the results to be sent to you (by post or email) when the study is completed. The final report will also be available online for the public to access. It is planned that the report will be published in an academic journal and may be presented to CAMHS teams and at clinical or research conferences.

### **Who will know I am taking part in the research?**

If your child currently attends a CAMHS or Child Development Centre the clinician you are working with will be informed that you plan to participate in the study. Someone at the location of the meeting and interviews will be informed that we are meeting to conduct a research interview.

### **What are the potential benefits of participating?**

We hope that the research might help other young people with a diagnosis of an ASC and their families to have better experiences of assessment, receiving and living with a diagnosis in the future. Some people find it helpful to have an opportunity to talk about and make sense of their experiences and to feel that they have been listened to. The young people who take part in the research will be given a £10 book voucher and certificate to recognise their efforts.

### **What are the potential disadvantages of participating?**

We do not anticipate that participants will find the interviews unduly stressful or distressing. However, we understand that some people, particularly those with a diagnosis of an ASC, may find it stressful to take part in a research interview. We hope that the initial meeting will help participants to feel more comfortable during the interview. Rona is also a trainee clinical psychologist with experience of working with children and young people with ASCs.

We recognise that some experiences might be difficult to describe and it is possible that some people might find the interview upsetting for this reason. If any participants become upset during an interview Rona will allow them some time, suggest they have a break or stop the interview. If any young people become very upset during the interview, their parent/carer will be informed (and, if necessary their CAMHS or Child Development Centre clinician if they are attending these services).

### **Who has reviewed the study?**

This study has been reviewed by the University of Glasgow Doctorate in Clinical Psychology Course team. It will also be reviewed by the NHS Greater Glasgow & Clyde Research and Development Service and a West of Scotland Research Ethics Committee.

### **If you would like to take part:**

If you and your child might like to take part please contact Rona Craig by **phone**: 0141 201 0915 or by **email**: [r.craig.1@research.gla.ac.uk](mailto:r.craig.1@research.gla.ac.uk), to discuss this.

### **Any further questions?**

If you or your child have any questions about the research please do not hesitate to contact Rona by **phone**: 0141 201 0915 or by **email**: [r.craig.1@research.gla.ac.uk](mailto:r.craig.1@research.gla.ac.uk). You could also speak to your child's CAMHS clinician about the study.

If you would like to speak to someone who is not directly involved in the study you can contact Dr Hamish MacLeod, Programme Director for Doctorate in Clinical Psychology. He will be able to answer questions or give advice about participating in the study. You can contact him by **email**: [Hamish.McLeod@glasgow.ac.uk](mailto:Hamish.McLeod@glasgow.ac.uk), or by **phone**: 0141 211 3920.

### **If you have a complaint about any aspect of the study?**

If you are unhappy about any aspect of the study and wish to make a complaint, please contact the researcher in the first instance but the normal NHS complaint system is also available to you.

***Thank you for your time.***

## Appendix 2.4 – Participant Information Sheet for Young People



### **Participant Information Sheet 2 – For Young People**

#### ***Experiences of Receiving and Living with a Diagnosis of an Autism Spectrum Condition: Listening to Young People and their Families.***

Hi!

We are asking whether you and your parent/carer would be interested in taking part in a research study. Before you decide whether you would like to join in, it is important that you know what the study is about, why the study is being carried out and what it would involve for you.

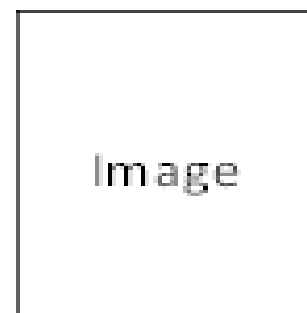
You might also find it helpful to talk about the study with a parent or carer or someone who gave you this information sheet (it might have been a doctor, nurse, therapist or psychologist). If you have any questions about the study, you or your parent/carer can phone us and we can discuss it with you (if you like) and/or your parent/carer.

Thank you for reading this information.

Rona

#### **Who is doing this research?**

Rona Craig is carrying out the research project. Rona is a Trainee Clinical Psychologist (she is learning to be a Clinical Psychologist) from the University of Glasgow. She has to complete a research project as part of her training.



#### **What is the research about?**



We would like to hear what it is like for young people and their parents/carers to have an assessment for an autism spectrum condition and to be told about their diagnosis. We would also like to hear what their lives have been like since they got this diagnosis. We hope that the *research might help to improve the experiences of other young people*

who receive a diagnosis of an autism spectrum condition in the future.

#### **Why have I been asked to take part?**

You have been asked to take part in this study because you are between 12 and 18 years old and have a diagnosis of an autism spectrum condition



(this includes diagnoses like: autism, Asperger's syndrome, atypical autism, high functioning autism or pervasive developmental disorder). You or your parent/carer said that you might like to take part in research and would like more information about this study.

### Do I have to take part?



No, you can decide if you would like to take part or not. Even if you think you would like to take part you can still change your mind at any time, you do not need to give a reason. Whether you do or do not take part in the research it will not change any of the services you have (e.g. if you see a therapist or doctor in CAMHS this will not change).

### What would happen if I took part in the research?

If both you and your parent/carer would like to take part in the research project your parent/carer should get in touch with Rona (by telephone or email).

What will happen next is:

1. Rona will contact your parent/carer by phone or email and you (if you would like to). She will tell you more about the study and answer any questions you might have.
2. If you would still like to take part, Rona will arrange to meet you both somewhere that you feel comfortable (this might be at your G.P. (local doctor's) practice, CAMHS Service or a private room in your school). The meeting will take around 30-45 minutes.

At this meeting Rona will:

- Ask you and your parent/carer some questions to get to know you better (e.g. what things you like to do, what school you go to, if you have any brothers or sisters).
- Answer any questions you have about the study.
- Talk to you and your parent/carer to check that you feel comfortable talking to her and taking part in a research interview.

3. After the meeting, Rona will arrange to meet with any young people and their parent/carer separately to carry out the research interview.



### What will happen in the research interview?

Before the interview starts, Rona will check that you would still like to do the interview and if you do she will ask you to sign your name to say so.

The research interview is a conversation. It will last around 45 minutes - 1 hour. Rona will usually speak to young people and parents/carers by themselves for the research interview (although some young people might like their parent/carer to stay in the room with them and this is



fine).

Rona will ask you some questions and she will listen to what you say. She will ask about what it was like to have an assessment for an autism spectrum condition. She will ask what it was like to be told you had a diagnosis of an autism spectrum condition and what your life has been like since you got this diagnosis. It is not a test and there are no right or wrong answers. Rona would just like to find out about your own experiences.

### **Where will the Research Interviews take place?**

Rona will meet with young people in a place they feel comfortable e.g. in a private room in their school or at a nearby CAMHS Team. Unfortunately we will not be able to give money for your travel costs and Rona cannot meet people in their houses.



### **What happens to the information I say in the interview?**

Rona will record the interview using a Dictaphone (a little sound recorder) so that she can remember all of the conversation. Then she will type it into a computer. Rona will keep your name and other information like where you live private. She will give you a pretend name on the computer file so only Rona, you and your parent/carer would know which information is yours.



Rona will then find out what all the young people with a diagnosis of autism spectrum condition say about their experiences and she will write this in her research report. Some of the things that you say and that your parent/carer say will be written in the report as quotations. Other people will be able to read the final report but they will not know the real names of the people who took part.

Apart from the report, Rona will keep the things you say private (e.g. she won't tell your teachers, your friends or her friends about what you say). Rona usually will not tell your parent/carer what you say (but they will be able to read short bits of what you said in the report). The only time that Rona cannot keep what you say private is if she is worried someone might be in danger. Then it is Rona's job to tell other people so that she can keep everyone safe.



### **Who will know I am taking part in the research?**

If you or your parent/carer usually meets with someone in a CAMHS team or at the Child Development Centre (e.g. a doctor or therapist) we will let them know that you are planning to take part in the study.

We will tell someone who works in the building where we meet that we are meeting to carrying out a research interview but we will not tell them what it is about.



Representatives of the study sponsor may look at information to make sure the study is being conducted correctly but they would keep your personal information private.

### Why might it be good to take part in the research project?



We hope that the research might help other young people with a diagnosis of an autism spectrum condition/diagnosis have better experiences of assessment, getting and living with a diagnosis in the future. Some people enjoy taking part in research as it might make them feel good that they could be helping other people. Some people might also like having a chance to speak to someone about their experiences. The young people who take part in the research will be given a £10 book voucher and a certificate to say thank you for their time.

### What might be bad about taking part in the research project?

Some people might find it worrying or stressful to talk to someone or to go to a new place for a research interview. Rona will meet with everyone first to get to know them a little and she will try to meet them in the same place for the interview. Rona will ask if there is anything that she can do to help people feel relaxed during the interview (e.g. have breaks during the interview to talk about things they like).



Some people might find it upsetting to talk about some of their experiences. It is OK for people to get upset during the interview. Rona will listen and wait until they feel better. She might suggest they have a break from the interview or they might want to stop the interview. If anyone is very upset Rona might let their parent/carer know (or if they usually see anyone in CAMHS) so that they can help them to feel better.

### Do you have any questions?



If you have any questions about the project you or your parent/carer can contact Rona by **email:** [r.craig.1@research.gla.ac.uk](mailto:r.craig.1@research.gla.ac.uk) or by **phone:** 0141 201 0915. You could also speak to your CAMHS worker about the study.

If you would like to speak to someone who is not directly involved in the study you can contact Dr Hamish MacLeod, Programme Director for Doctorate in Clinical Psychology. He will be able to answer questions or give advice about taking part in the study. You can contact him by **email:** [Hamish.McLeod@glasgow.ac.uk](mailto:Hamish.McLeod@glasgow.ac.uk), or by **phone:** 0141 211 3920.

### If you would like to take part:

If you and your parent might like to take part please contact Rona by **phone:** 0141 201 0915 or by **email:** [r.craig.1@research.gla.ac.uk](mailto:r.craig.1@research.gla.ac.uk), to let her know.

*Thank you for your time!*

## Appendix 2.5 – Letter to CAMHS Case Manager



University  
of Glasgow



University of Glasgow  
Department of Mental Health and Wellbeing  
Gartnavel Royal Hospital  
Administration Building  
1055 Great Western Road  
Glasgow, G12 0XH

Email: r.craig.1@research.gla.ac.uk

### RE: Child's Name DOB

Dear Clinician,

As we discussed, \_\_\_\_\_ and their parent/carer \_\_\_\_\_ contacted me to note their interest in participating in a research study titled '*Experiences of Receiving and Living with a Diagnosis of an Autism Spectrum Condition: Listening to Young People and their Families*'. I am writing to inform you that I have arranged to meet with \_\_\_\_\_ and their parent/carer to conduct research interviews about their experiences of receiving and living with a diagnosis of an autism spectrum condition.

You indicated that based on your assessment, \_\_\_\_\_ will/will not be able to give informed consent to participate in the study. I will gain consent and assent from \_\_\_\_\_ and their parent/carer \_\_\_\_\_ as indicated.

Although we do not anticipate that the research interviews will cause significant distress for participants some may find it upsetting to talk about their experiences. In this case, young people will be encouraged to discuss any difficult feelings with you at your next meeting and parents will be encouraged to seek support via their general practitioner. I will not be in contact again unless any concerns about risk should arise. In this instance, I will contact the relevant services in line with NHS GG&C policy which may include yourself or your colleagues.

Thank you for your help in recruiting participants to this study.

Yours sincerely,

Rona Craig

Trainee Clinical Psychologist

## Appendix 2.6 – Semi-Structured Interview Schedules

### Interview Schedule - Young Person

*“You might remember a little about today’s meeting from when we spoke about it the last time I met with you and your (Mum/Dad/Carer’s name). Today is called the research interview. It will last between 45 minutes and 1 hour. I will ask you some questions about what it was like to have an assessment for an autism spectrum condition, to be told that you had a diagnosis of an autism spectrum condition and what your life has been like since you got that diagnosis. I will listen carefully to your answers. Sometimes I will ask you some more questions about what you have said. I will also record the interview using this tape recorder so that I can type our conversation onto the computer afterwards. Remember that there are no right or wrong answers. I would just like to hear about your own experiences.*

*Remember that some of the things that you say (called quotes) will be written in the report. Other people will be able to read the final report but they will not know the real names of the people who took part. Only you and your (parent/carer) will know which things you said in the report. Apart from the report, I will keep the things you say private. There is one other time that I cannot keep what you say private. That would be if I was worried that you or someone else might be in danger. Then it is my job to tell other people so that I can keep everyone safe.*

*You do not have to take part in this interview, it is your choice. Remember that you can tell me at any time if you would like to have a break or would like to stop the interview (remind participant of agreed method). You can also tell me if you decide that you do not want to be part of the research project at all”.*

- *Check consent and get participant to sign written consent/assent form as appropriate.*
- *Discuss and remind re: prompts (break sign, would like to finish the interview, time to speak about special interest etc.).*

#### **Interview:**

***“I know that in (year) you were given a diagnosis of an autism spectrum condition and the particular name of your diagnosis is (autism/ Asperger’s syndrome/ high functioning autism)”.***

#### **1. Experiences of assessment**

*First I would like to ask you some questions about the assessment you had to get your diagnosis.*

***a) What happened during your assessment for an ASC?***

***b) What it was like to have an assessment for an ASC?***

#### **Prompts:**

- *How did you feel about having an assessment for an ASC beforehand? (Happy? Sad? Worried? Confused? Scared?)*



- How did you feel during the assessment? (Happy? Sad? Worried? Confused? Scared?)

**c) *Is there anything that might have made your experience of assessment better?***

- When did you first hear about autism?
- Did you know much about autism before your assessment?

## **2. Experiences of receiving a diagnosis –**

***Now I would like to ask you some questions about when you were told about your diagnosis.***

***I know you got your diagnosis in (year).***

**a) *Can you tell me what happened when you were told about your diagnosis?***

**Prompts:**

- Who told you?
- Can you remember what you were told?
- Was the appointment helpful in any way?
- Was the appointment unhelpful in any way?

**b) *How did you react to the diagnosis?***

**Prompts:**

- What did you feel like? (for example, Sad? Happy? Relieved? Surprised? Upset? Shocked?) / Say? / Do?
- What did you think about your diagnosis when you were first told?
- Did you know what an ASC was when you received your diagnosis/?

**c) *How did other people react to your diagnosis?***

**Prompts:**

- How did your family react?
- How did your teachers react?
- How did friends react?

**d) *Is there anything that would have made your experience of being told your diagnosis better?***

### 3. Experiences of living with a diagnosis

***Now I'd like to ask you some questions about what it's been like since you got your diagnosis.***

***a) Do you think your life changed in any way since you got a diagnosis of an ASC?***

**Prompts:**

- How was it changed?
- Has your diagnosis been helpful for you in any way?
- Has your diagnosis been unhelpful for you in any way?
- Is there anything that has helped you to understand your diagnosis?
- Is there anything that has helped you to accept or get used to your diagnosis?

***b) What is it like to have a diagnosis of an ASC?***

***c) What do you think about your diagnosis now?***

**Prompts:**

- What does having an ASC mean to you?
- How would you explain your diagnosis to someone else?
- Are there bad parts of having a diagnosis of an ASC for you?
- Are there good parts of having a diagnosis of an ASC for you?

***d) Is there anything that might make your experiences of having an ASC better?***

***e) Do you think having a diagnosis of an ASC has changed what you expect in the future?***

- ***How has it changed?***
- ***Why do you think that has changed?***

***Is there anything else about your experiences of ASC that I have not asked about that you would like to tell me?***

- ~ Thank participant for their time & give certificate and book voucher & list of helpful services & copies of consent forms.
- ~ Ask if they would like a summary of the findings of the study when it is completed.
- ~ If so, by post or email?

## **Interview Schedule - Parent/Carer**

*“You might recall from our previous meeting that today’s interview is likely to last up to one hour. I will ask you some questions about your experiences of (child’s name) being assessed for an autism spectrum condition, receiving a diagnosis of an autism spectrum condition and your experiences of living with your child’s diagnosis. I have some specific questions to ask but I am interested in hearing about your experiences from your point of view. I might also ask some follow up questions to get more information about some of things you say.*

*You will recall that you and your child will be given pseudonyms to protect your anonymity. Quotations from your interview will be included in the research report however, only you and your child will know which are yours. Other than the research report, the information we discuss is confidential unless I am worried that you, your child or someone else may be at risk of harm. In such cases, I would have to pass on information to the relevant services however, I would try to speak to you about this first, if possible.*

*Remember that you have the right to withdraw from the study without any impact on the services or care you or your child receive”.*

***Check consent and get participant to sign written consent form.***

*“Please let me know if you would like a break at any time or if you would like to stop the interview”.*

### **1. Experiences of assessment**

***a) Can you tell me what happened during your child’s assessment?***

***b) Can you tell me what it was like for you during your child’s assessment?***

**Prompts:**

- How did you find the process of assessment?
  - How did you feel during the assessment process?
  - 
  - c) How do you think your child felt during the assessment process?
- d) Is there anything that might have made your experience of assessment better?***

### **2. Experiences of receiving a diagnosis**

***a) Can you tell me what it was like when you were told about your child’s diagnosis?***

- What happened when you were told?
- How did you feel?

- What did you think about your child's diagnosis when you were first told?
- Did you know much about ASCs before you were told about your child's diagnosis?

**b) *How did your child react to their diagnosis?***

**c) *How did other people react to your child's diagnosis?***

**Prompts:**

- How did family, friends, teachers react?

**d) *Is there anything that would have made the experience of being told your child's diagnosis better for you?***

**e) *Is there anything that would have made the experience of being told their diagnosis for your child?***

### **3. Experiences of living with a diagnosis**

**a) *Has your life changed in any way since your child got a diagnosis of an ASC?***

- In what ways has it changed?
- Has the diagnosis been helpful for you in any way?
- Has the diagnosis been unhelpful in any way?
- Is there anything that has helped you to understand or accept your child's diagnosis?

**b) *Has your child's life changed in any way since they got their diagnosis?***

- In what ways has it changed?
- Has the diagnosis been helpful for them in any way?
- Has the diagnosis been unhelpful for them in any way?
- Is there anything that has helped your child to understand or accept their diagnosis?

**c) *What is it like to have a child with a diagnosis of an ASC?***

**Prompts:**

- How would you describe your child to someone else?
- How would you explain your child's diagnosis to someone else?
- What does the diagnosis mean to you?
- What are the bad parts of your child having a diagnosis of an ASC?
- What are the good parts of your child having a diagnosis of an ASC?

- Do you think there are differences to having an adolescent child with an ASC rather than a younger child?
- What differences do you think there are?

**d) *What do you think it is like for your child to have a diagnosis of an ASC?***

**Prompts:**

- How might they describe their diagnosis?
- What does the diagnosis mean to them?
- What are the bad parts for your child of having a diagnosis of an ASC?
- What are the good parts for your child of having a diagnosis of an ASC?

**e) *Is there anything that would make the experience of having an adolescent child with an ASC better?***

***Do you think that your expectations for the future have changed since your child received their diagnosis?***

- *How have they changed?*
- *Why do you think that is?*

***Is there anything else about your experiences of ASC that I have not asked about that you would like to tell me?***

- ~ ***Thank participant for their time & give list of helpful services & copies of content forms.***
- ~ ***Ask if they would like to be notified when the final thesis is available at: <http://theses.gla.ac.uk> and if they would like a summary of the findings.***
- ~ ***If so – by post or email?***

***Examples of General Prompt and Probe Questions:***

- *What is that like?*
- *What does that mean for you?*
- *What do you think about that?*
- *Can you tell me more about that?*
- *What do you mean by \_\_\_\_ ?*
- *How does it make you feel?*

## Appendix 2.7 – Example of Participant Consent Form for Parent/Carer



University  
of Glasgow



**University of Glasgow**  
Department of Mental Health and Wellbeing  
Gartnavel Royal Hospital  
Administration Building  
1055 Great Western Road  
Glasgow, G12 0XH  
Email: r.craig.1@research.gla.ac.uk

### Participant Consent Form – Parent/Carer

**Title of project:** Experiences of Receiving and Living with a Diagnosis of an Autism Spectrum Condition: Listening to Young People and their Families.

**Name of researcher:** Rona Craig

Please initial each box if you agree with the statement:

I have read and understood the information sheet for parents/carers (dated 13.01.15, version 7) for the above study. I have had time to think about the information given to me. I have had the opportunity to get satisfactory answers to any questions that I may have had.

I understand that my participation is voluntary. I am free to withdraw from this study at any time, without giving a reason and without my child's medical care or legal rights being affected.

I understand that this interview will be audio recorded but that any information that could identify me will be removed from the transcripts of this recording.

I understand that some quotations from the interview may be used in the write up and future publications of the study, but that only myself and my child would be able to identify which quotations are mine.

I understand that some of the data collected during the study may be looked at by Clinical Psychologists supervising the project (Dr Simon Smith and Dr Suzy O'Connor).

I understand that some of the data collected during the study may be looked at by the study sponsor (NHS Greater Glasgow and Clyde) for purposes of audit only.

I agree to take part in the above study.



## Appendix 2.8 – Example of Participant Consent Form for Young People



University  
of Glasgow



**University of Glasgow**  
Department of Mental Health and Wellbeing  
Gartnavel Royal Hospital  
Administration Building  
1055 Great Western Road  
Glasgow, G12 0XH  
Email: r.craig.1@research.gla.ac.uk

### Participant Consent Form – Young Person – 16-18 years

This form is to ask whether you give your permission to take part in the study.

**Title of project: Experiences of Receiving and Living with a Diagnosis of an Autism Spectrum Condition: Listening to Young People and their Families.**

**Name of researcher: Rona Craig**

Please put your initials in the boxes if you agree with each statement:

I have read the information sheet for young people dated 25.10.14 (version 6) for the study named above.

I have had the chance to discuss this study and ask questions.

I have received satisfactory answers to all of my questions.

I have received enough information about the study.

I understand that I do not have to take part in the study and that I can withdraw at any time, without giving any reason. My medical care or legal rights would not be affected.

I understand that this interview will be audio recorded but that any information that could identify me will be removed from the transcripts of this recording.

I understand that some quotations from the interview may be used in the research report and future publications of the study however, only me and my parent/carer will be able to identify me from these quotations.

I understand that some of the data collected during the study may be looked at by Clinical Psychologists supervising the project (Dr Simon Smith and Dr Suzy O'Connor).

I understand that some of the data collected during the study may be looked at by the study sponsor (NHS Greater Glasgow and Clyde) for purposes of audit only.

I agree to take part in the above study



-----  
Name of Participant

-----  
Date

-----  
Signature

-----  
Name of Parent

-----  
Name of Person taking consent

-----  
Date

-----  
Signature

***1 copy to the patient, 1 copy to the researcher, 1 original for the participant's CAMHS clinical notes.***

**Appendix 2.9 - Sample of Analysed Transcript – Young Person (Max)**

	<b>95. No, that's fine. And can you remember what happened at that appointment?</b>	
Assessment as something done to him not with him  Given the diagnosis and that was it – expectation of something more	96. They just told me that they diagnosed me with high functioning autism and that's basically it (laughs)	<i>They diagnosed me – <u>felt like they did it to him rather than with him?</u></i>  <i>That's basically it – wanted/expected more from receiving the diagnosis/the feedback session? <u>laughs – at absurdity of?</u></i>
	<b>97. Yeah, and what did you feel like when they said that?</b>	
Pleased that he got the diagnosis but worried he would be bullied  Difficult to make sense of emotions on hearing the diagnosis	98. I was pleased that (pause) I finally got the diagnosis but knowing that autism and being (pause) and had, very, was, is, I can't even think	Pleased he got the diagnosis, <u>finally – had been waiting a long time for it</u> <u>But – struggles to find words, make sentences, hesitant – difficult for him to make sense of?</u>
	<b>99. It's ok, you're doing well.</b>	
Worried that bullies would see him as a victim for having autism	100. Is like a bullying type, bullies would really think of victims	Bullies would think of victims – <u>worried he would be bullied because of autism – idea of autism as a weakness, something to be picked on</u>
	<b>101. Ok</b>	
Kept his autism and emotions hidden to protect himself	102. So I really kept it hidden mostly	Kept it hidden – to prevent bullying
	<b>103. Ok</b>	
	104. ..and didn't show my emotions	Didn't show emotions – <u>sounds lonely, isolated?</u>
	<b>105. Ok. and was that a change do you think? Were you somebody who may be used to show your emotions more?</b>	
	106. No, I'm, my style is really always really to hide my emotions	My style – <u>suggests this as a preference, what he does</u>
	<b>107. Ok</b>	
On going process of making sense of himself – what is him and what is autism	108. ...probably because of the autism but oh well.	Probably because of the autism – <u>still trying to make sense of what is just "his style" as a person and what is autism? – on going process</u>

### Appendix 3.0 - Sample of Analysed Transcript – Parent (Charlotte)

	172. And actually to a lot of people around me as well	Clearer to others – <u>perhaps added support to her own 'sense'?</u>
	<b>173. Ok</b>	
Wanting to know what we're dealing with	174. and I was hopeful that that would give us something a bit more, kind of concrete to work with	Felt hopeful that clearer difficulties would lead to something concrete ( <u>clearer difficulties would lead to diagnosis?</u> ) <i>"work with"</i> – <u>idea of then being able to do something, previously did she feel stuck?</u>
	<b>175. sure</b>	
Hoped diagnosis would guide  Things got worse before they could get better	176. in terms of, you know, I suppose the purpose of the diagnosis is if there is a diagnosis, is to provide us with guidance in terms of how to support her and I was hoping that, you know, that would be the route in, mm, so things had got worse but in some ways (laughs) I was hoping it would come up with something	diagnosis as giving guidance to support her <i>'guidance' – help give direction – did they feel lost?</i>  <i>'route' – mirrors this</i>  Although things had got worse – felt this might help <i>Laughter – at the contradiction of worsening as a positive thing – 'get worse before it can get better' idea? Or 'rock bottom'?</i>
	<b>177. sure</b>	
Wanting to know what we're dealing with	178. maybe a bit more concrete to get my teeth into, does that make sense?	<i>Repetition of 'concrete' – looking for something concrete rather than 'feeling' or 'sense' – would this help to confirm her sense and provide direction?</i> <i>'teeth into' – connotations of hard work, getting right into it – messy, painful?</i>
	<b>179. Yeah, that does make sense</b>	
Relief	180. So I have to say that there was some relief at the diagnosis	Sense of relief
	<b>181. Mm hm</b>	
'the whole milder thing...oh well it's actually not that bad'	182. Mm although the whole milder thing, I, I it was all, tended to say oh well it's actually not that bad but I know that, you know,(pause) it's very difficult for Sophie because of (pause)	'Milder thing' difficult – undermining Sophie's experiences?



## Appendix 3.2 - Major Research Project Proposal

### ***Experiences of Receiving and Living with a Diagnosis of an Autism Spectrum Condition: Listening to Young People and their Families.***

#### **Abstract**

*Background:* Autism spectrum conditions (ASCs) or 'disorders' are a range of developmental conditions characterised by difficulties in social communication, social interaction and social imagination. There is a need for more research into the lived experiences of young people who receive a diagnosis of an ASC and their families to further our clinical understanding and to aid service development. In particular, there is limited research exploring young people's experiences of receiving and living with a diagnosis of an ASC alongside the experiences of their parents/carers.

*Aims:* To explore the lived experiences of young people with ASCs and their parents/carers' of the process of assessment, receiving and living with a diagnosis of an ASC.

*Methods:* Three or four dyads of young people and a parent/carer will be recruited through purposive sampling. Their lived experiences will be explored through semi-structured interviews. Interviews will be transcribed and analysed using interpretative phenomenological analysis to explore emerging themes across each dyad and the group overall.

*Applications:* The findings from this study may enhance our clinical understanding of the experiences of young people with ASCs and their parents/carers. It may also inform service development to improve the process of assessment and diagnosis and the available services and support following diagnosis.

# ***Experiences of Receiving and Living with a Diagnosis of an Autism Spectrum Condition: Listening to Young People and their Families.***

## **Introduction**

### ***Background***

Autism spectrum conditions (ASCs) or 'disorders' are a range of pervasive developmental conditions characterised by difficulties in social communication, social interaction and restricted, stereotyped and repetitive patterns of behaviour, interests and activities, evident before the age of three years (ICD 10, WHO, 1992,1996; DSM-V, APA 2013). In 2001 the Public Health Institute of Scotland estimated that 7,714 children under the age of 19 years would meet criteria for an ASC in Scotland (PHIS, 2001). Until recently, diagnostic criteria included a range of diagnoses including 'childhood autism' and 'Asperger's syndrome'. The most recent version of the Diagnostic and Statistical Manual (DSM-5, APA 2013) replaced these diagnostic terms with a broader diagnosis of 'autism spectrum disorder'. The term 'autism spectrum conditions' is used in the current study to refer to all conditions on the autism spectrum. This is in reference to the changes in diagnostic criteria and the growing literature emphasising the importance of viewing the characteristics of ASCs as 'differences' rather than 'disordered' (e.g. Baron-Cohen, 2000).

The Scottish Strategy for Autism was produced in 2011 to improve services and support for people with ASCs and their families (Scottish Government, 2011). With the increasing emphasis on service user involvement in service development, there is a need for research exploring the experiences of individuals with ASCs and their families at both the clinical and service level. Similarly, 'autism 'stakeholders' (including individuals with ASCs and their families) have called for research that would make a difference to individuals' day-to-day lives (Pellicano et al., 2014). However, despite increasing investment in ASC research in the UK, biomedical research is still predominant. The existing literature is also limited in that it primarily involves parents, most commonly mothers. Few studies involve individuals with ASCs (Cridland, 2013) and fewer still, involve multiple members of a family system thus limiting our clinical understanding of families' experiences.

### ***Experiences of Parents/Carers***

All individuals with an ASC in the UK and their families are likely to share significant experiences such as taking part in an assessment, receiving a diagnosis and adjusting or adapting to life with an ASC and this is reflected in the literature. Quantitative research with parents suggests that the diagnostic process can be time consuming, stressful and frustrating (Howlin and Moore, 1997). The period following diagnosis is also associated with high levels of parental stress (Davis and Carter, 2008) as parents begin to come to terms with their child's diagnosis. Jardine (unpublished thesis, 2008) conceptualises a child's diagnosis as a "complex and dynamic process" (p.g.27) rather than a discrete event. Siegel (1997) developed a theoretical model to explain the stages of 'healthy coping' and 'complicated coping' with a child's diagnosis of autism. Notably, research suggests that the extent to which parents have accepted or adjusted to their child's diagnosis can influence their style of interaction with their child (Wachtel and Carter, 2008). Studies suggest that parents of children with ASCs experience higher levels of stress than other parents (Sanders and Morgan, 1997) however, in the longer term, most describe improvements in their adjustment and well-being (Gray, 2012).

A number of qualitative studies have developed our understanding of parents' experiences such as; Abbot et al. (2013), Fong et al. (1993), Huws et al. (2001), Jardine (unpublished thesis, 2008), Ludlow et al. (2011), Midence and O'Neill (1999) and Woodgate et al. (2008). These studies include parents of children and adolescents with various ASC diagnoses and explorations of specific and general experiences of having a child with an ASC. Despite their varied focuses, common themes emerging from these studies include:

- The 'journey' to receiving a diagnosis; recognising differences, searching for explanation, receiving incorrect advice or diagnoses before an appropriate referral.
- Intense and varied emotions prior to, during and after receiving a diagnosis.
- Coming to terms with and adjusting to ASC; some described finding it difficult to accept their child's diagnosis initially however most described adjusting to ASC and finding a 'new normal' for their family.
- The day-to-day challenges of parenting a child with an ASC.
- Feelings of isolation; from family and friends, services, society and from a 'normal' family life.
- The impact of ASCs on the family; parents, siblings and extended family.
- Recognising the positive aspects of having a child with an ASC.
- Experiences of support and services; advocating and 'battling' the system.
- Judgement and lack of understanding from society.

### ***Experiences of Individuals with an ASC Diagnosis***

Milton and Bracher (2013) argue that failing to explore the lived experiences of individuals with an ASC is "ethically and epistemologically problematic" (p.g. 61) and limits the impact of research in this area. Qualitative studies which have explored the experiences of individuals with ASCs include; Griffith et al., 2011 and Punshon et al., 2009 (adults with ASCs), Humphrey and Lewis, 2008 (11-17 year olds), Huws and Jones, 2008 and 2013 (16-21 year olds). These studies have focussed on specific and general aspects of individuals' experiences however, common themes emerging from these studies include:

- The positive and negative consequences of the diagnosis; helping to make sense of current and previous experiences, new opportunities, discrimination and disrupting aspirations.
- ASC and self-identity: accepting, incorporating or rejecting ASC.
- Feeling different; the desire to be 'normal' and to 'fit in'.
- The challenges of ASCs such as difficulties in social interaction, social naivety, the effort involved in navigating day-to-day life.
- The positive aspects of ASCs such as having heightened abilities, special interests and a unique way of thinking.
- The impact of societal beliefs about ASCs e.g. stereotyped beliefs about ASCs and negative views which influenced how individuals with ASC viewed themselves and their diagnosis.

### ***Experiences of Young People and their Parents/Carers***

As previously mentioned, there has been little research considering the perspectives of multiple members of a family unit. In a unique exploration, Molloy and Vasil (2004) used a narrative research approach to consider the perspectives of young people aged

12-18 years with Asperger's Syndrome and their parents/carers. The authors identified many similar themes to those discussed above, however, there were methodological limitations. Their recruitment methods are not specified and their work is not peer-reviewed. Furthermore, there is no formal comparison of similarities or differences between the narratives of young people and their parents/carers or of the groups overall.

The lack of peer-reviewed research exploring the experiences of young people with ASCs alongside those of their parents is a significant gap in our understanding of family functioning and the impact of having shared or differing narratives of receiving and living with an ASC. Being able to make sense and form a narrative of stressful events is related to psychological well-being in adults and children (Baerger and McAdams, 1999; Fivush et al., 2004). Studies suggest that parents can help children to co-construct a coherent narrative of stressful experiences and the associated emotional experiences when they are not yet able to do so themselves (Fivush and Sales, 2003). Although much of this literature relates to young children, such findings may still be relevant to adolescents with ASCs given difficulties with recognising and understanding one's own and others' emotional experiences. Fivush argues that adolescence serves as a critical period for the impact of a family's narrative style on the formation of personal narratives (Fivush, 2008). Furthermore, the way in which families form narratives of emotional events appears to be associated with young adolescents' self-esteem, self-efficacy and social competence (Bohanek et al., 2006; Marin et al., 2008). Abbott et al. (2013) described that receiving a diagnosis of an ASC can be very difficult for young people and their parents as it implies a pattern of development that will impact throughout their lives. As such, having a coherent and shared narrative about this significant life event would likely be beneficial for a family's coping and resilience.

### ***Summary of Relevant Qualitative Research***

Although it has not been directly explored, the qualitative literature discussed above suggests that there may be common themes across young people and parents/carers' experiences of ASCs, for example:

- Feelings of difference (from peers and from 'normal' family life) and a desire to be 'normal'.
- The day-to-day challenges of ASCs.
- Appreciating the positives aspects of ASCs.
- The impact of societal views and lack of understanding.
- The extent to which individuals have adjusted to or accepted the diagnosis.

Despite increasing qualitative research in ASCs there are a number of limitations in this literature. Many studies have focussed on one aspect of experiences in isolation however, the diagnostic process appears to be central to young people and parents' overall experiences of ASCs (Huws and Jones, 2008; Jardine, 2008). Studies exploring broader experiences include individuals who have had, or been aware of, their diagnosis for varied lengths of time and their experiences or perspectives may differ as a result. Furthermore, there is little research exploring the experiences of young people with ASCs despite findings that the age of diagnosis is declining (Howlin and Moore, 1997) and adolescence being considered a critical time in the development of self-identity (Erikson, 1959). The lack of peer-reviewed research considering the experiences of young people and their parents/carers presents a further gap in our understanding particularly given the potential benefits of a shared family narrative of stressful events. Cridland et al. (2013) also emphasise the need for family-focused research to understand the impact of ASCs across the family system and to inform



services, particularly at times of transition such as adolescence. In addition to developing our clinical understanding, an improved knowledge of families' experiences is crucial in the context of current policy related to service improvement (e.g. Scottish Autism Strategy, 2012) and requests for research from autism stakeholders (Pellicano et al., 2014).

Consequently, the current study aims to explore the experiences of young people with ASCs of assessment, receiving and living with an ASC diagnosis alongside those of their parents/carers. The study will explore the experiences of a specific subset of families; those attending Child and Adolescent Mental Health Services and at a specific time point; 1-4 years after diagnosis.

### **Research Question**

- How do young people and their parents/carers experience the process of assessment, receiving and living with a diagnosis of an ASC?

### **Aims**

- To describe the key features of young people and their parent/carer's experiences of assessment for an ASC, receiving and living with a diagnosis of an ASC.
- To explore similarities and differences in young people and their parent/carers experiences of the process of receiving and living with an ASC diagnosis.

### **Plan of Investigation**

#### **Design**

Semi-structured interviews will be conducted with pairs of young people and their parent/carers in this cross-sectional, qualitative study. Interpretative phenomenological analysis (IPA; Smith et al., 2009) will be employed to analyse the interview transcripts. IPA was considered best placed to offer insight into the experiences of young people and their parent/carers as it allows a detailed and flexible examination of individuals' lived experiences within their wider context (Smith et al., 2009). IPA has been used in previous research with young people with ASCs and parents to good effect (e.g. Huws and Jones, 2008; 2013, Jardine, unpublished thesis, 2012).

#### **Participants**

Three or four dyads of young people (12-18 years) who attend Child and Adolescent Mental Health Services (CAMHS) and their parent/carers will be recruited from two NHS Greater Glasgow and Clyde CAMHS Services.

#### **Inclusion / Exclusion Criteria**

(To be determined by a clinician involved with the family)

#### **Inclusion**

- i) Young people aged 12-18 years who have received a diagnosis of an ASC and their parent/carer.
- ii) Both the young person and parent wish to participate in the study.

- iii) The diagnosis was received at 11+ years old and 1-4 years prior to participation in the study<sup>1</sup>.
- iv) The young person was aware of the purpose of their assessment when it was carried out.
- v) The young person and parent/carer are able to recall the process of assessment and diagnosis.
- vi) The young person and parent/carer are able to communicate their experiences verbally and in English.
- vii) The parent/carer, clinician and young person subjectively believe that the young person is likely to cope with an interview situation.

### **Exclusion**

- i) Any active risk identified by CAMHS clinician e.g. suicidality.
- ii) If one member of a dyad does not consent to participate.

### **Recruitment Procedures**

Clinicians in two NHS GG&C CAMH Services will be invited to identify families they are working with that meet the inclusion criteria. A recent audit of the South CAMH service found that 23 young people aged 12-18 years were referred to the ASD Post-Diagnostic aspect of the service in the past year. In August 2014 the Tier 3 CAMHS team had 15 young people with a diagnosis of an ASC on their caseload. The South Tier 2 CAMHS team reported that they also have a number of young people with ASCs on their caseload at any one time. By recruiting across two CAMHS teams it is expected that a sufficient number of families who meet the inclusion criteria will be identified. A recent audit of the South Post-Diagnostic Service noted that 40% of parents contacted chose to participate in a face-to-face interview. A qualitative study with young people with ASCs (14-18 years) carried out in Australia reported that five of eight young people contacted about the study chose to take part (Carrington et al., 2003). While these rates may be optimistic, it suggests that it should be feasible to recruit 3-4 suitable families across two CAMHS teams within the time constraints of the study.

The clinician working with the family will provide them with participant information sheets<sup>2</sup> which includes contact details for the main researcher. Families who indicate interest in participating will be contacted by telephone or email by the main researcher to discuss the study. The researcher will inform the CAMHS case manager of families who intend to participate in the study and determine whether or not the clinician deems any young people 12-16 years old capable of giving informed consent.

As individuals with ASCs can find unfamiliar and social situations anxiety provoking (Attwood, 2006) an informal face-to-face meeting will be arranged prior to participation in the study. The aims of this meeting are to put the young person at ease prior to the interview (e.g. by finding out about their interests) and to discuss how to best support the young person during the interview. This might include for example, visual supports to aid communication, discussion of how the young person might indicate that they are finding the interview stressful or that they would like a break (Harrington et al., 2013). The meeting will also serve as secondary screening procedure to ensure that the family meet the inclusion criteria. If the researcher is unsure whether a young person or parent/carer are appropriate and/or will be able to cope, she will discuss this with the

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<sup>1</sup> Literature regarding autobiographical memory in adolescents (e.g. Habermas & de Silveira, 2008) and individuals with ASCs (e.g. Crane et al., 2012) was considered. With reference to the time elapsed since diagnosis for young people interviewed by Molloy & Vasil (2004), a time period of 1-4 years previously appears to be reasonable.

<sup>2</sup> Service user volunteers (young people with ASCs and parents/carers) attending CAMHS have given feedback on participant information sheets for to ensure that they are accessible.

family. Information detailed in the participant information sheets will be discussed and families will have the opportunity to ask any further questions. Parents/carers will be asked to give assent or consent (for those 12-16 years old deemed not capable of informed consent) for their child to participate in the study.

### **Sample Size**

Smith et al. (2009) note that studies using IPA usually benefit from an in-depth focus on a small number of cases. Such studies are carried out on homogenous groups of participants who are purposively selected due to a shared experience; in this case, receiving a diagnosis of an ASC. Smith, et al. (2009) comment that IPA is commonly used with samples as small as three participants however, for professional doctorate courses 4-10 interviews are most commonly conducted which appears to be appropriate. As such, it is intended that recruitment will continue until 6-8 interviews have been completed (i.e. 3 or 4 dyads) or when data saturation is reached, if this occurs sooner.

### **Research Procedures**

Following the initial informal meeting with families detailed above, the researcher will arrange to meet with young people and parents/carers separately to conduct interviews at a time and location convenient for them. Where possible both members of a dyad will be interviewed on the same day. Written consent will be gained from parents and consent or assent from young people as indicated by their CAMHS case manager, prior to commencing the interview.

As suggested in guidelines for IPA studies by Smith and Osborn (2004) a semi-structured interview guide will be developed (informed by existing research) for young people and for parents/carers to facilitate discussion about their experiences. This will follow a chronological exploration of participants' experiences from assessment, receiving a diagnosis and through to their experiences following diagnosis. The interview will be conducted flexibly and the interviews largely will follow participants' narratives. The researcher will use open-ended follow up questions to encourage participants to elaborate on their experiences. The interview schedule will be piloted with one young person-parent/carer dyad.

In recognition of the social communication and interaction difficulties associated with ASCs, interview questions are intended to be clear and unambiguous. Adaptations to the interview process will be made if required in line with each individual's needs e.g. a written/pictorial timeline of experiences may be used to facilitate discussion. It is intended that interviews will last between 45-60 minutes. Interviews will be recorded digitally and transcribed verbatim for analysis. The researcher will keep a reflective diary throughout the study. This will help to recognise the researcher's subjective views and allow these to be acknowledged throughout the process of analysis and identification of themes.

### **Analysis**

The interview transcripts will be analysed in line with the methodology of interpretative phenomenological analysis (IPA) (Smith, et al., 2009). Analysis will be conducted in six stages as documented by Smith et al. (2009). Initially this involves reading and immersing oneself in the data before commenting on the content of the transcripts in increasing depth. The researcher will analyse the data in dyad pairs. This will begin with identifying emergent themes in each individual transcript followed by comparing and contrasting themes across dyad pairs and finally at a group level.

## **Settings and Equipment**

Interviews will be conducted in a setting with which the young person and their family are familiar (e.g. local CAMHS, young person's school). An audio recorder will be used to record interviews and a laptop for transcription. Young people will also be supported during interviews according to their needs for example, using visual symbols (e.g. to indicate a break), written materials such as a timeline of events and 'fidget' toys to help with sensory needs.

## **Funding**

The project will not be funded with the exception of a limited budget to cover administrative costs such as stationary, postage and printing which is granted by the University of Glasgow Institute of Mental Health and Well-Being. The total of proposed cost of the study is £93.99 (see appendix iii).

This research will be submitted as part of the principle researcher's doctorate in clinical psychology. The principle researcher is funded by NHS Education for Scotland.

## **Ethical Considerations**

Ethical approval will be applied for through the Integrated Research Application System and the NHS GG&C Research and Development Department. Recommendations from good practice guidelines for involving individuals with ASCs in research have been considered (Brown, 2011; National Autistic Society, Harrington et al., 2013).

### *Informed Consent*

Appropriate informed consent will be attained from all participants prior to interview. CAMHS clinicians involved with the family will determine whether the young person is able to give informed consent. Young people aged 16-18 years and those 12-15 years deemed capable, will consent themselves (with parental assent). Parental consent will be sought for any young people 12-15 years who are not deemed capable of giving consent (with young person assent). The aims and process of the study along with ethical considerations will be discussed at the initial pre-interview meeting and written information will be provided.

### *Incentives for Participation*

As the study is interview based it was considered that a small incentive for participation may help with recruitment as ASCs are associated with difficulties with social interaction and communication and some individuals may find unfamiliar and social situations anxiety provoking. This is particularly important given the limited existing research involving young people with ASCs. It is proposed that the young people who participate will receive a £10 book voucher and certificate to recognise their efforts in participating in the study. This is not expected to influence participation unduly.

## **Health and Safety Issues**

### ***Researcher Safety Issues***

Interviews will be conducted between 9am-5pm and in settings with existing health and safety protocols e.g. NHS premises, schools and carers centres. The researcher will

ensure that other members of staff are within the building and that a qualified member of NHS staff (e.g. supervisor) is available by telephone at times when interviews are being conducted. Home visits will not be conducted.

### ***Participant Safety Issues***

#### *Data Handling*

The anonymity of participants will be maintained at all times in line with NHS policies and the Data Protection Act (1998). A University of Glasgow laptop computer encrypted to NHS standards and with access restricted to the principle researcher will be used for the purposes of the project. Participants will be given a pseudonym and any references which might compromise anonymity (e.g. references to a specific location or person) will be removed. A document with participant's names along with their assigned pseudonyms will be stored on the laptop for the purposes of research governance.

Participants will be informed that direct quotations will be used in the final report and in any subsequent publications and that their dyad partner (i.e. child or parent) may be able to identify their quotations as quotations will be compared across dyads and pseudonyms will be linked within the report.

Contact details of potential participants will be saved on the laptop within a Word document with restricted access to the main researcher only. The completed consent forms will be stored in a locked filing cabinet (with access only to the research team) within the University of Glasgow Institute of Health and Well-Being building.

Interview recordings will be stored and transcribed using the University laptop. All information will be removed from transcripts except participants' gender and age (in years). Interview recordings will be destroyed after transcription has been complete.

On completion of the study, all electronic files (interview transcripts, participant contact details, participant names and pseudonyms) will be transferred from the laptop via an encrypted memory stick to a folder on the University Server with restricted access to the research team. The documents will be kept there for five years before being destroyed.

#### *Well-Being of Participants*

It is recognised that some participants may find it upsetting to discuss their experiences. Due to the difficulties associated with ASCs, individuals may find unfamiliar and social situations stressful (Attwood, 2006). Consequently, steps will be taken to minimise any stress e.g. meeting participants prior to interview. If any participant becomes distressed during the interview the researcher will manage this within the situation e.g. suggest a short break or end the interview. An information sheet of services for additional support will be provided to all participants. If there are concerns about the safety of a participant or any other individual or clinical practice the relevant services and/or individuals will be informed in line with NHS policies.

## Research Schedule

Task	Planned Completion Date
Application to NHS R&D and Ethics via IRAS.	By end of August 2014
Attend Ethics Committee	By end of October 2014
Recruitment Commences	October/November 2014
Meeting with Research and Field Supervisors	End of October 2014
Research Progress Meeting 1	By mid-November 2014
Interviews Completed	By end of December 2014
Transcription (approx. 1 day per interview)	January 2015
Meeting with Research Supervisor	Start of January 2015
Research Progress Meeting 2	By mid-January 2015
Data Analysis	By mid-April 2015
Meeting with Researcher and Field Supervisors	Start of April 2015
Write up	April – June 2015
Meeting with Research Supervisor	Mid-April 2015
Research Progress Meeting 3	By mid-May 2015
1 <sup>st</sup> Draft to Supervisor	Mid May 2015
2 <sup>nd</sup> Draft to Supervisor	Mid June 2015
Final Submission	July 2015

## Planned Dissemination of Results

The completed thesis will be available online at <http://theses.gla.ac.uk>. It is planned that it will also be submitted for publication in a peer reviewed journal. The results of the study will also be presented to local CAMHS teams.

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***Experiences of Receiving and Living with a Diagnosis of an Autism Spectrum Condition: Listening to Young People and their Families.***

**Background**

Autism spectrum conditions (ASCs) or ‘disorders’ are characterised by difficulties in social communication, social interaction and social imagination. Research suggests that the process of assessment along with receiving and adjusting to a diagnosis of an ASC are significant and often stressful events for an individual and their family. Despite this, there is currently limited research exploring young people’s experiences and no peer-reviewed research exploring young people’s experiences along with those of their parents/carers’ experiences of these processes.

**Aims & Questions**

This study will consider young people and their families’ experiences of receiving and living with a diagnosis of an ASC by exploring their experiences of: i) Assessment for an ASC, ii) Receiving a diagnosis of an ASC and iii) living with a diagnosis of an ASC.

**Methods**

Three or four pairs of young people (12-18 years old) with a diagnosis of an ASC and their parent/carers will be recruited. Participants will be recruited from two Child and Adolescent Mental Health Services (CAMHS). Participants should be able to remember and discuss their experiences of receiving and living with a diagnosis of an ASC and should have been aware of the purpose of their assessment when it was carried out. The young people should have received their diagnosis at the age of 11 years or older and between 1 and 4 years prior to taking part in the study. Clinicians from the local CAMHS teams will offer information about the study to suitable young people and families whom they are working with.

The researcher will contact families who are interested in participating in the study by telephone initially and then meet with them informally in person. At this

meeting the researcher will get to know the family before the interview, answer any further questions they might have and gain their consent to participate. Following this, the researcher will meet with the parent and young person separately to carry out qualitative interviews about their experiences. The interviews will include discussion of broad topics but will be guided by what the person chooses to talk about. All the interviews will be recorded and transcribed. A qualitative approach (using interpretative phenomenological analysis) will be used to analyse the interview data by identifying any themes from the interviews.

### **Practical Applications**

The findings from the current study may develop our clinical understanding of families' experiences. It may also inform service development for young people with ASCs and their families. This might involve highlighting changes to services to improve the process of assessment and the support that is available to families following diagnosis. Once completed, the study will be available online. In addition, it is planned that the study will be submitted for publication in an international peer-reviewed journal in order that the findings may inform service development and delivery more widely.

## Appendix ii – Health and Safety Form

### WEST OF SCOTLAND/ UNIVERSITY OF GLASGOW DOCTORATE IN CLINICAL PSYCHOLOGY

#### HEALTH AND SAFETY FOR RESEARCHERS

1. Title of Project	Experiences of Receiving and Living with a Diagnosis of an Autism Spectrum Condition: Listening to Young People and their Families.
2. Trainee	
3. University Supervisor	Dr Suzy O'Connor
4. Other Supervisor(s)	
5. Local Lead Clinician	Dr Simon Smith
6. Participants: (age, group or sub-group, pre- or post-treatment, etc)	Young people (12-18 years old) with a diagnosis of an autism spectrum condition and their parent/carer.
7. Procedures to be applied (e.g., questionnaire, interview, etc)	Qualitative interviews will be conducted with young people and parents/carers using a semi-structured interview guide.
8. Setting (where will procedures be carried out?)  i) General	An initial informal meeting will be arranged with young people and their parent/carer followed by interviews with young people and parents separately. Where possible, these meetings will be conducted at a location convenient to the family (local NHS setting, young person's school or a local community setting e.g. carer's centre) within the hours of 9am-5pm.
ii) Are home visits involved	Y/ <u>N</u>

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<p>9. Potential Risk Factors Identified</p> <p>(see chart)</p>	<p><b>Participants</b></p> <p>As a result of the difficulties with social interaction, communication and imagination associated with autism spectrum conditions, individuals can find new situations and social situations stressful. It is possible that young people and parents/carers might find some of the interview topics emotive to discuss.</p> <p><b>Procedures</b></p> <p>It is not anticipated that the interviews will cause stress or distress for participants, however, it is possible that participants may become stressed or upset due to the content of the discussions or due to difficulties with social or new situations.</p> <p><b>Settings</b></p> <p>Meetings and interviews will be conducted within settings where there participants feel comfortable and where there are appropriate health and safety policies and procedures (e.g. NHS settings, school, and community setting such as local carers' centre).</p>
<p>10. Actions to minimise risk (refer to 9)</p>	<p><b>Participants</b></p> <p>Where possible steps will be taken to minimise any stress experienced by young people e.g. by meeting participants prior to interview, providing verbal and written information about process of the interview in advance, meeting in a familiar setting, using visual supports and allowing a parent/carer to be present during interviews.</p> <p><b>Procedures</b></p> <p>There is evidence to suggest that forming a coherent narrative around difficult experiences is beneficial as is having the opportunity to discuss these experiences with someone. It is not anticipated that the interviews will be highly stressful or distressing for participants. However, during the informal meeting prior to interview the researcher will identify with the young person and their parent/carer the signs that might indicate that the young person is stressed or distressed and agree how best to manage this (e.g. have a break to talk about a topic that interests them) or</p>

	<p>what would indicate it is appropriate to end the interview.</p> <p>If any participant becomes distressed during the interview the researcher will manage this at the time e.g. suggest a short break or end the interview. An information sheet of services for additional support will be provided to all participants (e.g. local Child and Adolescent and Adult Mental Health Services, National Autistic Society and Autism Resource Centre).</p> <ul style="list-style-type: none"> <li>• If a young person becomes highly distressed their parent/carer will be informed and if appropriate their case manager in CAMHS or the Child Development Centre will be informed.</li> <li>• If any concerns arise about the well-being of a parent/carer they will be encouraged to seek help from their G.P. who will also be notified if appropriate</li> <li>• If a participant discloses information that may indicate risk of harm to themselves or others, the researcher will pass on this information to the appropriate services in line with local NHS and professional policies (Child Protection 2010; Adult Support and Protection Act Scotland, 2007).</li> <li>• If a participant discloses information which could suggest poor clinical practice this will be passed to the local service manager.</li> </ul> <p><b>Settings</b></p> <p>When arranging the location for initial meetings and interviews the researcher will ensure that there are local health and safety protocols in place and that other professionals will be within the premises at the time of the interview. The researcher will also ensure that a qualified member of NHS staff (i.e. supervisor) is available by telephone at times when interviews are being conducted in case any difficulties are encountered.</p>
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Trainee signature: ..... Date: .....

University supervisor signature:..... Date: .....

**WEST OF SCOTLAND/ UNIVERSITY OF GLASGOW  
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**HEALTH AND SAFETY FOR RESEARCHERS**

Points to consider when assessing risk. If any answer is “no” then make a case for the design being safe or reconsider the design of the study.

<b>Participants</b>	
<u>Yes</u>	<b>No</b>
This participant sample is not normally associated with dangerous or unpredictable behaviour	This participant sample is associated with impulsive, irrational or unpredictable behaviour, and/or has poor emotional control

<b>Procedures</b>	
<u>Yes</u>	<b>No</b>
The procedures in the study are same/similar to those used by clinical psychologists with these participants and are not normally associated with production of significant distress.	These are novel procedures, are not used with this group and by their nature might produce anger, irritability or distress.

<b>Settings</b>	
<u>Yes</u>	<b>No</b>
These are clinical or University research settings, or other institutional settings, that participants routinely attend (e.g., a school). They have procedures in place to minimise risk to staff and these are thought to be adequate in the context of the proposed study.	A private or other setting where there are not health and safety procedures that are relevant to research or clinical work proceeding without risk

**Appendix iii – Research Equipment Form**

**RESEARCH EQUIPMENT, CONSUMABLES AND EXPENSES**

**Trainee** ...Rona Craig.....

**Year of Course** ...2<sup>nd</sup> Year..... **Intake Year**...2012.....

Please complete the list below to the best of your ability:

<b>Item</b>	<b>Details and Amount Required</b>	<b>Cost or Specify if to Request to Borrow from Department</b>
Stationary	N/A	N/A
Postage	N/A	N/A
Photocopying and Laser Printing (includes cost of white paper)	Printing and photocopying 145 sheets; 25 x 3 page parent participant information sheets, 20 x A4 Recruitment poster, 20 x 2 page consent/assent forms, 10 interview guides).	Paper: £2.50 Printing/Photocopy £0.05 x 45 = £2.25 Colour printing £0.15 x 100 = £15
Equipment and Software	Digital recorder, Laptop and pedal for transcription.	(all to be borrowed from department)
Measures	N/A	N/A
Miscellaneous	<ul style="list-style-type: none"> <li>• 5 x £10 gift voucher for young people’s participation in the study.</li> <li>• ‘Fidget’ toy (x5)</li> <li>• Coloured felt tip pens</li> <li>• A3 paper (100 sheets)</li> </ul>	<ul style="list-style-type: none"> <li>• £50 (Waterstones)</li> <li>• £8.95 (Amazon)</li> <li>• £10 (Tesco)</li> <li>• £5.29 (Ryman Stationary)</li> </ul>

Trainee Signature..... Date.....

Supervisor’s Signature ..... Date .....