

# YOUNG PEOPLE'S EXPERIENCES OF RECEIVING AN ASD DIAGNOSIS

Young People's Experiences of Receiving a Diagnosis of Autism Spectrum Disorder

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## **Chapter One: Executive Summary**

This thesis, comprising of three further chapters, focuses on young people’s experiences of receiving an Autism Spectrum Disorder (ASD) diagnosis. Chapter Two details a systematic review of the pre-existing qualitative research on the first-hand experiences of receiving an ASD diagnosis. This identified a lack of direct research exploring young people’s experiences, and helped provide a rationale for Chapter Three (Empirical Study), which reports on the qualitative study that explored how a group of young people perceived their experiences of receiving an ASD diagnosis. Chapter Four, (Integration, Impact and Dissemination Summary), integrates the findings from Chapters Two and Three, and discusses the study’s implications and plans for dissemination.

### **Systematic Review**

Autistic adults and other autism stakeholders have felt research should prioritise how to make a positive difference to autistic people’s lives, including how services can best support them. People can be diagnosed with ASD at any age, and this may have an impact on their life. For example, some have argued it can lead to a future of exclusion from mainstream society. Understanding autistic people’s experiences of getting their diagnosis may indicate how services can support people both as they receive their diagnosis, and thereafter.

Qualitative research has value in exploring individuals’ experiences in-depth, and a systematic synthesis of such research can provide a comprehensive understanding of this phenomenon. This review addressed the question ‘*What are the first-hand*

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*experiences of receiving an ASD diagnosis?*' From previous reading of autism literature it was noted that an individual's diagnostic experiences could be embedded within their experiences of *having* autism. Therefore, this review broadly defined what experiences were related to *receiving* a diagnosis, and was interested in findings relating to individuals' experiences of finding out about their diagnosis, and any other issues relating to its receipt, including how they interacted with it, and the impact it may have had on their life outside the moment they initially found out.

A search strategy was developed, capturing all aspects of the review's question, and three databases were searched: PsycINFO, PubMed/MEDLINE, and Academic Search Complete. Both published and unpublished research was searched, and studies were included if they a) involved participants with a formal diagnosis of ASD, b) had findings relating to participants' first-hand experiences of receiving their ASD diagnosis, c) were qualitative, or mixed-methods involving relevant qualitative findings for extraction, and d) were available in English. Participants could be of any age, no restrictions were placed on study settings, and a start date was not set for the search. Seven hundred and fifty one records were initially identified, and eligibility checks found 13 studies met inclusion criteria. Data was extracted and thematic synthesis was used, where findings were coded line-by-line and arranged into themes. This identified four themes.

*Reactions to Diagnosis:* Receiving their diagnosis evoked a range of different positive and negative reactions, which was sometimes a complicated picture, with feelings either being unclear to the individual, or a mixture of both positive and negative

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reactions. Experiences changed over time for some, with acceptance for the diagnosis often developing gradually.

*Perception of Self:* Many individuals spoke of feeling different to other people, either viewing this positively or negatively. Likewise, whilst some were glad they had received their diagnosis, embraced it, or were proud of it, others spoke of not wanting it. Furthermore, getting a diagnosis often brought new understanding and explanation for individuals about themselves, prompting them to reflect on, and reframe past experiences.

*Interaction with Others:* Many experienced changes in how others interacted with them following their diagnosis. This was sometimes in helpful ways, with others making adjustments for them in the context of their diagnosis. However, some experienced less positive changes, such as people acting strangely around them, leading to concerns about disclosing their diagnosis to others. Numerous individuals spoke of a lack of understanding for autism, and stigma within society.

*Services and Support:* Whilst some spoke of the support they had received post-diagnosis, others had frustrations over there being a lack of support.

This is thought to be the first systematic review of first-hand experiences of individuals receiving an ASD diagnosis. Searching both published and unpublished studies helped minimise publication bias, although restricting the search to qualitative findings may have meant potential relevant quantitative research was not captured. Furthermore, although second reviewer checks were conducted during full-text

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eligibility decisions, checks during quality appraisal and data extraction would have further enhanced the review.

Conducting this review revealed that the majority of participants were adults, with only 26 of the overall 218 participants being younger than 18. Furthermore, many were only diagnosed in adulthood, and young people's experiences may differ from those of adults.

This review's findings highlight that an individual's reaction to their diagnosis can vary, and change over time. Receiving an ASD diagnosis can have implications for an individual's self-perception, introducing feelings of difference, and offering a new framework of understanding for making sense of their experiences. Whilst a diagnosis can sometimes help others understand autistic people more, it seems more work is needed in enhancing society's understanding for autism. There were also differences in individuals' experiences of the support that was available post-diagnosis. The findings offer an insight into these experiences, and suggest ways professionals can best support individuals at diagnosis. Children and adolescents' experiences of receiving an ASD diagnosis are under-represented, and would benefit from further research.

### **Empirical Study**

There is currently limited guidance for professionals and parents on how to disclose and discuss a young person's ASD diagnosis with them, and understanding what it is like for young people to receive this may help us to best communicate such information, and support individuals following diagnosis. Numerous studies have

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explored parents' experiences of getting their child's ASD diagnosis, although only a handful has reported on first-hand experiences. As identified during the review, these have mostly focussed on adults' experiences of getting the diagnosis, with many only sampling those diagnosed in adulthood. Young people's experiences may be somewhat different to these late-diagnosed adults. To the researcher's knowledge, only four studies have involved young people discussing their experiences of getting their diagnosis. However, these were either not designed to directly explore this issue, or interviewed both parents and young people, resulting in the parents' views overshadowing the young people's.

This study aimed to address the identified gap by exploring '*How do young people perceive their experiences of receiving a diagnosis of ASD?*' Seven young people, aged between 12 and 15 years, and diagnosed with different forms of autism, were recruited from an NHS service in London specialising in assessing children with possible ASD. All participants, six male and one female, attended mainstream schools and had known of their diagnosis for 1-10 years. Participants were interviewed using semi-structured interviews, which explored how they found out about their diagnosis and what that experience had been like for them, the conversations they had about this, their thoughts on autism, and their advice for informing other young people about their diagnosis. Service user feedback was gained whilst developing the schedule. Interview transcripts were analysed through an inductive thematic analysis of the entire data set. To enhance reliability, external coder checks were completed on two transcripts. Five themes emerged through the analysis.

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*Experiences during Assessment:* Some young people remember this taking a long time, and how not knowing why they were being assessed could be distressing, triggering worries that something bad was going to happen.

*Making Sense of the Diagnosis:* Receiving the diagnosis prompted a process where the young people tried to make sense of this. For those without a prior understanding of autism, the uncertainties attached to this triggered worries about what this would mean for them. The young people learnt about autism in different ways over time, helping relieve any distress experienced through lack of understanding, and they thought about their diagnosis more or less at different points in their life. They reflected on their experiences to make suggestions for how other young people should be informed, such as possibly having autism introduced as a concept beforehand, and being given time to process information.

*Impact of Diagnosis on Self:* Getting a diagnosis allowed some young people to develop a greater self-awareness and make sense of their experiences, which sometimes fostered a greater self-acceptance for their differences. Receiving a diagnosis was also helpful in getting young people support for their learning and developing self-awareness.

*Impact of Diagnosis on Self in Society:* Receiving their diagnosis prompted young people to reflect on how they position themselves within society, such as feeling 'different' to others, and considering their future in the knowledge of their diagnosis. Getting the diagnosis prompted one young person to educate peers on autism.

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*Interaction with Others:* Some young people felt getting a diagnosis helped others understand them more, whilst, for others, it highlighted people's poor understanding of autism. Some experienced acceptance for their diagnosis from others, whilst others developed fears about people knowing. Some felt more awareness for autism was needed, such as in schools.

This is believed to be the first study to directly explore and offer an insight into the experiences of receiving an ASD diagnosis within a group of young people of this age. Consulting with a service user on developing the interview schedule helped ensure it captured issues relevant to this study's focus. However, this study only reflects the experiences of a particular self-selected group of seven young people, who were mostly high-functioning, recruited from one NHS London service, and attended mainstream schools.

Future research with larger samples of autistic young people, and greater diversity in the sample characteristics, could explore whether these young people's experiences fit with those of others, and help clarify outstanding issues such as whether there is an optimum age for a young person to find out, and who is best placed to tell them.

This study suggests that young people's experiences of receiving their ASD diagnosis are multifaceted, and best viewed as a process in which their understanding for the diagnosis, the thought given to it, and their feelings towards it changed with time as they made sense of it. The findings have possible implications, including considerations for professionals and parents about how they talk about the diagnosis with a young person. These are summarised in the next section.



### **Integration, Impact and Dissemination Summary**

The main similarities between the findings from the review and study relate to how receiving a diagnosis can impact on an individual's self-perception, through introducing feelings of 'difference', and offering a new framework through which to understand the experiences. Furthermore, both papers found that receiving a diagnosis could impact both positively and negatively on how others interacted with them, and that their experiences in relation to receipt of their diagnosis seemed to change over time. One of the main differences is in the study's theme of *Making Sense of the Diagnosis*, which was not found in the review.

There are several possible implications of this research. The young people who participated may have felt empowered by talking about their autism. It may also help other young people finding out they have autism to gain insight into their own experiences. Healthcare professionals may benefit from this research by gaining an insight into what it can be like for young people to receive their diagnosis, and in considering particular issues in their approach to feeding this back, such as offering to help the young person make sense of this when they wish to explore this further. This research may also help parents of children diagnosed with ASD reflect on how to talk to their child about the diagnosis in a contained way, and whether they may need support in preparing for this. School professionals may benefit from hearing these young people's calls for further awareness in schools, as they are in a position to achieve this.

Plans for disseminating the research involve developing a summary of the findings for the participants and their parents, and presenting the findings to professionals in the

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recruitment site. There are further possibilities for presenting at a local strategy group, and at national conferences. The findings will also be shared with the National Autistic Society for further dissemination to professionals and parents, and the final paper will be submitted for journal publication.

**Chapter Two: Systematic Review**

**First-Hand Experiences of Receiving an Autism Spectrum Disorder Diagnosis: A**

**Systematic Review and Thematic Synthesis**

## Abstract

Autism Spectrum Disorder (ASD) affects how individuals relate to their environment and interact with others, and can be diagnosed in both childhood and adulthood. Numerous studies exist on parents' experiences of getting their child's ASD diagnosis. However, little is known of the experiences of the individual receiving the diagnosis. This review aimed to explore the first-hand experiences of receiving an ASD diagnosis. The PsychINFO, PubMed/MEDLINE, and Academic Search Complete databases were systematically searched. Participants could be of any age, and studies were only included if they reported qualitative findings relating to the review's question. Thirteen studies met the inclusion criteria, and were assessed on their methodological quality using an adapted tool. A thematic synthesis of the findings identified four themes. These captured participants' reactions to receiving their diagnosis (*Reactions to Diagnosis*), the impact receiving the diagnosis had on participants' *Perceptions of Self*, and how others interacted with them (*Interaction with Others*). There were also differences in the reported experiences of the *Support and Services* participants received post-diagnosis. The current knowledge on individuals' experiences of receiving their ASD diagnosis is predominately based on those diagnosed as adults. Young people's experiences of this remain under-represented, and would benefit from further research.

## Introduction

Autism Spectrum Disorder (ASD) is a spectrum condition, affecting how individuals relate to their environment and interact with others (National Autistic Society [NAS], 2016a). The diagnostic categories for Autism Spectrum Disorders differ within the two classification systems (American Psychiatric Association, 2013; World Health Organisation, 1993), and the Diagnostic and Statistical Manual of Mental Disorders 5<sup>th</sup> ed. (DSM-5; APA 2013) publication saw the merging of previously separate diagnoses such as Asperger's Disorder into the collective term and diagnosis of ASD.

Prevalence rates of ASD<sup>1</sup> across individual studies vary, possibly explained by methodological differences (Baxter et al., 2015), although an extensive review estimated a 1% prevalence rate across all ages in the UK population (Brugha et al., 2009). There has been a dramatic increase in the rates of ASD since the first epidemiological study (Lotter, 1967), with changes in diagnostic criteria and increased awareness proposed as possible explanations for this (Weintraub, 2011). It is therefore important that efforts are made to improve our understanding of autism.

Autism is a lifelong condition, and can be diagnosed across all ages (Tidmarsh & Volkmar, 2003). Alongside an increase in prevalence, there has been a growth in the number of autism-related studies (Pellicano, Dinsmore, & Charman, 2014). This has typically been dominated by studies focussed on understanding the underlying biology, brain, and cognition in autism (Pellicano, Dinsmore, & Charman, 2013), and

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<sup>1</sup> For brevity, ASD will be used when discussing the diagnosis in line with the DSM-5; however when referring to the condition more generally, the term 'autism' will be used to cover the different labels given to individuals.

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autistic<sup>2</sup> adults and other autism stakeholders (families, practitioners, and researchers) felt research should instead prioritise how to make a difference to people's lives, including researching "How can public services best meet the needs of autistic people?" (Pellicano et al., 2014, p. 764).

Receiving a diagnosis of ASD has the potential to impact an individual's life, for example, some have argued it can promote a future of exclusion from mainstream society (Hodge, 2005). Understanding people's experiences on getting their diagnosis may help to address the above priorities of the autism community, so that services can support individuals both during, and after, diagnosis.

Numerous studies have explored parents' experiences of receiving an ASD diagnosis for their child. Parents described a range of emotional reactions to receiving the diagnosis, with some recalling relief, as the diagnosis offered an explanation for their child's behaviours and a means for accessing support (Chamak, Bonniau, Oudaya, & Ehrenberg, 2011; Mansell & Morris, 2004), whilst others described negative feelings such as sadness, powerlessness, shock, guilt, and helplessness (Chamak et al., 2011; Fernández-Alcántara et al., 2016). For some, receiving the diagnosis triggered a sense of loss of a "healthy" child (Fernández-Alcántara et al., 2016, p. 316). However, feelings appeared to change, with some for example, reporting they became more accepting of the diagnosis with time (Mansell & Morris, 2004). This acceptance helped some parents develop different relationships with their child (Fernández-

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<sup>2</sup> To keep with the preferences of the autistic community (Kenny et al., 2015), identity-first terms (such as 'autistic individuals') will be used when discussing those with an ASD diagnosis, rather than person-first language (such as 'people with autism'), which is often favoured by professionals.

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Alcántara et al., 2016), and realistic future expectations for them (Midence & O'neill, 1999).

Numerous parents across UK, Irish, and Canadian studies spoke of a lengthy wait between meeting the first professional and receiving the diagnosis (Abbott, Bernard, & Forge, 2013; Crane, Chester, Goddard, Henry, & Hill, 2016; Howlin & Asgharian, 1999; Keenan, Dillenburger, Doherty, Byrne, & Gallagher, 2010), with some expressing they would have liked a quicker process (Osborne & Reed, 2008). Parents often saw several professionals (Siklos & Kerns, 2007) through multiple referrals (Howlin & Moore, 1997).

Whilst some studies included parents who were reflecting on their experiences of receiving the diagnosis when their child was an adult (Chamak et al., 2011; Howlin & Moore, 1997), the remainder of those discussed here received their child's diagnosis before the age of 18. This is perhaps unsurprising as parents are likely to have had more involvement in the diagnostic process, when the diagnosis is made in childhood compared to adulthood. Parents of those receiving the diagnosis as a child may therefore be more likely to uptake an offer to participate in research, or to be a group specifically targeted by researchers. Whilst it is useful to hear the experiences of receiving an ASD diagnosis from people close to the individual with the diagnosis, parents' experiences may differ from those being given the diagnosis. Gaining an understanding of these first-hand experiences may offer a deeper insight into how best to support people when finding out about their ASD diagnosis, and in the support offered afterwards.

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Qualitative research can contribute to this understanding as it places importance on participants' experiences and meanings (Pope & Mays, 1995), allowing participants' stories to be told "in their own voices" (O'Day & Killeen, 2002, p. 10), and revealing realities that would not be captured within quantitative methods. Qualitative studies in this area would therefore offer a detailed understanding of the first-hand experiences of receiving an ASD diagnosis. A systematic synthesis of qualitative studies relevant to autistic individuals' experiences of receiving their diagnosis can yield a greater understanding of this phenomenon compared to considering independent individual studies. A systematic review of this would help identify themes within participants' experiences across studies, whilst also highlighting conflicting or contradictory findings, and revealing the complexities that may exist in these experiences (Gough, Oliver, & Thomas, 2012).

The purpose of this review was to synthesise the qualitative research related to the first-hand experiences of receiving an ASD diagnosis. A broader systematic review has been conducted into the lived experiences of autistic individuals across key life areas, the successes and challenges they may have faced, and exploring how developmental stages impacted on these experiences (DePape & Lindsay, 2015). Whilst one of their subthemes ('Identity') related to how individuals viewed their diagnosis in a general sense at that time, and how it impacted on their sense of self, there are no further findings relating to how individuals first found out about their diagnosis and what this was like for them. Instead, the remainder of the review mostly focused on individuals' experiences in other major life areas across developmental stages, with themes of 'Experiences at School' and 'Factors Related to Employment'. To the researcher's knowledge, there is yet to be a review specifically focussed on the



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diagnostic experiences of autistic people. This systematic synthesis would help provide a more complete understanding of the first-hand experiences of receiving an ASD diagnosis, which may contribute to thinking around policy development and clinical practices in this area. More specifically, this synthesis will be useful in gaining an insight into what it is like to receive an ASD diagnosis, and in considering how best to support individuals both when they find out about their diagnosis, and afterwards.

At present, the National Institute for Clinical Excellence (NICE) has published clinical guidelines to help standardise the support that autistic people receive following diagnosis. The guidance for diagnosing ASD in under 19 year olds states a diagnostic assessment's feedback should cover what autism is and how it may affect the young person, and that a 6-week follow-up appointment should be offered (NICE, 2017); and only recommends directly discussing this with the young person if appropriate. There is an additional guidance for the support and management of autism in those under 19 years old (NICE, 2013). Where appropriate, and the need is identified, this guidance recommends considering social-communication interventions for children and young people with difficulties in this area, and offering support to develop children and young people's coping strategies and life skills in accessing the community. It also recommends that professionals should anticipate and prevent behaviours that may challenge, or offer psychosocial interventions for these where needed, as well as offering families and carers personal, social, emotional, and practical support. Furthermore, it states that where young people are aged 16 or over, and will continue to need support, there should be a planned and collaborative transition into adult services.

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The guidance for supporting autistic adults (NICE, 2016) states that those who have received an ASD diagnosis should be offered a follow-up appointment, which should cover the implications of their diagnosis, any concerns they may have about this, and any support they may need in the future. Additionally, it also outlines that group-based social learning interventions should be considered for those with difficulties in social interaction, and anger management interventions for those with anger and aggression problems. They also state that interventions focussing on different life skills should be considered for those individuals that need help in improving these. This may be the case for individuals who are socially isolated, or having problems obtaining or keeping employment. Both the guidelines for adults and children and young people outline that the relevant recommended support should be offered for co-existing mental health problems, which should be adapted to the individual’s needs and their autism.

This review adopted a relativist idealist stance, aiming to explore the possible complexity in individuals’ different experiences, rather than “seeking a single ‘correct’ answer” (Gough, Thomas, & Oliver, 2012, p. 5). Furthermore, this review may also identify gaps in knowledge, or under-researched areas, which may be useful for professionals and researchers to explore in the future.

The synthesis addressed the question:

*What are the first-hand experiences of receiving an ASD diagnosis?*

Given that the researcher’s preliminary searches found that an individual’s diagnostic experiences could be embedded within their experiences of ‘having’ autism (Huws &

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Jones, 2008), experiences that are related to 'receiving' the diagnosis have been broadly defined. For the purpose of this review, this synthesis was interested in research related to individuals' experiences of finding out about their ASD diagnosis, and any other issues relating to having received their diagnosis, including how the person interacted with their diagnosis, and the impact this diagnosis may have had on their life outside of the moment they initially found out.

## **Method**

The PRISMA (Preferred Reporting Items for Systematic Reviews and Meta-Analyses) guidelines have been followed (Moher, Liberati, Tetzlaff, Altman, & Group, 2009).

### **Eligibility Criteria**

Studies were included if they involved participants with a formal diagnosis of ASD, and had findings related to their first-hand experiences of receiving this ASD diagnosis. See Page 24 for a definition of what experiences were deemed related to 'receiving' the diagnosis. Participants could be of any age. To allow for full exploration of these experiences, qualitative studies were included, or those employing mixed methodologies, for which only the qualitative findings were later extracted. Given the exploratory nature of much qualitative research, the search was not limited to studies with a primary aim of exploring experiences of receiving the diagnosis, but instead also included those that documented relevant findings as part of a wider study with a differing objective. Only studies available in English were included, although no restrictions were applied to the study setting. Likewise, not setting a start date for the search aimed to ensure relevant articles were captured.

Studies were excluded if participants did not have a formal ASD diagnosis, if they only reported second-hand diagnostic experiences (e.g. from parents), or if the first-hand accounts at no point related to diagnostic experiences. Studies reporting only quantitative results, or which were not available in English, were also excluded.

### **Databases Searched**

Three databases were chosen to cover wide-ranging disciplines, aiming to make the search more comprehensive and identify relevant studies: PsycINFO (behavioural and social sciences database), PubMed/MEDLINE (biomedical and life sciences database), and Academic Search Complete (multi-disciplinary full-text access database). In line with criteria for quality appraising systematic reviews (Critical Appraisal Skills Programme [CASP], 2017), and to minimise publication bias (Gough, Oliver, & Thomas, 2012), the databases were searched for both published and unpublished studies (e.g. theses).

Given the qualitative nature of this review's question, it would have been useful to search the CINAHL (The Cumulative Index to Nursing and Allied Health Literature) database, as it has a wider collection of qualitative research than other databases (Boland, Cherry, & Dickson, 2017). However, this was unfortunately not possible, due to accessibility issues through the academic institution.

### **Search Strategy**

An optimal search strategy was produced through piloting and testing the strategy against relevant studies already known to the researcher. In order to identify relevant studies, terms relating to five search concepts were used. The Boolean operator 'OR' was used to search within each concept.

The first four concepts were searched within the titles and abstracts of studies, and the Boolean operator 'AND' was used to combine the first four concepts. Wildcard asterisks (\*) were used to capture words with multiple spellings or endings.

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1. Terms relating to autism: autism\*, autistic\*, ASD, ASC, Asperger\*
2. Terms to capture experience: perceive\*, perception\*, perspective, experience\*, reaction\*, lived experience\*, first-hand account, first hand account
3. Terms relating to a diagnosis: diagnos\*, label
4. Terms to capture the receiving (of a diagnosis): receiv\*, disclos\*, give\*, realis\*, realiz\*, negotiat\*, make sense, making sense

Due to the known large quantity of studies relating to parent/sibling/carer experiences of receiving an ASD diagnosis, the Boolean operator 'NOT' was used to exclude studies with the following terms in their titles:

5. Parent\*, sibling\*, brother\*, sister\*, carer\*, mother\*, father\*

Search alerts were created, which notified the researcher of new literature matching the search terms. This kept the search up-to-date, during the search period 20<sup>th</sup> July 2017 to 29<sup>th</sup> January 2018.

### **Study Selection**

Endnote (a referencing software manager) was used to remove duplicated sources from the collated search results. The titles and abstracts of studies were screened to check for eligibility against the criteria outlined above. Those identified as potentially relevant were read in full to confirm eligibility (n=20). A quarter of these were passed on to the researcher's supervisor to check for agreement on eligibility decisions. This was a randomly selected proportion that the researcher felt met the eligibility criteria (n=4), and a proportion that did not (n=1). It was planned to discuss discrepancies and

make decisions on eligibility after carefully reviewing the criteria together, although a 100% agreement between the reviewers meant this was not needed. Reasons for excluding studies during full-text review are reported within Figure 1 in the results.

### **Data Extraction**

For the 13 included studies, data was extracted relating to the study setting and geographical location, participant characteristics, study objective, qualitative methods for data collection and analysis, and the authors' findings relating to this review's question.

### **Quality Appraisal**

Opinions differ on whether the quality of qualitative research can be judged against the same standards of quantitative research, or instead require qualitative specific criteria (Mays & Pope, 2007). This review supports the latter position, that qualitative research should be assessed in its own terms, considering methodological issues relating to this type of research. Numerous tools specifically appraising qualitative research exist, although a lack of consensus on which tools to use has been widely documented (Centre for Reviews and Dissemination [CRD], 2009; Leung, 2015; Russell & Gregory, 2003).

The Critical Appraisal Skills Programme (CASP) is a well-known tool comprising 10 questions in appraising qualitative research (CASP, 2018), although some reviews have adapted the CASP to offer more extensive and specific criteria, capturing different areas of methodological quality (Campbell et al., 2003; Malpass et al., 2009). The Qualitative Research Quality Checklist (QRQC) alternatively offers an

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extensive 25-point checklist (Saini & Shlonsky, 2012). Whilst more comprehensive than the CASP, some of its items were not relevant to the studies included in this review, making it not possible to adhere to the tool.

Therefore, the CASP and QRQC were adapted to develop a tool relevant to this review (Appendix 1). A published adaptation of the CASP also informed these criteria (Atkins et al., 2008), and general issues related to evaluating qualitative research were considered (Mays & Pope, 2007). In line with guidance on critically appraising qualitative research (Hannes, 2011), this tool was developed to assess the credibility, transferability, dependability, and confirmability of the eligible studies.

Overall quality scores were not used, as it has been argued considering separate areas of methodological quality is more meaningful (CRD, 2009). Instead, each study was assessed against the screening question and subsequent 16 criteria. Given the lack of consensus on how to quality assess qualitative research, and how to use this (Dixon-Woods, Agarwal, Jones, Young, & Sutton, 2005), no studies were excluded or weighted based on quality evaluations. Instead, a summary of what was noticed during this process is given.

### **Data Synthesis**

Thematic synthesis was chosen for its suitability in synthesising findings from studies of various types, with differing aims and methodologies (Gough, Oliver, & Thomas, 2012). This approach followed the stages described by Thomas and Harden (2008), which Gough, Oliver, & Thomas, (2012) also clearly described.



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There are different approaches in deciding what constitutes as qualitative findings for extraction and synthesis (Noyes & Lewin, 2011), with it acknowledged that there are strengths and limitations with each approach. This review adopted a selective approach, where findings were considered to be themes or statements supported by direct quotations from participants. This approach was chosen to avoid extracting second-order interpretations, and increase the face validity of the reported data (Noyes & Lewin, 2011). Therefore, findings were extracted ready for synthesis if they met these criteria and related to the review's question. Findings were deemed relevant to the review question if they related to participants finding out about their diagnosis, or any other issues relating to its receipt, including how they interacted with it, and the effect receiving the diagnosis had on them outside of the moment they first found out about it.

Once extracted, findings were coded line-by-line according to the data's meaning, using as many codes as needed. This followed an inductive process without pre-determined themes, where each study was coded before moving onto the next one. NVivo, a qualitative analysis software, was used to help store and organise the codes, which were then arranged into themes and sub-themes. The original data was then reviewed again to test that the thematic framework fitted with the findings.

**Results**

After duplicates were removed, 494 studies were screened. Twenty studies were assessed for eligibility by reading the full-text, from which 13 were included in the review and synthesis. This process is summarised in Figure 1.

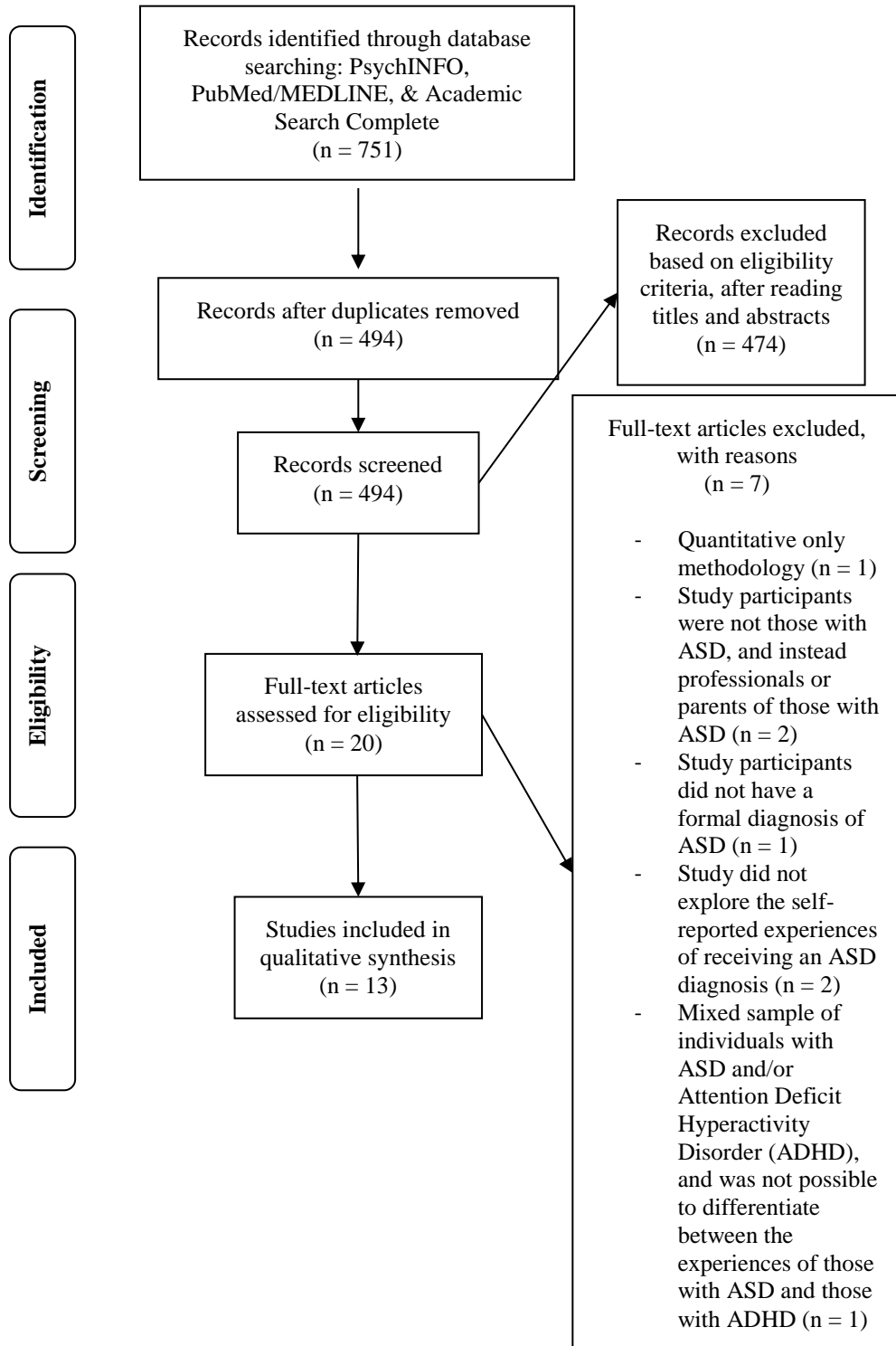


Figure 1. PRISMA flow diagram of the search

### **Characteristics of Included Studies**

Thirteen studies published between 2008 and 2017 were included in the review. Study characteristics, and the author's findings relevant to the review question, are summarised in Table 1. Eight were conducted in England, three in the United States, one in Wales, and one in Australia. There were 218 participants in total with ASD across the studies, with sample sizes ranging from 3-77. Seven studies had adult-only samples (i.e. over the age of 18), two with late adolescents and young adults, and four with children and adolescents, with the youngest child at nine years old. Seven studies involved mixed samples of males and females, one involved only female participants, one male-only sample, and three did not report their sample's gender. The studies were conducted across a number of settings: educational settings, workplace settings, specialist autism clinics/services, community settings, and online.

Most (n=10) studies used semi-structured interviews to collect data, one used an online open-ended survey, another used feedback forms with open-ended questions, and another used group discussions. Data were analysed using interpretative phenomenological analysis, other forms of phenomenological approaches, content analysis, framework analysis, narrative inquiry, and thematic analysis.

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Table 1

*Characteristics of Included Studies*

<b>Reference and Location</b>	<b>Participant Characteristics</b>	<b>Study Setting</b>	<b>Study Objective</b>	<b>Data Collection Method</b>	<b>Data Analysis Method</b>	<b>Author’s key findings related to first-hand experiences of receiving an ASD diagnosis</b>
Altman (2010) United States	13 college students with ASD, 6 females and 7 males, ages = 18-23 years	Educational - College	Explored the social experiences of college students with ASD, and the process of self-disclosure. The interview schedule involved asking how participants first reacted when they found out they have autism	Semi-structured interviews	Content Analysis	Initial reactions to learning of their diagnosis were mixed, with some not reporting a reaction, some feeling angry or upset, and for some a sense of relief. Many spoke of a process of acceptance over time, and taking pride in their diagnosis

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Reference and Location	Participant Characteristics	Study Setting	Study Objective	Data Collection Method	Data Analysis Method	Author’s key findings related to first-hand experiences of receiving an ASD diagnosis
Calzada, Pistrang, and Mandy (2012)	9 young people with high-functioning autistic disorder or Asperger’s disorder, all males, ages = 9-16 years	Hospital clinic specialising in assessing young people with queried high-functioning pervasive developmental disorder	Explored the utility of pervasive developmental disorder diagnoses within young people with high-functioning autistic disorder or Asperger’s disorder, and their parents	Semi-structured interviews	Framework analysis	Two themes relating to advantages of diagnosis: Bringing understanding to others, and Practical support.  Two themes relating to limitations of diagnosis: Diagnosis ineffective as communication, and Stigma
Hickey, Crabtree, and Stott (2017)	13 adults with different autism diagnoses, all diagnosed in later adulthood. 10 males and 3 females, ages = 51-71 years	Recruited through an adult autism diagnostic service, and via city-wide autism support groups	Explored the lived experiences of individuals diagnosed with autism in later adulthood, and their perceptions on the helpfulness of the diagnosis	Semi-structured interviews	Thematic Analysis	One relevant theme: Life Review (understanding the past, externalising autism, and self-acceptance)

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Reference and Location	Participant Characteristics	Study Setting	Study Objective	Data Collection Method	Data Analysis Method	Author’s key findings related to first-hand experiences of receiving an ASD diagnosis
Huws and Jones (2008)  Wales	9 college students with ASD, 3 females and 6 males, ages = 16-21 years	Educational - College	Explored participants’ perceptions of autism and their diagnosis experiences	Semi-structured interviews	Interpretative Phenomenological Analysis	Five themes identified: Disclosure delay, Providing explanations, Potential effects of labelling, Disruptions and opportunities, and Acceptance and avoidance
Kanfiszler, Davies, and Collins (2017)  England	7 adult females, diagnosed with ASD aged ≥ 18 years, ages = 20-59 years.	Recruited through community mental health teams, inpatient service for women with intellectual disabilities, and a voluntary support organisation	Explored the lived experiences of women with ASD: what it means to be autistic, and how it feels.	Semi-structured interviews	Narrative Inquiry	Some participants spoke of how their diagnosis had helped them reframe their past experiences, and develop skills

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Reference and Location	Participant Characteristics	Study Setting	Study Objective	Data Collection Method	Data Analysis Method	Author’s key findings related to first-hand experiences of receiving an ASD diagnosis
Lewis (2016)  United States	77 adults with ASD diagnosed aged ≥ 18 years.  32 females, 40 males, 4 other.  Ages = 18-65 years	Recruited through online forums and support groups.	Explored the experiences of being diagnosed with ASD as an adult	Online open-ended survey	Colaizzi’s (1978) phenomenological method (p348)	Six themes identified:  Feeling different from others, Riding an emotional rollercoaster, Striving for self-acceptance, Strategising to improve their lives, Maintaining normalcy, and Wandering into the future
MacLeod, Lewis, and Robertson (2013)  England	6 adults with autism/Asperger syndrome in higher education.  Information on sample’s gender and age was not reported.	Educational - University	Explored how participants made meaning of their autism/Asperger syndrome diagnosis.	Semi-structured interviews	Interpretative Phenomenological Analysis	Two relevant themes: Acquired knowledge of Asperger syndrome, and Personal identifications with Asperger syndrome

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Reference and Location	Participant Characteristics	Study Setting	Study Objective	Data Collection Method	Data Analysis Method	Author’s key findings related to first-hand experiences of receiving an ASD diagnosis
Mogensen and Mason (2015)  Australia	5 young people with different forms of autism, ages = 13-19 years.  Gender of sample not reported.	Community	Explored how autistic young people made sense of their diagnosis, and the impact of this on their identity.	Semi-structured interviews, using participants’ preferred communication methods (face-to-face, drawings, photos, emails, or telephone)	Thematic Analysis	Three over-arching themes identified: Meanings of the diagnosis at the individual personal identity level, Meanings of diagnosis for identity at the socio-relational or public level, and Meaning of the diagnosis in terms of negotiating impairments
Price, Luszkat, Mann, and Locke (2017)  England	3 adult medical trainee doctors with Asperger Syndrome, diagnosed in adulthood. Ages and gender of sample not reported.	Workplace – Hospital’s Professional Support Unit, which provides support to trainee doctors	Explored the effect of receiving an Asperger Syndrome diagnosis for trainee medical doctors, and its impact on developing insights into particular challenges in medical training.	Semi-structured interviews	Thematic Analysis  (Constant Comparison Approach)	Three themes identified: The diagnosis as a double-edged sword, Developing insight into problems, and The effect of disclosing the diagnosis.



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Reference and Location	Participant Characteristics	Study Setting	Study Objective	Data Collection Method	Data Analysis Method	Author’s key findings related to first-hand experiences of receiving an ASD diagnosis
Powell and Acker (2015) England	54 adults with Asperger syndrome or High Functioning Autism, diagnosed ≥ 18 years. 59% males, 41% females, Average age = 36.08 years.	Clinic specialising in diagnosing autism	Explored how participants felt about their Asperger syndrome or High Functioning Autism diagnosis.	Mixed Methods: Quantitative (including diagnostic tools, and a Satisfaction with Life Scale) and Qualitative (post-diagnostic feedback forms, with open-ended questions covering the diagnosis’ impact on participants’ emotions and life.	Thematic Analysis	Themes identified for “emotional reaction” to assessment (p75): Relief, Positive feelings, Mixed feelings, Negative feelings, and No clear feelings.  Themes identified for “effect on life” of assessment (p76): Understanding and explanation, Feeling better, Support, and Social interaction.

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Reference and Location	Participant Characteristics	Study Setting	Study Objective	Data Collection Method	Data Analysis Method	Author’s key findings related to first-hand experiences of receiving an ASD diagnosis
Punshon, Skirrow, and Murphy (2009) England	10 adults with Asperger syndrome formally diagnosed aged ≥ 18 years. 3 females, 7 males, ages = 22-45 years	Clinic for adults with Asperger syndrome	Explored the experiences of adults receiving a diagnosis of Asperger syndrome	Semi-structured interviews	Interpretative Phenomenological Analysis	Five relevant themes: Experience of services, Beliefs about symptoms of Asperger syndrome, Identity formation, Effect of diagnosis on beliefs, and Effect of societal beliefs of Asperger syndrome
Rosello (2015) United States	4 adolescents with Asperger’s disorder, 3 females and 1 male, ages = 13-17 years	Community – agency specialising in working with Asperger’s disorder	Explored ways in which Asperger’s disorder is disclosed, and how this disclosure impacted participants	Semi-structured interviews	Phenomenological Approach (specific method not stated)	Overall, adolescents “reported positive feelings, behaviours and attitudes to finding out about their diagnosis” (p6)  Author also state that the findings propose disclosing an Asperger’s disorder diagnosis to adolescents “is more beneficial than detrimental to their mental health” (p6)

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Reference and Location	Participant Characteristics	Study Setting	Study Objective	Data Collection Method	Data Analysis Method	Author’s key findings related to first-hand experiences of receiving an ASD diagnosis
Stevenson, Cornell, and Hinchcliffe (2016)  England	8 adolescent school students with ASD, 3 females and 5 males. 4 students were from Key Stage 4, and 4 from sixth form.  Specific information on ages was not included.	Educational– specialist school for students with ASD	To make it more acceptable to talk about autism within the school – named the ‘Let’s Talk Autism’ project.	Discussion groups around what ASD meant to the participants	Thematic Analysis	Three relevant themes:  Experiences of the diagnosis of autism,  Experiences of difference, and Strategies to manage

### **Methodological Quality of Included Studies**

The quality evaluations for each study are reported in Table 2. The appraisal process revealed that whilst all 13 studies adequately stated their aims, which appeared appropriate for a qualitative methodology, only eight offered a clear justification for adopting a qualitative approach or element in conducting their study. Ten studies adequately described their study's context. Eight studies sufficiently described their recruitment strategy, although only five clearly explained why their recruitment strategy was appropriate for their study's aims.

All thirteen studies clearly described their data collection methods, nine of which justified their choices. Eleven studies described how they considered ethical issues, although only five clearly described the role of the researcher in terms of reflexivity. Eight studies adequately justified their chosen analysis method, and all thirteen clearly described the steps during data analysis, and used quotes to support themes. Eleven studies met the criteria for conducting and reporting on credibility checks. All thirteen studies gave a clear statement of their findings, and eleven made claims that were supported by their data.

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Table 2

*Methodological Quality of Included Studies (n = 13)*

	Altman (2010)	Calzada et al. (2012)	Hickey et al. (2017)	Huws and Jones (2008)	Kanfischer et al. (2017)	Lewis (2016)	MacLeod et al. (2013)	Mogensen and Mason (2015)	Powell and Acker (2015)	Price et al. (2017)	Punshon et al. (2009)	Rosello (2015)	Stevenson et al. (2016)	Total Number that Met Criterion
Screening Question: Is the study qualitative, or reports qualitative findings?	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	13
1. Was there a clear statement of the aims of the research?	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	13
2. Is a qualitative methodology appropriate?	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	13
<i>Study Design</i>														
3. Was the research design appropriate to address the aims of the research?	✓	✓	✓	✓	✓	✓	U	✓	U	U	U	✓	U	8

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	Altman (2010)	Calzada et al. (2012)	Hickey et al. (2017)	Huws and Jones (2008)	Kanfischer et al. (2017)	Lewis (2016)	MacLeod et al. (2013)	Mogensen and Mason (2015)	Powell and Acker (2015)	Price et al. (2017)	Punshon et al. (2009)	Rosello (2015)	Stevenson et al. (2016)	Total Number that Met Criterion
<i>Study Setting</i>														
4. Is the study context clearly described?	✓	✓	U	✓	✓	✓	✓	U	✓	✓	✓	U	✓	10
<i>Sampling Procedures</i>														
5. Is the recruitment strategy clearly described?	✓	✓	✓	✓	✓	✓	×	U	✓	U	✓	U	×	8
6. Was the recruitment strategy appropriate to the aims of the research?	U	✓	U	✓	✓	✓	U	U	U	U	✓	U	U	5
<i>Data Collection</i>														
7. Has the data collection method been clearly described?	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	13
8. Was the data collected in a way that addressed the research issue?	✓	✓	✓	✓	✓	✓	U	✓	U	U	✓	✓	U	9

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	Altman (2010)	Calzada et al. (2012)	Hickey et al. (2017)	Huws and Jones (2008)	Kanfiszer et al. (2017)	Lewis (2016)	MacLeod et al. (2013)	Mogensen and Mason (2015)	Powell and Acker (2015)	Price et al. (2017)	Punshon et al. (2009)	Rosello (2015)	Stevenson et al. (2016)	Total Number that Met Criterion
<i>Reflexivity</i>														
9. Has the role of the researcher been clearly described?	✓	×	✓	✓	×	✓	×	U	×	×	×	✓	×	5
<i>Ethical Issues</i>														
10. Have ethical issues been taken into consideration?	✓	✓	✓	✓	✓	✓	U	✓	×	✓	✓	✓	✓	11
<i>Data Analysis</i>														
11. Was the analysis suited to the research question?	U	✓	✓	✓	✓	✓	✓	✓	U	U	U	✓	U	8
12. Were the steps in data analysis clearly described?	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	13
13. Have credibility checks been conducted?	✓	✓	✓	✓	✓	✓	✓	✓	✓	×	✓	×	✓	11

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	Altman (2010)	Calzada et al. (2012)	Hickey et al. (2017)	Huws and Jones (2008)	Kanfischer et al. (2017)	Lewis (2016)	MacLeod et al. (2013)	Mogensen and Mason (2015)	Powell and Acker (2015)	Price et al. (2017)	Punshon et al. (2009)	Rosello (2015)	Stevenson et al. (2016)	Total Number that Met Criterion
14. Are quotes used to support themes or concepts derived from the data?	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	13
<i>Findings</i>														
15. Is there a clear statement of findings?	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	13
16. Are the claims supported by the data found?	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	U	U	11

Note. ✓ = Met Criterion (high quality/very clear reference to the criterion issue)

✗ = Did Not Meet Criterion (no reference to the criterion issue)

U = Unclear (some reference to the criterion issue, but it remains unclear/is of poor quality)



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### Thematic Synthesis

Four themes were identified: Reactions to Diagnosis (Positive Reactions, Negative Reactions, Neutral Reactions or Difficulties Identifying Feelings, Mixed Reactions); Perception of Self (Difference and Identity, Gaining Understanding and Explanation on Self); Interaction with Others; Support and Services (Problems with Available Support, Brings Opportunities for Support). Table 3 shows each study’s contribution to the thematic synthesis.

Table 3

*The contribution of each study to the thematic synthesis*

	Reactions to Diagnosis	Perception of Self	Interaction with Others	Services and Support
Altman (2010)	✓	✓	✓	
Calzada et al. (2012)	✓		✓	✓
Hickey et al. (2017)		✓	✓	
Huws and Jones (2008)	✓	✓	✓	✓
Kanfisz et al. (2017)		✓		
Lewis (2016)	✓	✓	✓	✓
MacLeod et al. (2013)		✓	✓	✓
Mogensen and Mason (2015)		✓	✓	✓
Powell and Acker (2015)	✓	✓	✓	✓
Price et al. (2017)		✓	✓	
Punshon et al. (2009)	✓	✓	✓	✓
Rosello (2015)	✓	✓	✓	
Stevenson et al. (2016)	✓	✓	✓	✓

***Reactions to diagnosis.***

*Positive reactions.*

Many participants in the larger Powell and Acker (2015) study described a range of seemingly positive reactions from when they found out about their diagnosis. Many spoke of feeling “*pleased*” or “*happy*”, and one participant described an intense positive experience:

*I was so happy I could not sleep that night. I was ‘high’ for about two weeks*  
(Powell & Acker, 2015, p. 75).

Furthermore, several adult participants and one adolescent participant across three studies spoke of feeling relieved when they found out they had autism (Lewis, 2016; Powell & Acker, 2015; Rosello, 2015). Some spoke further of the way this brought them relief; for example:

*[it was] almost relief to be able to put a name to the combination of symptoms*  
*I’ve had my entire life* (Lewis, 2016, p. 350).

*Negative reactions.*

Many participants spoke of negative reactions to receiving their diagnoses, reporting feeling “*shocked*”, “*daunted*” (Powell & Acker, 2015, p. 75), “*sort of scared*”, “*upset*” (Rosello, 2015, p. 66), “*disappointed*” (Huws & Jones, 2008, p. 102), and “*devastated*” (Lewis, 2016, p. 349).

For some adult participants, receiving their diagnosis led to a sense of hopelessness (Lewis, 2016; Powell & Acker, 2015; Punshon et al., 2009), which seemed linked to their beliefs around what having autism meant for their future. For example:

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*...I was feeling a bit hopeless, you know that maybe this wasn't something I could overcome* (Punshon et al., 2009, p. 278).

Some adolescent participants reported feeling “*a little bit angry*” and “*mad*” after being informed of their diagnosis (Rosello, 2015, p. 66). Whilst adults also described feelings of anger, this was linked to only receiving the diagnosis as an adult (Lewis, 2016; Powell & Acker, 2015): “*angry that it wasn't picked up earlier*” (Powell & Acker, 2015, p. 75). For some, this diagnosis delay led them to feel misunderstood (Punshon et al., 2009).

*Neutral reactions, or difficulties identifying feelings.*

A number of adults however reported “*no reaction*” (Powell & Acker, 2015, p. 76) to receiving their diagnosis, as did one 19 year old who stated, “*I didn't really have much of a reaction*” (Altman, 2010, p. 46). Some also reported having no clear feelings, for example: “*I don't know how I feel about it*” (Powell & Acker, 2015, p. 76). This may be linked to difficulties in emotion recognition sometimes found in autism. Some young people within the youngest sample (9-12 years) felt indifferent about their diagnosis. For example, one stated, “*I'm not interested*”, when talking about the meaning of ASD (Calzada et al., 2012, p. 235). Others spoke in neutral terms about their reactions to being diagnosed, which seemed to link with the diagnosis not being a surprise, or perhaps something that was expected. For example:

*Since this is something I have had from birth, it wasn't a big surprise”, or “it was an expected outcome* (Lewis, 2016, p. 349).

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### *Mixed reactions.*

Many participants' statements portray a complicated picture of experiences, with numerous feelings about receiving their diagnosis (Altman, 2010; Powell & Acker, 2015; Punshon et al., 2009; Rosello, 2015). These contained both positive and negative reactions; for example, some adults described a sense of relief alongside feeling daunted or sad (Powell & Acker, 2015), or relief and elation alongside feelings of anger (Punshon et al., 2009). Some individuals' accounts also demonstrated fluid experiences, where their feelings in relation to receiving their diagnosis changed over time; for some, initial negative reactions evolved to more positive or neutral feelings (Altman, 2010; Rosello, 2015), and for others a progression from positive to negative feelings (Powell & Acker, 2015). Individuals across several studies also recalled that despite initial negative feelings towards their diagnosis, they had gradually grown to accept it over time (Altman, 2010; Huws & Jones, 2008; Lewis, 2016; Stevenson et al., 2016), whilst it was an “*ongoing journey*” for one person (Lewis, 2016, p. 352). For some, this was a painful process:

*Slowly I have become more accepting of my condition, but it still causes me a lot of grief* (Lewis, 2016, p. 350).

### ***Perception of self.***

#### *Difference and identity.*

Exploring their experiences of receiving their diagnoses led many individuals across different ages to talk of feeling different from other people (Altman, 2010; Lewis, 2016; Punshon et al., 2009; Stevenson et al., 2016), which was viewed in different ways.

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Some viewed this difference as being bad, for example one individual described:

*I had to go through a mourning period, as I thought I was a unique individual because I was different, but it all seems to be autism that made me think/ behave this way (Lewis, 2016, p. 349).*

This led to a negative sense of self for some, as they described there being “*something wrong with me*” (Altman, 2010, p. 47; Lewis, 2016, p. 348; Punshon et al., 2009, p. 275) or how “*it makes me feel like I’m retarded or something*” (Stevenson et al., 2016, p. 220).

However, a number of other individuals spoke of this difference in positive terms (Altman, 2010; Lewis, 2016; Mogensen & Mason, 2015; Stevenson et al., 2016). For example, one school student described:

*having autism can be good though, like I feel I look at the world in a different way...a bit like what an artist would look at it, or a film director, and it’s a really interesting way like, to see it from my eyes (Stevenson et al., 2016, p. 219).*

Others demonstrated how this difference had been positively integrated into their sense of self (Lewis, 2016; Mogensen & Mason, 2015; Powell & Acker, 2015), for example:

*the overall thing that I must emphasize is that I have never had the feeling that there was anything wrong with me. Different – yes, special – yes, unique – yes,*

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*able – very much so, superior – yes, special – yes, but defective – never!*

(Lewis, 2016, p. 351).

Some individuals wished they did not have their diagnosis because they “*didn't want to be labelled*” (Huws & Jones, 2008, p. 103), or felt “*I would have less limits*” without the diagnosis (Altman, 2010, p. 47), with one individual talking of a longing to be ‘normal’ (Stevenson et al., 2016). Whilst others spoke with pride of their diagnosis, with autism incorporated as an integral part of their identity (Altman, 2010; MacLeod et al., 2013; Mogensen & Mason, 2015), for example:

*It's up to you to create an identity and be proud of it. I'm proud of it and able to reach out to others. I look at it as a good thing now because I'm more secure in myself. It's different* (Altman, 2010, p. 48).

*Gaining understanding and explanation on self.*

Individuals across all but one study spoke of how receiving their diagnosis gave them knowledge, bringing some understanding and explanation to aspects of their life, and gaining self-insight, such as why they struggled socially, or found school difficult (Altman, 2010; Hickey et al., 2017; Huws & Jones, 2008; Kanfiszler et al., 2017; Lewis, 2016; MacLeod et al., 2013; Mogensen & Mason, 2015; Powell & Acker, 2015; Price et al., 2017; Punshon et al., 2009; Rosello, 2015). For many, the diagnosis helped them make sense of their lives, and led to the sense of relief that was discussed within the Reactions to Diagnosis (Positive Reactions) theme (Lewis, 2016; Powell & Acker, 2015; Rosello, 2015).

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For some this process was experienced as a “*revelation*” (Price et al., 2017, p. 2), liberating (Mogensen & Mason, 2015; Powell & Acker, 2015) and empowering (Lewis, 2016; Powell & Acker, 2015). For many, this newly acquired understanding in the context of their autism, helped them make sense of their past experiences (Hickey et al., 2017; Kanfischer et al., 2017; Mogensen & Mason, 2015; Powell & Acker, 2015; Punshon et al., 2009), “*with autism lenses*” (Lewis, 2016, p. 350). For example:

*I mean, after the sort of diagnosis and learning what it was about, sort of almost every day I'd think of some incident way back: 'Ah yes, that happened because I was Asperger* (Hickey et al., 2017, p. 5).

Some individuals spoke of how the diagnosis reduced shame that they previously held about aspects of their character (Hickey et al., 2017), and absolved them of blame for their past problems. For others, the diagnosis and the understanding this gave them, led to them developing new skills or strategies for things they previously struggled with (Kanfischer et al., 2017; Lewis, 2016; Mogensen & Mason, 2015).

*I got the letter saying that I had Asperger syndrome, it was a bit like standing up in court and hearing the jury say 'not guilty* (Punshon et al., 2009, p. 277).

*I wanted to be labelled because I suddenly knew what I could do and I knew there was a way I could cope with that problem once it had been identified. It was like a diagnosis in a way, saying that 'Oh, for this certain thing like you use this certain method and it works well* (Mogensen & Mason, 2015, p. 259)

For some individuals, there was a sense they would have benefitted from knowing about their diagnosis earlier, due to the understanding this brought for them; whether

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this was linked with a delay in being diagnosed (Punshon et al., 2009), or a delay in being told about their diagnosis by their parents (Huws & Jones, 2008; Mogensen & Mason, 2015). For example, an individual diagnosed in adulthood explained:

*I wouldn't have blamed myself because I used to self-harm when I was younger and I don't think I would...if I had known I had Asperger's earlier. I would have been more aware of my problems...and better able to cope with them* (Punshon et al., 2009, p. 276).

### ***Interaction with others.***

Many individuals spoke of changes in how people interacted with them after they received their diagnosis (Calzada et al., 2012; Huws & Jones, 2008; Lewis, 2016; Mogensen & Mason, 2015; Powell & Acker, 2015; Rosello, 2015; Stevenson et al., 2016). For some this change was helpful, which was sometimes linked to the diagnosis bringing understanding for other people. For example some participants said: “*work understands more now*”, and “*my family is more understanding now*” (Powell & Acker, 2015, p. 77). Accounts from the child and adolescent studies echo this, for example:

*I was struggling at school and I was always getting into trouble (...). It helped like, the staff understand that, why I was always struggling and that* (Huws & Jones, 2008, p. 103).

However, some spoke of unwanted or unhelpful changes in how others behave around them after receiving their diagnosis (Calzada et al., 2012; Lewis, 2016; Mogensen &



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Mason, 2015; Powell & Acker, 2015; Stevenson et al., 2016). For example, as one adult explains:

*It limits the expectations of others, who watch me more closely, or assume I will never be able to do things at work or socially that I think I can do (Powell & Acker, 2015, p. 77).*

Young people also reported such unpleasant changes, for example:

*Students act differently because they know I'm autistic, they're like he's the weird kid (Calzada et al., 2012, p. 237).*

For some individuals, specifically children or adolescents, these experiences led them to have concerns or hesitations around sharing their diagnosis (Calzada et al., 2012; Mogensen & Mason, 2015; Stevenson et al., 2016), either currently choosing to not tell others, or historically not wanting to disclose their diagnosis to others. For example:

*I didn't want to tell them at first because I wanted them to have their own opinion before they find out something that could...you know, let them treat me differently...I didn't want to be perceived as different. (Mogensen & Mason, 2015, p. 262).*

A number of individuals, both adults and young people, also spoke of the often inaccurate understanding of autism in wider society (Hickey et al., 2017; Huws & Jones, 2008; Lewis, 2016; MacLeod et al., 2013; Mogensen & Mason, 2015; Punshon et al., 2009; Stevenson et al., 2016). For most, this related to stereotyped views of autism that they felt existed in society, which in their experience had influenced how

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others interact with them (Huws & Jones, 2008; MacLeod et al., 2013; Price et al., 2017; Punshon et al., 2009). For example:

*And the problem is, people meet me and they go, well what's wrong with you?  
And I go, well, there's nothing wrong with me. I thought you'd got Aspergers?  
And they always think of Rain Man. Oh you're not like Rain Main, and I go  
Why should I be like bloody Rain Man?! Because it's just a stereotype.*  
(MacLeod et al., 2013, p. 44).

Furthermore, several adolescents reported that their parent(s) lacked a good understanding of autism when they first found out about their diagnosis (Altman, 2010; Rosello, 2015; Stevenson et al., 2016). For one individual, this seemed to negatively impact on their experiences of receiving the diagnosis:

*Finding out was very traumatic because my parents were completely ignorant  
and didn't know what it meant or understand why I lashed out (Altman, 2010,  
p. 47).*

### ***Services and support.***

#### *Problems with available support.*

Across two studies exploring adults' experiences, some individuals reported difficulties in getting their diagnosis. These problems related to difficulties in accessing services to assess them, and it generally being a lengthy process to finally receive their diagnosis (MacLeod et al., 2013; Punshon et al., 2009), which for some meant they lacked trust in services (Punshon et al., 2009). There was a commonality across these studies that the individuals were active during this lengthy process, doing

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independent research to look for information to help understand themselves, whilst in the limbo of trying to seek a diagnostic assessment outcome. For example:

*It's really difficult when you're between the phases, thinking that you might have Asperger syndrome and then getting the official diagnosis because it can take so long and it can be so difficult to access... You know, it's not like I could switch off from it or anything so I was spending a lot of time doing the research and finding out anyway (MacLeod et al., 2013, p. 45).*

Additionally, some individuals within the MacLeod et al. (2013) study expressed problems with the available literature about autism, and in particular with the post-diagnostic leaflets provided by services. For example: *"I tend to disagree with the simplifications in leaflets"* (MacLeod et al., 2013, p. 44). Also in relation to the post-diagnostic information provided, another individual from a different study described:

*...experiencing a feeling of being overwhelmed with information and how to move forward (Powell & Acker, 2015, p. 75).*

Furthermore, several individuals diagnosed in adulthood described difficulties in finding support for their autism, and a lack of support available (Lewis, 2016; Powell & Acker, 2015; Punshon et al., 2009), with one for example feeling *"daunted by the lack of professional support"* (Powell & Acker, 2015, p. 77). One individual also spoke of what they appear to see as an injustice in the support available for adults compared to children and adolescents:

*I am appalled and lament for the thousands of adult aspies who have struggled... I do get weary, admittedly, of hearing about all the wonderful things that are happening for autistic/aspie children. I think, and it's entirely*

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*justifiable, what of the adults? Why are we the forgotten ones?* (Lewis, 2016, p. 351).

Interestingly however, one adolescent experienced the “*sudden focus*” (Mogensen & Mason, 2015, p. 258) she received from health professionals following her diagnosis as oppressive.

*Brings opportunities for support.*

On the other side, individuals across studies spoke of how receiving their diagnosis had opened up opportunities of support available to them (Calzada et al., 2012; Huws & Jones, 2008; Lewis, 2016; Mogensen & Mason, 2015; Powell & Acker, 2015; Punshon et al., 2009; Stevenson et al., 2016). These opportunities related to gaining practical support (such as in school, or adapting workplaces to be autism friendly), financial support, and other forms of autism specific support (such as in learning communication skills).

*It has opened a lot of things and a lot of support and a lot of help* (Punshon et al., 2009, p. 277)

## Discussion

This qualitative synthesis of 13 studies addressed the question “*What are the first-hand experiences of receiving an ASD diagnosis?*” (see Page 24 or 30). This identified four themes: Reactions to Diagnosis, Perception of Self, Interaction with Others, and Services and Support.

The first theme (Reactions to Diagnosis) showed that individuals experienced a range of seemingly positive and negative reactions to receiving their diagnoses, as has been found in parents' experiences of receiving their child's ASD diagnosis (Chamak et al., 2011; Fernández-Alcántara et al., 2016; Mansell & Morris, 2004). The findings, however, suggest this can be a complicated picture, with feelings either being unclear to the individual, or a mixture of negative and positive feelings. For some, these experiences changed over time, with acceptance for the diagnosis often developing gradually. These findings suggest receiving an ASD diagnosis is arguably better viewed as a process over time, rather than a one-off event. Therefore it may be useful for practitioners to support individuals in helping them gradually make sense of their diagnosis, and thinking about what it means for that person. Although the current national guidelines acknowledge that a diagnostic assessment's feedback should explore what future support the individual may need (NICE, 2016; NICE, 2017), it might be beneficial to incorporate into the guidance that the individual may require on-going support in helping them make sense of their diagnosis as part of this.

Furthermore, some individuals' reactions seemed to be explained by particular factors. For example, experiences of relief were often the result of the diagnosis providing an answer, and helping the person make sense of their life; also linking with

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the second theme of Perception of Self. Additionally, neutral reactions were sometimes explained by the diagnosis being somewhat expected or not a surprise, whereas anger within some of the adult samples was linked to a delay in getting diagnosed. This fits with research exploring experiences of receiving a Type 2 diabetes diagnosis, which proposes an individual's route to getting their diagnosis is an important factor in the later feelings they experience in adjusting to the diagnosis (Peel, Parry, Douglas, & Lawton, 2004). In regards to an ASD diagnosis, individuals suspecting they had autism might not be shocked by the diagnosis, whereas those who had noticed things about themselves for which they lacked an explanation, may experience relief or other positive reactions. Those not expecting it, or who had difficulties obtaining their diagnosis, may be more likely to have a negative reaction. Therefore, it may be useful for practitioners to consider an individual's route to getting their diagnosis, the possible implications of this for them, and the support they may benefit from afterwards. By acknowledging and responding to these factors, practitioners may help people foster a positive adjustment to the diagnosis, even in cases where the individual had a difficult journey to getting the diagnosis, or was not expecting it.

In the second theme (Perception of Self), a commonality across many individuals' experiences was that they spoke of feeling different to other people. However, whilst some perceived this difference positively, and as unique, which sometimes improved their sense of self, for others, the diagnosis and the difference this introduced, led them to hold a negative view of themselves, as somebody with 'something wrong'. Likewise, whilst some were glad they had received their diagnosis, embraced it, or were proud of it, others spoke of not wanting the diagnosis, and a desire to be without

it. This same range of effects of the diagnosis on individuals' self-perception was also found in the DePape & Lindsay (2015) qualitative meta-synthesis. Furthermore, this finding echoes other wider research into first-hand experiences of autism, where both adults and young people have spoken of feeling different from others without autism, and whether this difference was integrated either positively or negatively into their sense of self (Baldwin & Costley, 2016; Cridland, Caputi, Jones, & Magee, 2015; Humphrey & Lewis, 2008; Jones, Huws, & Beck, 2013; Jones, Zahl, & Huws, 2001). Receiving a diagnosis can therefore have implications on an individual's self-perception, which can later become embedded in the broader experiences of *having* autism. This supports this review's inclusive approach in defining what is related to experiences of receiving a diagnosis, as some of these experiences may be difficult to tease apart from those of having autism. Taylor's (1983) cognitive adaption theory to adjusting to threatening events (like health diagnoses), proposes that this adjustment process is partly achieved through the individual searching for a meaning in the experience of receiving the diagnosis, such as what impact this will have on them and what it means for their life now. Research into the psychological adjustment to a HIV diagnosis found those that attributed more positive meanings to their diagnosis had higher levels of psychological well-being and lower depression levels (Farber, Mirsalimi, Williams, & McDaniel, 2003). Aylott (2000) argues that practitioners have a role in helping autistic individuals explore difference, and why they may find particular things challenging, whilst helping them develop a positive self-identity. Understanding how an individual's perception of difference may impact on their sense of self would indicate further support that may benefit that person, for example, in cases where it may be negatively impacting on their sense of self. Helping

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individuals ascribe to positive meanings for their diagnoses may help promote a positive adjustment to their diagnosis, and foster psychological wellbeing.

Furthermore, across all but one of the studies, receiving their diagnoses brought new understanding and explanation for individuals about themselves, which for many prompted them to reflect on past experiences and reframe these in the context of their autism. This could lead to a sense of relief (as discussed in Theme 1), a reduction in shame over behaviours/characteristics, or the removal of blame for past problems. There are parallels to the reactions seen in individuals' experiences of receiving an ADHD or dyslexia diagnosis, where relief and a shift of blame from the self to the condition, stemmed from a new understanding of their difficulties they acquired from receiving their diagnosis (Kong, 2012; Powell & Acker, 2015; Young, Bramham, Gray, & Rose, 2008). This fits with Taylor's (1983) theory of cognitive adaption to threatening events (such as health diagnoses), which proposes that part of an individual's adjustment to the diagnosis is achieved through efforts for self-enhancement and restoring their self-esteem (Walker, Littlejohn, & Jackson, 2004).

This acquired understanding led some to feel more able to cope with their difficulties, through developing new skills or strategies. For some however, the insight their diagnosis gave them on themselves, meant they wished they had received it earlier, as it could have saved them from earlier experiences of self-blame. Although this sub-theme (gaining understanding and explanation on self) was not found in the Calzada et al. (2012) study, this study had the youngest sample (9-16 year olds). Therefore, these individuals may have been too young to reflect on these types of experiences. Furthermore, it is possible they found out about their diagnosis younger than some



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individuals from other studies (especially those diagnosed in adulthood), meaning they may have fewer memories prior to becoming aware of their diagnosis. These findings suggest that depending on the individual's age, it may be useful to support them in making sense of their previous experiences in the context of their diagnosis, which may also promote a positive adjustment to the diagnosis (Farber et al., 2003; Taylor, 1983) and a positive sense of self. This may be especially suitable where an individual holds blame or shame for their difficulties or experiences. Therefore, it might be useful for the guidance around supporting individuals following an ASD diagnosis (NICE, 2016; NICE, 2017) to consider whether an individual has had negative life experiences which might be explained by their autism, to help them gain a new understanding for these which may remove any shame or blame they previously held for these.

The third theme (Interaction with Others) found that many individuals experienced changes in how others interacted with them, after they received their diagnosis. For some, this was in helpful ways, with others (e.g. family, teachers, or work colleagues) making adjustments for the individuals in light of their autism as they have more of an understanding about their presentation and needs; suggesting a diagnosis can bring understanding for both the individual diagnosed, and those around them. This supports research on parents' experiences, who have reported that receiving their child's diagnosis offered an explanation of their presentation, and like the first-hand experiences synthesised in this review, parents also linked this to a sense of relief (Chamak et al., 2011; Mansell & Morris, 2004).

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Some had, however, found the diagnosis had changed how others interacted with them in less positive ways, for example with people acting in an odd way towards the individual after they found out about their autism. These reactions from others, had led some individuals to develop concerns around disclosing their diagnosis to others. Linked to this, the DePape & Lindsay (2015) review found that some individuals felt their diagnosis had negatively impacted on their family, however it does not explain what is meant by that. A number of individuals in this current review also spoke of a lack of understanding about autism, by parents (for those told of their diagnosis by parents), as well as societal misconceptions and stigma about autism, which they felt impacted on how others interacted with them. Stigma has been discussed in relation to concerns around self-disclosing diagnoses of HIV (Hogwood, Campbell, & Butler, 2013; Obermeyer, Baijal, & Pegurri, 2011) and epilepsy (Scambler & Hopkins, 1986), and a review of autistic autobiographies and personal narratives found societal stigma was also a factor in the complex decision and process of self-disclosure of autism (Davidson & Henderson, 2010). This review's findings indicate more work is needed in enhancing society's understanding of autism, and reducing its stigma. Some have argued that professionals must contribute to this by removing the obstacles that discriminate against autistic people (Aylott, 2000).

The final theme (Services and Support) found that some of those diagnosed in adulthood experienced delays in being diagnosed, leaving some individuals to do their own research to try and understand their experiences. Additionally, some reported a lack of available support post-diagnosis, which some felt was an injustice compared to the support that autistic children and adolescents receive. Parents have reported feeling dissatisfied with the post-diagnostic support available for their child following

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diagnosis (Crane, Chester, Goddard, Henry, & Hill, 2016; Howlin & Moore, 1997), and the only quantitative survey in this area found that autistic adults, (some of whom were diagnosed as a child), were requesting more post-diagnostic support for others in the future (Jones, Goddard, Hill, Henry, & Crane, 2014). However, it should be noted that there are national and geographical differences in the services and support available for autistic people and their families (e.g. NAS, 2018a). Therefore, although lack of support was only raised in this review by those diagnosed as adults, no strong conclusions can be drawn on whether a disparity exists between the post-diagnostic support for adults and young people. Further research may help identify particularly under-supported groups of people being diagnosed with ASD. Furthermore, some individuals spoke of over simplifications of autism within the post-diagnostic literature provided through services. Diagnostic services should consider linking with the autistic community to collaboratively develop resources of this kind.

In contrast, a number of studies showed that receiving an ASD diagnosis opened opportunities of support for individuals across ages. Previous studies have found autistic children, adolescents, and adults to be at increased risk of experiencing mental health problems such as depression and anxiety (Howlin, 2000; Leyfer et al., 2006; Tantam, 2000), attention difficulties and educational challenges (Leyfer et al., 2006), and experience difficulties in obtaining and maintaining employment (Hendricks, 2010; Hurlbutt & Chalmers, 2004). A diagnosis can therefore open avenues for support tailored to an individual's needs, which may help ameliorate psychiatric difficulties, and increase psychosocial functioning. However, the preceding finding that some participants reported a lack of support, suggests a diagnosis may not lead to support for everyone, and that perhaps improvements are needed in how to help

everyone feel supported following diagnosis. The Department of Health's updated statutory guidance (Department of Health [DoH], 2015) outlines the requirements for local authorities and NHS England organisations in implementing the Autism Fulfilling and Rewarding Lives (DoH, 2010) and updated Think Autism (DoH, 2014) strategies, which involve providing tailored support to individuals at different life stages, and to prevent possible difficulties from events that may significantly impact autistic individuals (such as employment, or housing). This guidance fits with the wishes of autistic adults, who have reported a desire for "flexible support" in relation to their needs, which may change with time and specific life events (Jones et al., 2014, p. 3042).

### **Study Strengths and Limitations**

The majority of participants across the studies were adults, with only 26 of the overall 218 participants being younger than 18 years (Calzada et al., 2012; Mogensen & Mason, 2015; Rosello, 2015; Stevenson et al., 2016). Furthermore, many were only diagnosed in adulthood, and young people's experiences may differ from those of adults. Whilst the small group of young people's experiences contributed to the thematic synthesis, this review's findings may not be representative of other autistic young people. Additionally, many of the studies involved participants with high-functioning ASD who were able to engage verbally in an interview. Whilst there are challenges attached to this, future research exploring the diagnostic experiences of autistic people with different abilities would offer a more representative picture of this issue. Furthermore, from those that documented the recruitment strategy, the findings are based on self-selected samples, where participants responded to advertisements or

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an opportunity to participate. Therefore, the findings from such samples may differ from the experiences of those who did not opt-in.

All of the included studies were conducted in Western countries, with nine being in the UK. Whilst this is useful in considering recommendations for UK guidance and clinical practice, the findings may not apply to the experiences of those in different countries. Furthermore, the majority of studies did not provide information on the cultural backgrounds for their samples, or socioeconomic factors, meaning it is unclear whether this review represents the experiences of people across backgrounds.

Given the importance of reflexivity within qualitative research (Elliott, Fischer, & Rennie, 1999), eight of the thirteen studies did not clearly describe the researcher's role, making it difficult to establish whether they considered the possible influence of this on the study's conduct and findings, and how they tried to minimise this. Future qualitative studies of this kind should be transparent about this process within their write-up, to help readers have confidence in their conclusions. It is, however, positive that all but two of the studies clearly reported on the credibility checks they used, which increases the research's trustworthiness for readers.

A strength of the studies, however, is that although four studies did not report on their sample's gender, there was a good ratio of male-to-female participants (13:9) across the remaining studies. Given the estimated male-to-female ratio for the disorder is 4:1 (Loomes, Hull, & Mandy, 2017), females are well represented across this review's studies. Furthermore, the studies were conducted in a range of settings, gaining the experiences of those in clinical and non-clinical settings.

### **Review Strengths and Limitations**

This is thought to be the first systematic review into the first-hand experiences of receiving an ASD diagnosis. A notable strength is that the review searched both published and unpublished studies. Whilst this approach lengthens the process, it helps to minimise publication bias, and arguably may improve the comprehensiveness and quality of the review (Gough, Oliver, & Thomas, 2012). Furthermore, second reviewer checks were used during a proportion of the eligibility checks at the stage of full-text reading.

However, the limitations should also be considered. Firstly, the search was restricted to qualitative-only findings, as it was felt more relevant to the review question, and would offer a rich insight into the first-hand experiences of receiving an ASD diagnosis. Therefore, potential relevant quantitative data may not have been captured by the review, which might have impacted on the review's findings. Secondly, the search was restricted to only those studies available in English. Thirdly, the quality appraisal and data extraction stages were only carried out by the lead researcher. Additional second reviewer checks during these stages could have further enhanced the review's strength, although this was unfortunately not possible due to resource issues. Finally, a selective approach was adopted in extracting data for synthesis, where only findings supported by direct quotes were included. This was chosen to increase the face validity of the derived themes, and avoid coding and synthesising second-order interpretations (Noyes & Lewin, 2011). However, constraints placed on authors (such as journal length) may limit the number of quotes they report. Furthermore, all reported data is arguably the result of authors' interpretations, as they are likely to report the quotes and findings that fit the message they want to convey,

reflecting their priorities and perspectives (Gough, Oliver, & Thomas, 2012). Whilst there is no right or wrong approach in selecting what is considered as findings for synthesis, a more inclusive approach (also including findings not supported by a quote) is more resource intensive, but arguably also more comprehensive.

### **Future Directions**

This review has identified that only a handful of studies have reported on the first-hand experiences of receiving an ASD diagnosis exist, with the experiences of children and adolescents especially being underrepresented compared to those of autistic adults. This echoes what another qualitative systematic review concluded, which explored more broadly the first-hand experiences of those with ASD across all ages (DePape & Lindsay, 2015). It may be that research has typically focussed on gaining experiences from parents, rather than from autistic young people themselves, as discussed in the introduction. A number of this current review's studies included participants who formally received their diagnosis in adulthood. It has been suggested that the process of obtaining a diagnosis may be more complex in adulthood, due to the likelihood of being misdiagnosed with mental health difficulties along this journey, and seeing a number of different professionals, with longer delays (Jones et al., 2014). Therefore, the experiences of those diagnosed in childhood or adolescence may be somewhat different to those diagnosed as adults. Furthermore, although some participants in the other studies may have reported their experiences of being diagnosed as a young person, retrospective recollections may have inaccuracies. Therefore, research directly exploring the first-hand experiences of receiving an ASD diagnosis within children and adolescents may mean the individuals are more likely to recall this experience, as they are likely to have found out about their diagnosis more

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recently. Such research would help give young people a voice in talking about their autism, and may further the understanding around the post-diagnostic support that should be offered to young people and their families; including the recommendations that parents may receive on how to disclose or discuss the diagnosis with their child.

### **Conclusion**

This synthesis explored the first-hand experiences of receiving an ASD diagnosis. It found these experiences were linked to their reactions in response to receiving their diagnosis, the impact this had on their self perception and how others interacted with them, as well as differences in their experiences of the support that was available post-diagnosis. The findings inform our understanding of this process, and how professionals can best support individuals when they are diagnosed. However, the review has highlighted that children and adolescents' diagnostic experiences of ASD are under-represented, and would benefit from further research.



**Chapter Three: Empirical Study**

**Young People's Experiences of Receiving a Diagnosis of Autism Spectrum  
Disorder**

## **Abstract**

There is currently limited guidance for professionals and parents on how to inform young people of their Autism Spectrum Disorder (ASD) diagnosis. Understanding the ways that young people receive their diagnosis, and what this is like for them, may help us understand how best to communicate such information to young people. This study explored how young people perceived their experience of receiving their ASD diagnosis. Seven autistic young people aged between 12 and 15 were recruited from a service specialising in ASD diagnostic assessments, and were interviewed using semi-structured interviews. Thematic analysis of the interviews identified five main themes: Experiences during assessment, Making sense of the diagnosis, Impact of diagnosis on self, Impact of diagnosis on self in society, and Interaction with others. This study suggests that young people's experiences of receiving their diagnosis are multifaceted, and a process in which their experiences can change over time. Clinical implications and areas for future research are also discussed.

## **Introduction**

Autism Spectrum Disorder (ASD) is the term for a collection of neurodevelopmental conditions, which is classified by both the Diagnostic and Statistical Manual of Mental Disorders 5<sup>th</sup> ed. (DSM-5; American Psychiatric Association, 2013) and International Classification of Diseases 10<sup>th</sup> ed. (ICD-10; World Health Organisation, 1993) by persistent difficulties in social communication and interaction, in addition to restricted and repetitive patterns of behaviour, interests or activities. Prevalence rates for autism have been estimated at 1% of the general population (Brugha et al., 2009). Identification of autism within children or adolescents is increasing (Matson & Kozlowski, 2011). Research has found autistic<sup>3</sup> children and adolescents are at greater risk of mental health problems (Leyfer et al., 2006; Simonoff et al., 2008), and more likely to experience bullying and victimisation compared to typically developing peers (Cappadocia, Weiss, & Pepler, 2012; Sreckovic, Brunsting, & Able, 2014). However, these findings are typically based on parental or teacher reports of the child’s experiences, which may lead to inaccurate prevalence rates. Nonetheless, research indicates that autistic young people are vulnerable to emotional and social difficulties, making it important to understand how best to support them.

## **Diagnosing ASD**

Getting an ASD<sup>4</sup> diagnosis has the potential to impact a young person’s life. It has been argued that although a diagnosis often leads to additional support, it can

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<sup>3</sup> Identity-first terms (such as ‘autistic young person’) are used instead of person-first terms (such as ‘young person with autism’). This meets the preferences of autistic people, who have viewed autism as “intrinsic to the person”, and something that could not be separated from them (Kenny et al., 2015, p. 447).

<sup>4</sup> For brevity, ASD will be used when discussing a diagnosis, whereas ‘autism’ will be used when discussing the condition more generally.

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“pathologise a child” and promote a future of segregation and exclusion (Hodge, 2005, p. 346).

The national guidance for diagnosing ASD in under 19 year olds states a diagnostic assessment's feedback should cover what autism is and how it may affect the young person, and that a 6-week follow-up appointment should be offered (National Institute for Health and Care Excellence [NICE], 2017). This guidance is relatively broad, and may be approached by professionals in different ways. Furthermore, although it states the diagnosis should be communicated sensitively and without delay, it only recommends directly discussing this with the young person if appropriate, without specifying when. Therefore, the diagnosis may sometimes be communicated with the parents/carers, who later inform their child when they feel appropriate.

There are currently no consistent recommendations for how parents should explain their child's diagnosis to them. However, some have recommended this information to come from a family member who the young person feels comfortable with (NAS, 2016b), and starting the conversation by introducing difference in a positive way (Wheeler, 2003). Having no real guidance for parents, and limited guidance for professionals, in discussing a diagnosis with a young person, may mean that young people are told in different ways, which may or may not be helpful for them. Understanding what it is like for young people to receive an ASD diagnosis may help us understand how best to communicate such information.

### **Experiences of Receiving an ASD Diagnosis**

Numerous studies have explored parents' experiences of getting their child's ASD diagnosis. Parents often reported it taking a long time to get the diagnosis (Abbott, Bernard, & Forge, 2013; Crane, Chester, Goddard, Henry, & Hill, 2016; Howlin & Asgharian, 1999; Keenan, Dillenburger, Doherty, Byrne, & Gallagher, 2010). Some spoke of experiencing constantly changing negative emotions such as sadness, shock, helplessness and guilt (Fernández-Alcántara et al., 2016), whereas others reported relief from having their questions answered (Chamak, Bonniau, Oudaya, & Ehrenberg, 2011; Mansell & Morris, 2004). Two large UK surveys found that up to half of parents were dissatisfied with the amount of support following diagnosis (Crane et al., 2016; Howlin & Moore, 1997). Whilst these studies offer a comprehensive insight into this issue, their findings are based on self-selected samples, possibly reflecting parents who had more extreme negative or positive experiences of the diagnostic process, than those of non-responders. Furthermore, they fail to give insight into the first-hand experiences of receiving an ASD diagnosis. To date, only a handful of studies have reported on this. The majority of these relate to autistic adults' experiences of getting their diagnosis, which have typically adopted qualitative interviewing methods.

Within these, some adults spoke of feeling 'different' to others (Punshon, Skirrow, & Murphy, 2009), which for some was viewed positively and with pride (Altman, 2010; Powell & Acker, 2015), but for others led to a negative self-image (Altman, 2010; Lewis, 2016). Some individuals reported reactions of negative feelings such as shock, devastation, and hopelessness (Lewis, 2016; Powell & Acker, 2015), others reported positive experiences of happiness and relief (Lewis, 2016; Powell & Acker, 2015),

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whilst some reported a mixture of positive and negative feelings (Altman, 2010; Lewis, 2016; Powell & Acker, 2015; Punshon et al., 2009).

Getting their diagnosis helped some gain insight to themselves, and make sense of their experiences through an autism lens (Altman, 2010; Kanfischer, Davies, & Collins, 2017; Lewis, 2016; MacLeod, Lewis, & Robertson, 2013; Powell & Acker, 2015; Price, Luszkat, Mann, & Locke, 2017; Sandell, Kjellberg, & Taylor, 2013), and absolved them of shame or self-blame for their difficulties (Hickey, Crabtree, & Stott, 2017; Punshon et al., 2009).

Whilst some felt their diagnosis helped others understand them more (Powell & Acker, 2015), others felt it negatively impacted how people treated them (Lewis, 2016; Powell & Acker, 2015), with some describing societal stigma of autism (Hickey et al., 2017; Lewis, 2016; MacLeod et al., 2013; Price et al., 2017; Punshon et al., 2009). Additionally, whilst some spoke of the opportunities and support they received following diagnosis, others had frustrations over a lack of support (Lewis, 2016; Powell & Acker, 2015; Punshon et al., 2009). Finally, the only quantitative study (Jones, Goddard, Hill, Henry, & Crane, 2014) found that the perceived quality of post-diagnostic support they received, the time taken to get a diagnosis, and the number of professionals seen, significantly predicted individuals' satisfaction with the diagnostic process.

However, some of these studies were not designed to explore participants' experiences of receiving their diagnosis, although it is interesting they were still discussed. Kanfischer et al. (2017) aimed to explore what it meant to be autistic within

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a group of autistic females, and Altman (2010) wished to explore the social experiences within 18-23 year old autistic students. Additionally, although MacLeod et al. (2013) explored how adults made sense of their ASD diagnosis, all except one participant talked about their diagnostic experiences despite not being directly asked. This might indicate the significance of these experiences, suggesting people may want to talk about them.

Importantly, all but one of the remaining qualitative studies only recruited those diagnosed after the age of 18 (Hickey et al., 2017; Lewis, 2016; Powell & Acker, 2015; Price et al., 2017; Punshon et al., 2009; Sandell et al., 2013). The process of being diagnosed in adulthood, compared to childhood, is proposed to be possibly more complex as it may involve seeing more professionals over a longer time, with a greater chance of mental health misdiagnoses (Jones et al., 2014). Young people's experiences may be somewhat different to these late-diagnosed adult samples. Although the only quantitative study recruited some people diagnosed as young as eight years old (Jones et al., 2014), they discuss that retrospective recollections as adults may be susceptible to error. Therefore it is important to explore this issue within young people.

Whilst Huws and Jones (2008) aimed to explore the perceptions of what it was like to 'have' autism, through interviewing a group of 16-25 year olds, they modified their interview after participants spontaneously talked about issues relating to their diagnosis. As aforementioned, this further suggests the significance of diagnostic experiences for people. Participants felt that receiving a diagnosis helped them make sense of earlier experiences, but whilst some described positive effects of having the

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'autism' label (e.g. their bullying stopped), others spoke of negative effects (e.g. associated perceived stigma). Whilst a diagnosis could disrupt individuals' lives, for example impacting on their college options, it also created opportunities through accessing autism services. Furthermore, although some were accepting of their diagnosis, others avoided thinking about it. However, the authors acknowledge they did not ask about the age at which participants received a diagnosis, and participants may therefore have been recalling experiences from some years ago. Studies with younger samples, who may have more recently become aware of their diagnoses, may yield different findings.

Mogensen and Mason (2015) interviewed a younger sample of 13-19 year olds, exploring how they made sense of their ASD diagnosis and the impact this had on their identity. Whilst one participant experienced the diagnosis as negative and oppressive, others found it liberating as it helped them understand their experiences, helped them gain control of their lives, and was sometimes positively framed within their identity. Although participants were mostly accepting of themselves, some spoke of societal stigma and their efforts to try and hide their differences. Whilst offering some insight into these experiences, it does not give an in-depth insight into this issue. The study did not appear to explore how they necessarily *received* their diagnosis, that is, they did not interview and explore how the young people first found out about their diagnosis, and what that was like for them. Further research is needed to fully exploring this within autistic young people.

Calzada et al. (2012) interviewed nine autistic young people (aged 9-16), and their parents, around the perceived utility of their own/their child's diagnosis. The



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perceived advantages were linked with increased understanding and access to support, whilst disadvantages were linked with stigma. However, the interview schedule reveals that only one of the ten main questions asked to the young people related to their experience of receiving the diagnosis ('Who told you about it?'), and therefore it was arguably not designed in a way to fully explore their experiences of receiving the diagnosis, including what finding out was like for them. Furthermore, the parental views significantly dominate and overshadow the minimal contributions from the young people themselves within the findings; which may have influenced the author's conclusions. Studies solely focussing on young people's experiences of receiving their ASD diagnosis would arguably help to get their voices heard, and prioritise their experiences over others'.

Although unpublished, the doctoral thesis by Rosello (2015) is important to acknowledge. Autistic adolescents (13-17 year olds) and their parents were interviewed separately, exploring the ways the diagnosis was disclosed to the adolescents, and how this impacted on them. They found the adolescents were, to some extent, all pleased that they knew about their diagnosis, with most wishing to have been told sooner. Some spoke of feeling relieved as the diagnosis helped them make sense of their experiences, whilst others recalled feeling angry, upset, or scared after being told. Some also felt their parents did not fully understand the diagnosis at the time. Echoing an earlier criticism, only four adolescents were interviewed compared to twelve parents, and the conclusions are weighted more on the parents' experiences of preparing to disclose the diagnosis, and their confidence in this. Therefore, whilst this is the only study to specifically explore the experiences of receiving an ASD diagnosis within young people, further directed research

interviewing more young people is needed to gain greater insight on this phenomenon.

### **The Current Study**

To summarise, whilst there is research around autistic adults' experiences of receiving their ASD diagnosis, and young people's experiences of *having* autism, there is a lack of research exploring young people's experiences specifically about receiving an ASD diagnosis. Although research has begun to offer an insight into this phenomenon (Calzada et al., 2012; Mogensen & Mason, 2015; Rosello, 2015), the studies are flawed by either not being designed to fully explore young people's experiences of receiving an ASD diagnosis, or have ended up with findings which are dominated by the views of the young peoples' parents, in the cases where both parents and young people have been interviewed. This study aimed to address this gap in the literature, by exploring the experiences of receiving an ASD diagnosis in-depth with young people, and only with the young people themselves.

This study may help further understand the ways young people find out about their diagnoses and what this is like for them, and might indicate areas for further research. In addition to giving young people a voice in talking about their autism, who are typically under-represented within research (DePape & Lindsay, 2015), this study may be relevant when considering recommendations that are given to parents and professionals on how and when to disclose the diagnosis to young people. The current guidance on this is limited. Additionally, autism stakeholders have called for more research into post-diagnostic support (Pellicano, Dinsmore, & Charman, 2014), and this study may indicate target areas when offering support following diagnosis.

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Given this is an under-researched area, into experiences that are likely to hold complexities, exploratory qualitative research has value in allowing freedom and scope to explore this with individuals in-depth (Barker, Pistrang, & Elliott, 2002). A qualitative approach has therefore been chosen over quantitative measures.

### **Research Question**

How do young people perceive their experiences of receiving a diagnosis of ASD?

## **Method**

### **Design**

A phenomenologically-informed approach has been adopted, which is more concerned with perceived meanings of experiences (i.e. descriptions given by participants), rather than whether these accounts reflect a factual and objective reality. Furthermore, it assumes individuals' perceptions are based on their assumptions about themselves, the world, and others, and that multiple perspectives from different individuals are as valid as each other (Barker et al., 2002). This is underpinned by critical realist ontological assumptions, as there is assumed to be some agreement between what participants say and their subjective experience, but that this knowledge is socially-affected, meaning researchers can only partially access this (Braun & Clarke, 2013; Harper & Thompson, 2011).

Thematic analysis offers a flexible approach to evaluating qualitative data, and can be informed by different theoretical frameworks (Braun & Clarke, 2006). This was chosen over the common phenomenological approach - Interpretative Phenomenological Analysis (IPA) – because it was felt the developmental diversity in this study's sample, and the diversity in when young people received their diagnosis, might challenge the homogeneity assumptions of IPA (Smith, Flowers, & Osborn, 1997). Thematic analysis can be used with samples where heterogeneity may exist, and with a range of research questions (Braun & Clarke, 2013). Thematic analysis is not linked to a particular epistemology, and instead can be applied across a range of epistemological and theoretical approaches (Braun & Clarke, 2006). This study adopted a phenomenological epistemology, prioritising participants' perceived

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experiences to help understand about the experiences of receiving an ASD diagnosis in young people. This approach was underpinned by critical realist ontological assumptions, as has been described above.

### **Participants**

#### *Sample characteristics.*

The final sample consisted of seven young people aged between 12 and 15 years, diagnosed with different forms of autism. Six participants were male, and one female.

Table 4 reports further sample characteristics.

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Table 4

*Participant Characteristics*

<b>Pt. no.</b>	<b>Gender</b>	<b>Ethnicity</b>	<b>Age at interview</b>	<b>Age at diagnosis (years)</b>	<b>Age made aware of diagnosis (years)</b>	<b>Diagnosis</b>	<b>Place of interview</b>	<b>Interview duration (minutes)</b>	<b>School type</b>
1	Male	Asian British (Bangladeshi)	12yrs 1m	11	11	Autism Spectrum Disorder	Participant Home*	49	Mainstream with additional support
2	Male	Asian British (Indian)	13yrs 3m	9	9	High Functioning Autism	Participant Home	42	Mainstream
3	Female	Asian British (Malaysian/Chinese)	13yrs 3m	11	11	High Functioning Autism	Recruitment Service Site	45	Mainstream with specialist support
4	Male	Asian British (Indian)	13yrs 6m	11	11	Asperger’s Syndrome	Participant Home*	45	Mainstream with additional support

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<b>Pt. no.</b>	<b>Gender</b>	<b>Ethnicity</b>	<b>Age at interview</b>	<b>Age at diagnosis (years)</b>	<b>Age made aware of diagnosis (years)</b>	<b>Diagnosis</b>	<b>Place of interview</b>	<b>Interview duration (minutes)</b>	<b>School type</b>
5	Male	White British	13yrs 7m	9	9	Atypical Autism	Participant Home*	50	Mainstream with additional support
6	Male	White British	15yrs 8m	10	10	Asperger Syndrome	Participant Home	43	Mainstream with specialist support
7	Male	White British	15yrs 9m	5	5	Asperger’s Syndrome	Participant Home*	35	Mainstream with specialist support

*Note.* \* = Parent present for the interview as requested by the young person

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Participants were recruited from a North London service specialising in the assessment and diagnoses of children who may have ASD. Participants were eligible on the basis that they:

- Were aged between 12-16 years
- Had a confirmed ASD diagnosis, which they were already aware of
- Used verbal communication and had a level of cognitive functioning that allowed them to engage in an interview
- Had good spoken English, as determined by the researcher during recruitment.

Initial plans were to recruit young people aged 9-16, to capture a broad range of young people's experiences who may have known of their diagnoses for different amounts of time. However, the Research Ethics Committee (REC) raised concerns this might be too developmentally diverse to provide meaningful results. Feedback from a 12-year-old on the interview schedule, meeting the study's criteria, revealed they felt able to answer the questions. Consequently, 12-16 years was felt suitable to both the researcher and REC, as it addressed concerns raised over younger children's abilities to engage in the study, whilst still capturing younger adolescents' experiences to address the research gap.

Like other research with young autistic children (Kirby, Dickie, & Baranek, 2015), a participant's ability to engage in an interview was determined through parent and clinician feedback to the researcher, and during the researcher's initial meeting with the young person. Questions such as "What activities do you enjoy doing?" helped further establish whether they could respond to open-ended questions.



### *Sample size.*

There are no clear rules on sample sizes when using thematic analysis. However, this study's sample of seven is in keeping with the suggestion of six to ten participants for studies using interviews and thematic analysis (Braun & Clarke, 2013), and ensured sufficient data was collected to provide a detailed story within this study's time constraints.

### **Recruitment**

Potential participants were identified from the service's database by a clinician working there. Invitation letters were sent to them and their parents (Appendix 6), and followed up by phone two weeks later. For those that expressed an interest, consent was obtained before the researcher made contact to arrange an introductory face-to-face appointment with the young person and their parent(s). This meeting explained the purpose and nature of the research, along with the possible benefits or risks in participating, and their rights to withdraw at any time. Two participant information sheets were used, one developed for the parents, and one for the young people (Appendix 7 and 8). Those choosing to take part met with the researcher for a second meeting, during which informed written consent and assent was obtained from the young person and parent (Appendix 9 and 10), and the interview was completed. Figure 2 shows the recruitment flow chart.

Participants were only invited to participate after full ethical approval was received from the London-Camden and Kings Cross REC (ref 17/LO/1213), the local NHS trust, and Royal Holloway University of London.

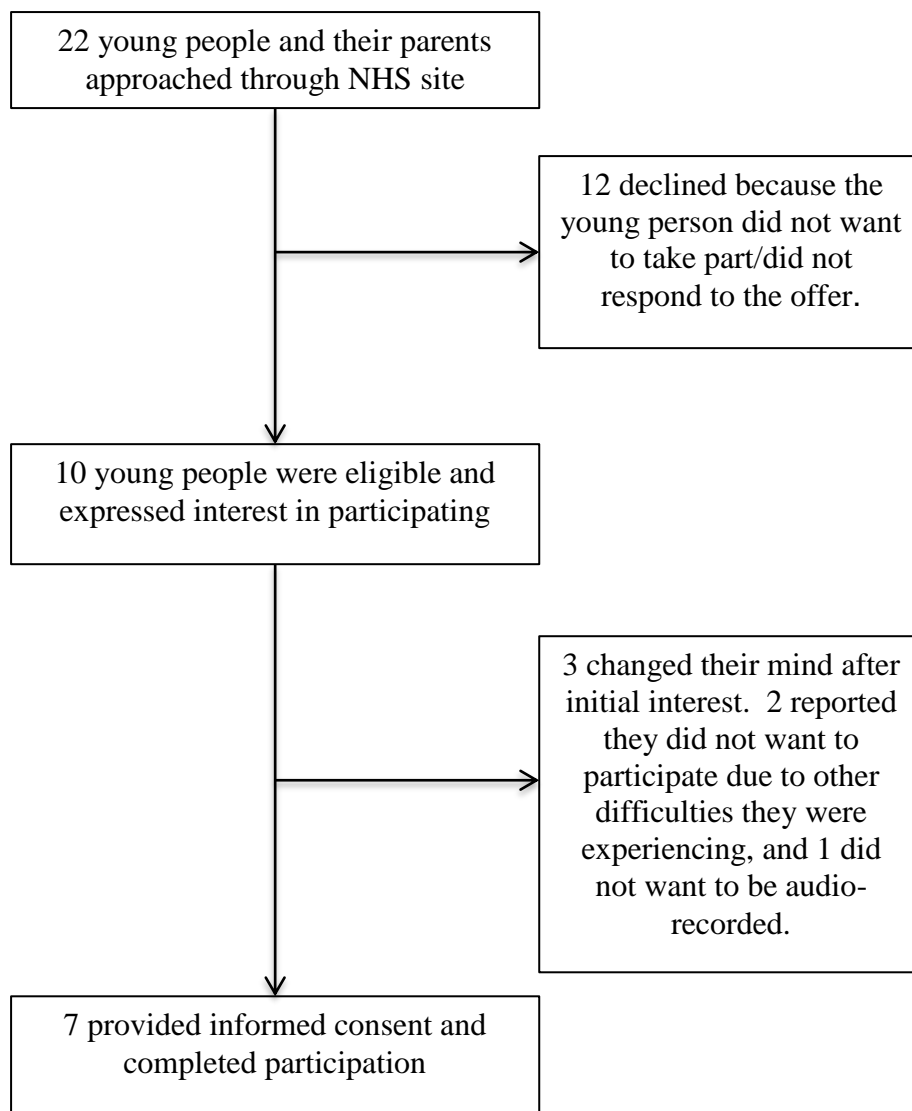


Figure 2. Recruitment flow diagram

## Materials

Before interviews, parent(s) completed a demographics form (Appendix 11), gathering routine information (e.g. age diagnosed), and other information that may help the researcher engage them (e.g. their interests).

Semi-structured interviews were chosen to explore participants' experiences, as they are recommended as a flexible method of qualitative data collection (Smith, Flowers,

& Osborn, 1997), and have successfully yielded meaningful results with other autistic children of this study's age (e.g. Calzada et al., 2012; Daniel & Billingsley, 2010). Whilst being suitable to the study's objective, this approach also provides young people with opportunities for independence and free expression.

Given that other research has suggested an individual's diagnosis, and the disclosure of this, is embedded within their experiences of 'having' autism (Huws & Jones, 2008; MacLeod et al., 2013), it did not feel appropriate to tightly define what constituted as experiences relating to receiving the diagnosis. Instead, it was hoped asking a range of broad questions would generate discussions with the young people, and help the researcher access their experiences around getting their diagnosis. The schedule explored their experiences of how they found out about their diagnosis and what that experience had been like for them, the conversations they had about this, their thoughts on autism and what it means for them, and their advice for informing other young people about their diagnosis.

Feedback was sought from a 12-year-old with a diagnosis of ASD, on a draft interview schedule, regarding the questions asked, wording, and length of interview. Minor changes were made based on their feedback, which mostly related to follow-up prompts, and not the main open-ended questions. Feedback was also sought on the wording and layout of the young person participant information sheet, and assent form; with minor wording changes only made to the information sheet. The interview schedule is shown below in Figure

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Listening back to the first interview's recording highlighted that, at points, the researcher had used prompts too soon. Therefore in subsequent interviews, a conscious effort was made to first open up exploration, before using prompts about more specific issues.

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### **Key**

#### **Main Question**

Possible Prompts/Follow-Up Questions (dependant on participant's response)

#### **1) What do you think autism (or substitute term) is?**

- Can you tell me more about that?
- Can you give me examples of that?

#### **2) Can you remember the first time someone told you that you have autism (or substitute term) (If no, go to Q7)**

- If they don't remember, explore process of knowing/finding out more: conversations with people? What they remember of this.

#### **3) How did you find out that you have autism (or substitute term)?**

- When was that?
- Where were you?
- Who told you/who were you with?
- What was that like for you?
- Had you heard of autism (or substitute term) before?
- Would you like anything to have been different about the way you found out you have autism?
- Did you get enough information? Would you have liked more/less?

**4) What was it like for you to find out that you have autism (or substitute term)?**

- How did you feel? (Try to elicit thoughts, feelings, reactions, if possible).
- For those that are struggling to articulate was this was like for them: Children often react differently to finding out they have autism, some people feel sad, some people angry, some happy. How did you feel?
- For those that are struggling to articulate was this was like for them: If it is hard to say how you felt/what you thought/what you did, can you draw me a picture of it? What did you draw? Why? What's happening in the picture?

**5) Have you spoken to anyone about it? What's it been like to talk to them?**

- Parents? Teachers? Friends? Professionals?
- What did you say to them?
- What did you like about what they said?
- Anything you didn't like about what they said?
- Did they say anything helpful to you?
- Did they say anything unhelpful to you?
- What was helpful/unhelpful?

**6) Do you think you have autism (or substitute word)?**

- Why don't you think you have autism?

**7) What does having autism (or substitute word) mean to you?**

- Can you tell me more about that?

**8) Do your friends think/know (depending on response to Q6) that you have autism (or substitute term)?**

- What do your friends think about that?
- How did you tell them/how did they find out?
- Why did you tell them/why not?
- How did you friends react? / How do you think they might react?

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- Did they act any different when they found out? In a good way? In a bad way?
- Has this changed anything?
- Are you pleased you told them?
- Is there anyone else you might tell? If 'yes', who would you tell? Is there anyone you wouldn't tell? Why not?
- What do you hope may happen if you tell them? / If they express worries about telling others: What worries you about doing this?

**9) Only ask to those who responded 'Yes' to 'Do you think you have autism?: Do you think autism (or substitute term) will affect what you do in the future?**

- Are there things about the future that you think might be the same for you and people without autism?
- Are there things that you think might be different?

**10) Is there anything good about having autism (or substitute term)? Is there anything bad about having autism (or substitute term)?**

- What types of things?
- Can you think of an example?

**11) Depending on young person's age/ability to answer such a question: If someone asked for your advice about how to tell someone that they have autism (or substitute word), what would you tell them?**

- Are there things you would tell them definitely not to do?

**Closing questions:**

**12) If I could tell people one thing about autism (or substitute term), what would you want me to tell them?**

- Is there anything else you would want to tell other young people just finding out they have autism?

- 13) Only ask to those who responded 'Yes' to 'Do you think you have autism?': If you could summarise what it means to have autism in one sentence, what would you say?**
- 

*Figure 3. Interview Schedule*

### **Procedure**

To facilitate rapport and minimise anxieties for the young person, interviews were done in a familiar and comfortable place of their choice (see Table 4), and time was spent beforehand having general discussions (e.g. about their interests). Both the young person and parent(s) were given the choice on whether they wished for the parent(s) to be present for the interview. For those choosing to be interviewed alone, it was explained that parental support could be accessed during the interview. Participants were offered breaks during the interview, and drawings were suggested as another way to express their thoughts and feelings. However, all participants preferred answering questions verbally. Participants were then thanked for taking part, and it was explained that the results would be fed back at the end of the study. The young person and their parent(s) were also provided with a sheet listing local services they could approach for further support if the interview had raised difficult feelings.

Given its sensitive nature, it was recognised that asking participants to reflect on their experiences of receiving their diagnosis might have caused distress. Participants were fully briefed on what participation would involve beforehand, and were aware the interview could be stopped or rescheduled at any point. The researcher regularly

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checked with participants during the interview, to ensure that any distress could be managed accordingly. Furthermore, difficulties in social communication for some of the young people may have made it difficult to verbally express their wish to decline or withdraw. Therefore, the researcher also looked for non-verbal cues that might reflect withdrawal of participation, such as repeatedly walking away, or staying silent.

The interviews were completed within one meeting for each participant, and lasted between 35 and 50 minutes. Interviews were recorded on a password-protected recorder, and transcribed verbatim before deleting the audio recording.

### **Data Analysis**

Thematic analysis involves developing themes based on “repeated patterns of meaning” (Braun & Clarke, 2006, p. 15). The entire data set was analysed. This allowed for a rich description of the data, and minimised researcher bias, as assumptions were not made about what data was relevant to the research question; this approach is favoured for under-researched areas (Braun & Clarke, 2006). Furthermore, an inductive approach was used, where the analysis was driven by the data, as opposed to a theoretical pre-existing coding framework.

The analysis involved the following stages:

1. Becoming familiarised with the data through reading and re-reading the verbatim transcriptions.
2. Transcripts were read line by line, and initial codes were generated to capture what was said in segments of data.



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3. The individual codes were then searched, and sorted into possible overarching themes and subthemes, based on patterns of meaning. To maintain flexibility (Braun & Clarke, 2006), themes were not developed based on the frequency of codes across the data. Whilst data was coded at a semantic level, developing themes helped the analysis move to a more interpretative level, attempting to make sense of the patterns with a broader understanding (Patton, 1990).
4. The themes and their supporting extracts were then reviewed, to ensure that individual themes formed a coherent pattern, whilst being distinct from each other (Braun & Clarke, 2006; Patton, 1990). Transcripts were then re-read, to code data that may have been missed, and check the themes accurately reflected the entire data set. Themes were named using words/phrases that best captured their essences.

Like other approaches for qualitative analysis, thematic analysis has its own strengths and weaknesses. Thematic analysis offers a very flexible approach that can be adapted according to different theoretical frameworks, research questions, data collection methods, and sample sizes (Braun & Clarke, 2013; Nowell, Norris, White, & Moules, 2017). However, thematic analysis is sometimes also criticised. Its flexibility means that it lacks specific guidance on higher-level analyses, involving interpretations of participants' descriptions (Braun & Clarke, 2006; Braun & Clarke, 2013). It has also been argued that its flexibility can result in an inconsistent approach, which lacks cohesion (Holloway & Todres, 2003; Nowel et al., 2017). However this study aimed to promote cohesion and consistency by explicitly stating the epistemological and ontological positions underpinning the analysis (see Page 85), as well as clearly

describing the different decisions made, and steps undertaken during the thematic analysis of the data.

### **Reflexivity**

As a trainee clinical psychologist who has worked with autistic people, the researcher was mindful of the influence their preconceptions may have on the research process. The researcher views autism positively, in that whilst autism can create challenges for individuals, it can also bring strengths. The researcher kept a journal to track their thoughts during the research process, which included reflecting after each interview, on whether it raised any particular issues or assumptions (for example, see Appendix 15).

Furthermore, the researcher was aware they had already been exposed to research on the experiences of autistic people, which at times related to getting their diagnosis. To enhance reliability (Elliott, Fischer, & Rennie, 1999), credibility checks were completed during analysis. Two transcripts (29%) were also coded by an independent second rater, which ensured that codes were not just generated from the researcher's perspective. This helped to reduce bias.

**Results**

The thematic analysis identified five main themes, and seventeen subthemes (Table 5). Participants have been given a unique code when presenting the quotes (e.g. P01), and Table 6 shows the contribution of each participant to each theme and subtheme. To maintain confidentiality, these do not correlate with the numbers listed in Table 4. As there was only one female participant, gender pronouns have been avoided. Further supporting quotes are listed in Appendix 14.

Table 5

*Themes and Subthemes from the Thematic Analysis*

<b>Theme</b>	<b>Subthemes</b>
<b>Experiences during Assessment</b>	
<b>Making Sense of the Diagnosis</b>	The Unknown Process of Learning about Autism Perceptions of Autism Relief with Understanding Changing with Time Reflections based on Experiences of Receiving a Diagnosis
<b>Impact of Diagnosis on Self</b>	Self-awareness Self-acceptance Support after Diagnosis
<b>Impact of Diagnosis on Self in Society</b>	Difference Thinking Ahead Responsibility to Educate Others
<b>Interaction with Others</b>	Others Understand you More Acceptance from Others Poor Understanding in Others Fears of Others Knowing More Awareness Needed

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Table 6

*Themes and subthemes contributed to by participants*

	P1	P2	P3	P4	P5	P6	P7
<b>1. Experiences during Assessment</b>	✓		✓	✓		✓	✓
<b>2. Making Sense of the Diagnosis</b>							
The unknown	✓			✓		✓	✓
Process of Learning about Autism	✓	✓	✓	✓	✓	✓	✓
Perceptions of Autism	✓	✓	✓	✓	✓	✓	✓
Relief with Understanding			✓	✓		✓	
Changing with Time	✓				✓		✓
Reflections based on Experiences of Receiving a Diagnosis	✓	✓	✓		✓	✓	✓
<b>3. Impact of Diagnosis on Self</b>							
Self-awareness	✓		✓	✓			✓
Self-acceptance			✓	✓			✓
Support after Diagnosis		✓		✓	✓	✓	✓
<b>4. Impact of Diagnosis on Self in Society</b>							
Difference	✓		✓	✓	✓		✓
Thinking Ahead	✓	✓	✓		✓	✓	✓
Responsibility to Educate Others			✓				
<b>5. Interaction with Others</b>							
Others Understand you More		✓		✓			✓
Acceptance from Others		✓		✓	✓	✓	✓
Poor Understanding in Others			✓	✓		✓	✓
Fears of Others Knowing			✓	✓			✓
More Awareness Needed			✓			✓	✓

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### **Experiences during Assessment**

One participant had only “*very distant memories*” of the assessment process, and “*how the room looked to some extent*” (P01), possibly as they were trying to recall something from four years ago.

However, four participants recalled their experiences of the assessment period, pre-diagnosis. One participant was stressed from not knowing why they were being assessed, and worrying “*nasty things might happen*”:

*I found it quite stressful at the start... Because I'd always think 'I'm being taken here [diagnostic service] because there's something wrong with me'. (P03).*

The other three participants (P04, P06, and P07) spoke of it taking years to get their diagnosis. For example, Participant 07 spoke of feeling “*a bit impatient*” in “*the period from when it was brought up first to when it was actually diagnosed*”, and “*just waiting to finally get the diagnosis*”, which took around two years.

One young person recalled their parents seeking a second opinion after the first service felt they did not have autism, and spoke of their annoyance at feeling misunderstood: “*I felt annoyed. I felt like they didn't understand.*” (P04).

### **Making Sense of the Diagnosis**

Receiving their diagnosis prompted a process whereby the young people tried to make sense of this. For those without a prior knowledge or understanding of autism, receiving their diagnosis could trigger unpleasant thoughts and worries. They spoke

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of the ways they learnt about autism, with understanding developing over time, including the people that supported their learning, and the tools that facilitated this process. This process led the young people to develop their perception of what autism is and helped relieve any distress they initially experienced, when they lacked an understanding of autism. They thought about their diagnosis more or less at different points in their life, and sometimes an acceptance for the diagnosis gradually developed. Reflections were also made, based on their experiences, on how to help other young people make sense of their own diagnosis.

### *The unknown.*

Four young people remember autism being a new concept that they did not understand when they first found out about their diagnosis. For example:

*...I do remember the therapist telling me I had something called autism and I really had no idea, no clue what it was. (P01).*

This triggered a range of thoughts and feelings. For example, one participant uses their own thinking style to make sense of their vague memories, on how they would have felt at the time:

*Confused. I don't clearly remember, but from logical reasoning I think I would have been confused because I really didn't know what autism was. So then to kind of be told you have something that you have no idea what it is can be quite confusing (P01).*

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Participant 06 recalled feeling “*upset at the beginning*” because they had “*no idea what it was*”. Another participant felt “*weird*”, and talked about it being difficult to understand what it meant at first:

*...it was kind of weird to find out that I had something that I didn't properly know and understand...I didn't get, it sounded like kind of complicated... (P04).*

Lacking this understanding meant some had uncertainties and worries around what this meant for them, and the unknown impact it might have on them:

*what does this mean for me? (P07)*

*scared it might be something bad (P04)*

*...I was worried about how it was going to affect me really...just generally in life sort of thing. (P07).*

### ***Process of learning about autism.***

There were a variety of ways in which the young people first became aware of their diagnosis, and in how they learned over time what autism meant, as well as what this learning process looked like.

Three participants were informed by a professional in a clinical setting with their parent(s) present (P02, P07, and P06), one participant remembers being told about their diagnosis by their therapist without their parent(s) present (P01), and two were told by their mothers at home (P03 and P04). The remaining participant was diagnosed ten years ago and could not recall when they first found out, but reflected that they picked up on things gradually by:

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*hearing people talk about autism and feeling the effects of it in terms of the schools I went to” (P05).*

For one young person, the learning began before the diagnosis was disclosed to them, as their mother gradually started talking about autism and explaining how it could affect people, using a comic book about Asperger Syndrome. They began to relate some of their own experiences to this information during this process, and became curious and “*interested*”, which meant that when their mother told them this was something they have, they were:

*...slightly surprised, but not too surprised because I kind of thought that I had it, because I was thinking ‘these sound a lot like me. (P03).*

For the others that could remember, this learning process began when they found out about their diagnosis, and continued in different ways over time, involving conversations with parents, teachers, doctors, or therapists. Different tools, such as books, websites, or videos/films, often facilitated these conversations. For example:

*I think it was right after I got diagnosed. My mum, she told me to come over and watch this (film), and she basically explained to me you’re diagnosed with autism, and this is autism, that type of stuff. (P04).*

Some young people also did their own research on the Internet, although one participant spoke about the negative impact this information had on their feelings about their diagnosis, as it focussed on difficulties and neglected to discuss strengths associated with autism:



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*I was watching something...and it was like bullet points of things it does, and then reading through them there's nothing like 'oh that's a good thing', 'that's something that I'm happy to have'. It's sort of 'oh they're bad with eye contact', 'they're bad with things like that'. Seeing that is like 'oh, it's probably a worse thing to have (P07).*

One young person picked up some of their understanding about autism through watching the news:

*I think in the news, or something, they said it...and all autistic people like manga..." (P02).*

### ***Perceptions of autism.***

The understanding that the young people acquired through the different learning processes, led them to develop an understanding of what they felt autism to be. Their descriptions partly related to the nature of autism. These included viewing it as a difference in biology where *"the brain is different"* (P02), as a *"developmental disorder"* (P07), or *"mental illness"* (P06).

These perceptions also related to its effect on people. For example, how it can make it *"hard to learn something"* (P04), or cause someone to be *"worse in social situations"* (P07). Several also developed the understanding of autism as a spectrum, affecting people in different ways. For example:

*Autism affects people differently, and people are different so it could affect someone more by logic, or by creativity, or struggle with certain subjects. (P06).*

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However, some appeared to have developed a generalised view of autism, based on their own experiences and traits. For example, *...all autistic people like trains.* (P02).

The young people often viewed autism (and their diagnosis) as having both pros and cons. For example:

*...it has positive and negative differences... the negative side is that I can't really concentrate, but the positive side is that when I do concentrate, I concentrate even more.* (P03).

Although one young person did not associate anything negative with their diagnosis (P02), and another was more ambivalent as they did not consider there to be anything positive about it, but feeling that their diagnosis was *"not the end of the world, and it's not that serious of a problem"* (P07).

Despite offering suggestions about what autism is, accompanying comments from two young people like *"I don't know much"* (P02) and *"I don't really understand it"* (P04) suggest they felt they did not fully understand their diagnosis.

### ***Relief with understanding.***

For three young people (P03, P04, P06), developing an understanding of what autism meant appeared to allow them to re-evaluate their initial worries about negative consequences, which then alleviated the distress they had when they lacked understanding. For example:

*...I kind of felt relieved because autism apparently isn't extremely bad. As Mr X [teacher] said, it's nothing to be ashamed of. Just really relieved...[talking*

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*about how he felt before speaking to the teacher] I was just scared it might be something bad. (P04).*

### ***Changing with time.***

For some young people the relevance of their diagnosis appeared to change over time, suggesting that receiving a diagnosis is more of a process rather than an 'event' with a start and end point. Some gave little thought to their diagnosis initially, with their curiosity about it gradually increasing as they got older. For example:

*...I really kind of pushed that to a side [at the time of first finding out] ...I think I kind of felt more intrigued and interested about this autism thing [talking about when 12 years old] .... I asked my therapist more about it. (P01)*

However, for one of the oldest participants, it seemed their priorities changed with age, and they reported they thought less about their diagnosis over time:

*I've gone past the autism age. I don't really think about autism that much. I'm mostly thinking about things like school and politics. (P05).*

Feelings about the diagnosis appeared to also change over time. Participant 01 describes "bad events as like a circle", and recalls feeling like a "pariah" when they first received the diagnosis. However they appeared to accept the diagnosis gradually, using a circle analogy to explain that "over time it gets bigger and bigger and it hits you much less".

The two oldest participants felt they were "not mature enough to really understand" their diagnosis (P05) when they first found out about it, or were only "able to take it

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*on board more*" in the last year (P07). This may relate to how knowledge of autism is gradually acquired, but also perhaps reflects the developmental abilities required to understand the complexities of the autism concept at the time.

### *Reflections based on experiences of receiving a diagnosis.*

The young people had a number of reflections based on their own experiences, about ways they thought helpful to both inform other young people finding out, and how to support them in helping them make sense of their diagnosis.

One suggestion was around the possible benefit of introducing autism as a concept before telling someone they have it. One young person reflects on how their feelings may have been different if this had been done for them (P01), and another, whose mother explained autism before disclosing the diagnosis, talks of how they might have felt scared finding out if this had not been the case (P03):

*...maybe get them to know a little about it, before they're told...I don't know if I would have been told what autism was beforehand I don't know maybe it would have been different, maybe not. (P01).*

*If she told me just 'Asperger's, you've got it', I'd be 'what's that?!' and be really scared. (P03).*

There was also a sense for some, that young people should be given information slowly, and given "*time to think*" (P02) and process this information, before being asked how they feel about the diagnosis. It was felt individuals might be more likely to accept the diagnosis with this approach. For example:

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*My advice would be to take it slow. If you wanna [sic] get it in and you wanna [sic] make sure they're OK with it, it's going to have to be slow...With any situation if you just shove it right in their face people kind of push it out the way, and they're going to go 'no'. If you put it in slowly then maybe they'll eventually agree. (P06).*

Taking an honest and realistic approach in explaining the diagnosis was also felt to be helpful, focusing on the individual's strengths, but also considering the challenges they may face:

*...But also not to ignore the weaknesses. Because in all honesty if you ignore the weaknesses that's never going to go well either. But first of all, embrace what gifts they do have. (P06).*

Whilst some felt they received enough information and support at the time of diagnosis, others felt more was needed to help them make sense of their diagnosis, and explore their feelings about it:

*...it would have been nicer to know more about it...they don't tell you if it's bad or good..." (P07).*

*I think more service for when I found out, asking if I was surprised and stuff in general...and it would have been important if I said 'sometimes I was scared, sometimes I was really excited, sometimes I was really paranoid'" (P03).*

### **Impact of Diagnosis on Self**

This theme relates to how receiving their diagnosis allowed some young people to develop a greater self-awareness, helping them make sense of their experiences,

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which sometimes fostered a greater self-acceptance for their differences. It was also helpful for getting young people support with learning, and developing their self-awareness.

### *Self-awareness.*

For some young people, receiving their diagnosis facilitated a greater self-awareness, providing them with an understanding for their experiences and difficulties, which could be explained by their autism. For example:

*...I think autism means you fidget around a lot. And also I find stuff really uncomfortable...when I sit down on a [plastic] chair...I feel so uncomfortable and I fidget around... (P04).*

For one of the oldest participants (P07, aged 15 years), this insight developed over time, “*as I got older I started thinking more about how I acted*”, and they described having “*become more self-aware*”.

For some, this prompted them to reflect on their past experiences, and gain a retrospective understanding. For example:

*I really think a lot about the past....I find it very hard to be in a group of people” (P01).*

This self-awareness allowed some to find ways to adapt and cope with past difficulties. For example:

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*...before I wouldn't have known why I'm going wrong, whereas I've now sort of become more aware...and then that's what led me on to thinking about what I'm going to do before I meet someone... (P07).*

### ***Self-acceptance.***

The self-awareness that developed after diagnosis led some to feel more comfortable about their differences. For one young person, this new framework of understanding meant they ruminated less on their social difficulties:

*Just like putting a reason behind the things I might struggle with, and sort of the traits of autism. Being able to link them back with how I am, and it's like 'oh that's why I'm like this', and it's not like something that nags on me because I know why. (P07).*

Another spoke of a pressure to conform to societal norms, meaning “*I was always forcing myself to do these things and act normal...thinking 'I need to help myself, to teach myself to stop it' (P03), which “upset” them. Receiving their diagnosis, and learning “how it affects you socially”, empowered them to tell others “I feel uncomfortable doing that” (looking people in the eyes), when peers questioned “what is wrong with you?”. No longer trying to mask their differences made them feel “relieved”.*

Receiving their diagnosis, and the subsequent process of making sense of this, appeared to absolve one young person of blame for aspects of their behaviour:

*I found out about it, it's not my fault I do some stuff, it just happens randomly” (P04).*

*Support after diagnosis.*

Five young people spoke of the support they got as a result of receiving their diagnosis. Sometimes this was related to help with their learning at school, such as “getting a laptop in lessons” (P02), which for this person “helps me do more work...to do good work”. For others, the support they received post-diagnosis seemed to assist the development of their self-awareness, linking to the earlier sub-theme. For example, this young person talks positively about accessing emotional support from a teacher:

*If I'm mad he talks to me and I tell him why I was angry and he sorts it out....he'll say I was doing that because I have autism and then he has to explain why...it makes me feel happy because I have someone to talk to. (P04)*

As another example, Participant 07 talks about the counselling they have received. Whilst counselling does not appear to be a direct result of getting the diagnosis, it helped guide the work's focus, and helped them make sense of their social difficulties:

*...he brought to my attention with autism...sort of let me know what it does, how it makes me react...And then realising that, and seeing that I actually do do that, made me look at how I could maybe try to improve it. (P07).*

**Impact of Diagnosis on Self in Society**

Part of the young people's experiences of receiving and making sense of their diagnoses seemed to prompt reflections on how they position themselves within



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society. These related to the perception of themselves as 'different', considering how their future may be different in light of their diagnosis, and for one young person, taking on the role of educating peers on autism.

### *Difference.*

Getting their diagnosis, and the subsequent perceptions of autism they developed, led all but one of the young people to perceive themselves as 'different' to other people.

For example:

*Just made me think a lot about how I'm different. (P01).*

Although one young person felt like an "outsider" (P04) as "most of the people in my year, they don't have autism and I do", this did not appear to negatively impact on how they saw themselves in relation to peers. In fact, linking to a later theme, they talked of peer acceptance of the diagnosis.

The remaining young people also did not seem to perceive this difference in a negative way. Some felt difference was OK, and something to be accepted. Whilst others regarded this difference as a positive characteristic, and some even took pride in it. For example:

*...autism does not make someone inferior, it just makes them different (P01).*

*I've got something that makes me stand out. And unique...it's a good thing...it would be boring to be the same. (P03)*

*I think it's made me a more different person...I think it's enhanced my differentiation, my individuality. (P05).*

*Thinking ahead.*

Becoming aware of their diagnosis, and the knowledge they acquired about autism, had led all but one participant to feel their future will be different from non-autistic people. For one young person this related to social skills:

*...maybe I won't be able to enjoy them [social things] or take part in them like other people would do... (P07).*

For the other five, these reflections related to their future careers. Some spoke of their autism meaning it might be more difficult to get jobs, or particular types of jobs. For example:

*I think some jobs, they don't want people with autism in... like a lawyer or something, or a solicitor or something, I don't know. (P02).*

This was worrying for one young person:

*I've heard that maybe only on average, maybe 1 in 6 people with autism probably do get a proper job or something...and that did feel kind of intriguing and worrying. (P01).*

However the others did not appear concerned by their perceived differences; feeling they would still get a job, or may even be more desirable for some companies, based on their individual strengths. One individual even celebrated the different path they would have to their peers:

*More companies will want me because I've got Asperger's, and it's like a special skill [technology jobs]. (P03).*

*I've been liberated from traditionalism (P05).*

***Responsibility to educate others.***

One young person adopted an educator role after receiving their diagnosis, whilst also standing up for the diagnosis:

*It's always been that someone's talking about it, and then I've come over and corrected them.... Or they're making fun of it, and I'll say 'look you're not using it correctly, please stop taking fun of it. (P03)*

**Interaction with Others**

Some of the young people felt getting a diagnosis could impact on how others interacted with them. Whilst some felt it could help others understand them more, others spoke of people's poor understanding of autism. Some had experienced acceptance for their diagnosis from others, whereas some had developed fears around other people knowing. Some felt that more awareness for autism was needed.

***Others understand you more.***

For three young people, there was a sense that getting a diagnosis could help others understand the person with the diagnosis more, if they were aware of it. For one young person, this view was the result of direct experience, as they spoke about teachers knowing of their diagnosis:

*...people can understand you slightly more...say sometimes I did something by accident, they understand why I did it and they would know why. (P04).*

Another felt the diagnosis might make others more tolerant of certain behaviours, for which they might have been punished without the framework of understanding the

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diagnosis brings. However, it is unclear if they personally experienced this, or observed it:

*... maybe some people let [sic] off getting in trouble or something...so if they like do something they don't know what it is...they might not get in trouble much" (P02).*

The third talks about how they would like their friends to know of their diagnosis, "because then they could understand" (P07) why they struggle talking to people, but then explains their concerns, which are stopping them from sharing the diagnosis with peers.

### ***Acceptance from others.***

A number of young people spoke of how their friends reacted to their diagnosis, not changing how their friends were with them, and appearing to be something they accepted. For example:

*They were fine with it...They were just like 'oh, OK'... (P06).*

### ***Poor understanding in others.***

Whilst some felt their diagnosis helped others better understand them, a few spoke of experiences following their diagnosis, which made them aware that some people have a poor understanding of autism.

For two individuals, this related to their experiences with teachers. For example, one felt that some teachers did not understand that their spontaneous laughing out loud could be explained by their autism, despite trying to explicitly explain this:

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*I just say to them, 'I'm autistic, like, I can't help it, it just comes out of me'... with really bad teachers, they say 'so what, you're autistic, it doesn't mean you can get out of trouble'... It makes me feel annoyed because I'm trying to explain something to them... and they don't understand what's happened.*  
(P04)

A few of the young people's experiences related to poor understanding within their peers. Stigma regularly came up when this was talked about, and they were made aware of this through different ways. For example, this young person talks about experiencing enacted stigma and victimisation after peers became aware of their diagnosis:

*Once I got scared because someone insulted me, and they found out and said I should go to hospital, and be locked up in a loony bin.... (P03).*

Another talks about the stigma attached to the diagnosis, which they observed in interactions between peers and other autistic young people, where their condition is perhaps more 'visible':

*I've overheard plenty of conversations at my school of saying 'oh he's got autism, avoid him'...Because I act normal and it doesn't seem like I have anything, I can just pass off... (P06).*

The same young person also spoke of how the media and Internet can portray an inaccurate view of autism, which feeds into the stigma attached to the label. For example:

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*...if you look onto YouTube and search up 'autism', you're going to get a bunch of videos where there's kids running around screaming...You're also going to get a bunch of people who are like 'oh my god he has autism', and act like it's Ebola or something." (P06).*

### ***Fears of others knowing.***

Some young people developed concerns that others finding out about their diagnosis would change how they were perceived and/or treated by peers.

For one young person, these were historical fears, which resulted from a peer's negative reaction:

*...at primary school I said to someone I'm autistic and he said 'why aren't you dumb' .....[then talking about why they did not initially want to tell people in secondary school] I thought they'd say like 'oh you're stupid, you're dumb', they might look down at me or something. (P04).*

For others, their fears were ongoing. For Participant 03, the negative reaction they received after telling peers about their diagnosis ("*big ears has a new problem*"), meant they had concerns around telling others in the future, including family members:

*...it seems to be a bit of a secret because even a few people in my family I haven't told yet... Because I think 'oh they'll make fun of me like the boys in school did (P03).*

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However, whilst another young person's family had accepted their diagnosis, barriers existed to telling friends because of worries that it may change how they are treated:

*...I wouldn't want people to think that I'm, look at me in a different way because I've told them...I wouldn't want to be pushed away by people for having it... (P07).*

### ***More awareness needed.***

Some of the young people reflected on ways they felt others could be helped to understand more about autism, to possibly reduce the stigma around it, and allow them to feel more comfortable sharing their diagnosis. They felt more awareness was needed, which could be achieved through learning about autism at school. Whilst it seemed some schools had started this to some extent, they felt more was needed. For example:

*I mean teaching it in the schools would be number one. Because I know for a fact most schools do not teach things about SEN, so things like autism...They don't teach it as a main thing that should probably be focussed on. (P06).*

## **Discussion**

This study aimed to explore young people's experiences of receiving an ASD diagnosis, within the recruited sample of 12-15 year olds. A thematic analysis revealed five overarching themes, which are discussed in relation to existing literature, along with their clinical implications. The study's limitations are considered, and suggestions for future research made.

### **Experiences during Assessment**

Some of the young people remember the assessment process taking a long time, which echoes some parents' experiences of getting their child's ASD diagnosis (e.g. Crane et al., 2016), but also some autistic adults' recollections of receiving their diagnosis (MacLeod et al., 2013; Punshon et al., 2009).

Not knowing why they were being assessed could be a stressful experience, triggering worries that 'something was wrong' or something bad was going to happen. This is a novel finding, and has not been discussed in the limited research involving young people talking about getting their ASD diagnosis. It is likely that some of those young people were also not aware of the reason for their assessment; however, these other studies were not designed to fully explore diagnostic experiences.

### **Making Sense of the Diagnosis**

For several young people, finding out about their diagnosis was initially confusing, weird, or upsetting, as they knew nothing about autism or diagnosis. The uncertainties around this unknown concept could lead to worries about how autism would impact on their life. Whilst others have reported negative reactions (Lewis,



2016; Powell & Acker, 2015), these do not appear linked to the individuals lacking an understanding for their ASD diagnosis. As aforementioned, the current research has mostly focussed on the experiences of receiving a diagnosis in adulthood. Such samples may have a greater 'baseline' understanding of autism before diagnosis, compared to those finding out as children; through contact with services, and day-to-day 'exposure' to autism (e.g. through television programmes).

Acquiring an understanding of autism relieved the young people of this initial distress; as autism was no longer an unknown concept, and allowed them to re-evaluate their previous worries. Whilst autistic adults have also reported relief after getting their diagnosis (Lewis, 2016), this was through gaining answers to help make sense of their lives, rather than relief from distress caused by lacking an understanding for autism. This again, might be due to differences in levels of understanding prior to diagnosis.

Learning about their diagnosis was a process, typically over time, with an understanding of autism gradually increasing. This is the first study to explore this in detail, and has highlighted these different processes for young people, in who was part of this, and what tools/literature helped facilitate this. Calzada et al. (2012) found their sample of 9-16 year olds had not tried to understand what their diagnosis meant, whereas some of this study's young people had actively engaged in this process, asking people questions, or researching the Internet. All but one had known about their diagnosis for at least two years. Given the younger age range, it is possible the young people in the Calzada et al. (2012) study had their diagnosis disclosed to them more recently, and were at different points on this learning 'process'.

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The information young people are given after diagnosis, or subsequently access, may affect how they view autism and themselves. The dissatisfaction one young person had with the information they read, links with other autistic people's accounts on getting their diagnosis (MacLeod et al., 2013). The focus on difficulties associated with autism negatively impacted this young person's feelings about their diagnosis, and interestingly, they were the only one to not think of anything good about having their diagnosis.

For some of the young people, the significance of their diagnosis appeared to change over time, with them sometimes thinking about it more as they got older. This may link to their developmental ability to understand the complexities of autism when they found out, and two young people reflected on being too young to understand it at the time. It seemed that their priorities changed with age and a curiosity could develop gradually, with them trying to make sense of their diagnosis as time passed, possibly as they entered adolescence, a time important for individuals in developing their identity (Erikson, 1994). It appeared their feelings towards the diagnosis could also change with time. Like this study, other autistic adolescents and young adults have also reported a gradual acceptance of their diagnosis over time (Huws & Jones, 2008; Stevenson et al., 2016). This study suggests receiving an ASD diagnosis may be best viewed as more of a process over time, rather than a single 'event'. This supports the proposals of other researchers (Punshon et al., 2009). Taylor (1983)'s cognitive adaptation theory proposes that psychological adjustment to a threatening event (such as a health diagnosis) is partly achieved by the diagnosed individual searching for a

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meaning in this experience (i.e. diagnosis). This study suggests these meanings may be developed over time for young people.

Since receiving their diagnoses, all of the young people had developed their own perceptions of what autism is. Whilst for some, this understanding seemed specific in relation to their individual characteristics, as other autistic young people have reported (Calzada et al., 2012), others had broader understandings of autism as a spectrum of differences.

The young people also reflected on their experiences of receiving their diagnosis, to offer suggestions on how to inform other young people. For relevance, these are discussed in the study's clinical implications.

### **Impact of Diagnosis on Self**

The diagnosis provided some of the young people with a framework to understand and make sense of their experiences and differences, in the context of autism, and enabling some to develop ways to adapt and manage in the future. This finding is frequently documented in research with adolescents and adults, where individuals' experiences of receiving their ASD diagnosis have been directly explored, or where individuals have discussed issues in relation to their diagnosis (see Pages 48-50 for a review). This study suggests that getting a diagnosis can develop self-awareness in children as young as 12.

The understanding that the diagnosis provided for their experiences enabled some young people to be more accepting of themselves. This fits with the cognitive

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adaptation theory, which proposes that individuals make efforts to use the diagnosis, and its attached understanding, to restore their self-esteem (Walker, Littlejohn, & Jackson, 2004; Taylor, 1983). Other autism research has found that getting a diagnosis helped individuals feel better about themselves, as they made sense of their experiences (Hickey et al., 2017; Mogensen & Mason, 2015; Powell & Acker, 2015; Rosello, 2015). Punshon et al. (2009) noted that whilst receiving an ASD diagnosis in adulthood could exonerate individuals from self-blame for their negative life experiences (like one young person in this study experienced), growing up without a diagnosis meant they lacked a framework to make sense of these, and therefore could internalise negative things said by others. Humphrey and Lewis (2008) found autistic adolescents felt pressurised by social norms to adapt themselves around peers, and hide their autism, and a recent study suggests such 'camouflaging' could negatively impact an individual's mental health (Cage, Di Monaco, & Newell, 2018). For one young person in this study, the self-acceptance they developed following their diagnosis meant they stopped masking their differences. Receiving a diagnosis in childhood, rather than later in life, may therefore have a positive impact on that individual's sense of self and identity, which may prevent future difficulties or mental health problems.

Furthermore, over half the sample spoke positively of the support they have received since getting their diagnosis. For the majority this related to support in school, helping their learning, or developing their self-awareness. Adults have also spoken of the support they had accessed due to their ASD diagnosis (Powell & Acker, 2015; Punshon et al., 2009), as well as young people, who reported greater educational support from their diagnosis (Calzada et al., 2012; Stevenson et al., 2016)

### **Impact of Diagnosis on Self in Society**

Getting their diagnosis, and having autism, led all but one of the young people to view themselves as 'different' to others. Other young people have reported feeling different, in studies exploring how they made sense of their diagnosis (Mogensen & Mason, 2015), and broader studies exploring experiences of having autism (Cridland, Caputi, Jones, & Magee, 2015; Humphrey & Lewis, 2008; Jones et al., 2013).. Some of this study's young people perceived this difference as positive, identifying themselves as being unique and having pride in their diagnosis, echoing other autistic young people's accounts (Cridland et al., 2015; Humphrey & Lewis, 2008; Jones et al., 2013; Mogensen & Mason, 2015). This is promising as research into the psychological adjustment of a HIV diagnosis found that ascribing to a more positive meaning for a diagnosis was linked to higher levels of psychological well-being and lower depression levels (Farbery, Mirsalimi, Williams, & McDaniel, 2003). Therefore, this study's young people who seemed to have found a positive meaning for their ASD diagnosis and the difference this introduced for them, may also potentially have higher levels of psychological well-being compared to other young people who may have ascribed to a more negative meaning of their diagnosis.

Furthermore, there are also differences in this study compared to others. None of the young people seemed to perceive this difference negatively, whereas other autistic young people have spoken of not wanting to feel different (Altman, 2010; Cridland et al., 2015), or being victimised by peers for this difference (Jones et al., 2013). The reason for this is unclear. It may link to the way others have talked to them about autism, or the information they have read. The young people were recruited from the same service, where there is a common language of autism being talked about as a

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neurodiversity. The young people's positive perceptions of autism align with the neurodiversity model of autism, which emerged during the 1990s by autism self-advocates (Ortega, 2009), and views autism as a condition and brain-based difference, and something that cannot be separated from the person (Sinclair, 1993), and should not be cured (Larsen, 2018; Ortega, 2009). This model evolved as a criticism of the previously dominant medical model, which sees autism as a disorder, focussing on impairments, with the idea it should be treated to 'fix' the individual so they can function in society normally (Robertson, 2009). Furthermore, this is up-to-date research, with young people diagnosed relatively recently, in a time where societal education of autism is increasing and societal views of autism may be becoming more positive, possibly influencing the young people's perceptions of themselves. However, given some young people also spoke of stigma for autism, this may play less of a role; this is discussed later.

The knowledge of their diagnosis had prompted the majority to believe their future held differences to those of non-autistic people, mostly relating to the job they would get when older. On the whole, these re-evaluations did not seem to cause the young people any particular distress. Considering their future in the context of their ASD diagnosis is believed to be a novel finding within research with young people, and suggests it may be something to consider when discussing a diagnosis with young people.

One young person adopted an educator role after receiving their diagnosis, correcting peers when they talked about autism in factually incorrect ways. This could be viewed as an element of self-advocacy, which alongside campaigning for basic rights for

autistic people, involves educating others about autism to try and eradicate prejudice and discrimination (Waltz, van den Bosch, Ebben, van Hal, & Schippers, 2015; Ward & Meyer, 1999).

### **Interaction with Others**

Receiving their diagnosis could sometimes help others become more understanding of their characteristics, with a tolerance that did not exist before the diagnosis, like research with older adolescents and adults has found (Calzada et al., 2012; Huws & Jones, 2008; Powell & Acker, 2015). However, some also experienced interactions highlighting a poor understanding of autism. Many also spoke of a stigma attached to the autism label existing within their peers. Goffman (2009) referred to stigma as “an attribute that is deeply discrediting” (p. 3), where stigmatised individuals possess “a trait that can obtrude itself upon attention and turn those of us whom he meets away from him” (p. 5). Scambler and Hopkins (1986) make a distinction between *enacted* and *felt* stigma, where enacted stigma refers to experiences of overt discrimination, and felt stigma to where there is a fear of prejudice or discrimination despite not actually having experienced this (Scambler, 2009). Within this study, these realisations were based on examples of enacted stigma they had either personally encountered, or observed other autistic children experiencing. Societal stigma of autism is something other autistic young people have raised when talking about their diagnoses (Calzada et al., 2012; Mogensen & Mason, 2015), and what it is like to have autism (Jones, Gallus, Viering, & Oseland, 2015), and is something that adults too have experienced (e.g. Punshon et al., 2009). This study suggests more work is needed to improve society's understanding of autism and dispel the stigma that exists, and indeed, some of the young people discussed how this awareness could be

promoted through teaching on autism in schools. Whilst some autistic people feel that self-advocates have a role in this (Jones et al., 2013), others argue professionals have a duty to contribute to this by removing the barriers that discriminate against autistic people (Aylott, 2000). This is further discussed within the Integration, Impact and Dissemination Summary.

Whilst some of the young people had experienced acceptance for their diagnosis from other people, some had fears around others knowing. These were linked to past negative experiences after disclosing their diagnosis to peers, as well as perceived fears that telling others would lead to victimisation or ostracism. This finding fits with a review of autistic autobiographies, which found the decision to, and process of self-disclosure is complex, with some choosing to 'keep safe' and not disclose, to avoid negative consequences (Davidson & Henderson, 2010).

### **Clinical Implications**

This study has clinical relevance in helping professionals and parents consider potentially helpful ways for a young person to receive their ASD diagnosis. The young people should be held in mind throughout this process, including what their understanding is of why they are being assessed, and what this may be like for them.

A key finding is that receiving an ASD diagnosis should be considered a process, with young people's feelings towards their diagnosis changing over time as they think about it more and make sense of it. This study suggests it is important for practitioners to consider a young person's level of understanding of autism before they are told, so that information can be tailored to help them understand the concept,



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and avoid/relieve them of any distress they may experience from being told they have something they do not understand. Some of this study's young people even suggested starting to introduce the concept before disclosing the diagnosis, so the individual is less scared or shocked by it. Given that parents may choose to independently inform their child later on, and some parents reported feeling confused and overwhelmed with the information given to them (Abbott et al., 2013), practitioners must support parents to develop the understanding and resources to help them share the diagnosis in a contained way with their child, and adequately explain the condition and help them make sense of it. Supporting the national guidance, this information should include what autism is and how it may affect the young person (NICE, 2017), as this study found that such knowledge helped young people resolve their concerns about what the diagnosis meant for them. Some also suggested the explanations should focus on an individual's strengths, as well as the challenges they may face. This may foster positive perceptions of autism for young people, and of themselves.

The findings suggest practitioners and families should support young people to help make sense of their experiences in the context of their autism, as this can develop a greater self-awareness, which in turn may foster self-acceptance for their differences. This may be especially key where young people hold blame for their behaviours and past difficult experiences, or where they have low self-esteem. Helping young people make sense of their past experiences early on in their lives, may positively impact on their future sense of self.

Some of this study's sample felt young people should be given information slowly, and time to process this. It was felt they might be more likely to accept the diagnosis

in this way. The NICE guidance (2017) recommends offering a 6-week follow-up appointment after feeding back a diagnosis, although this study suggests a more flexible approach may be beneficial. Support may need to be tailored and offered according to when the young person wishes to explore and make sense of their diagnosis.

### **Methodological Strengths and Limitations**

This is believed to be the first study to directly explore the experiences of receiving an ASD diagnosis within a group of young people of this age. By recruiting a younger sample than previous studies, participants were reflecting on relatively recent memories of what it was like for them to receive their diagnosis, and this study has helped to offer an insight into these experiences. Furthermore, consulting with a young autistic person on developing the interview schedule helped to ensure the questions captured issues relevant to this study's focus.

However, the study's limitations should be considered. Whilst qualitative research does not aim to make generalisations to wider populations, this study's findings reflect the experiences of a particular group of seven young people, recruited from the same service in one London borough. The young people were mostly high-functioning due to the inclusion criteria, and all attended mainstream schools. Whilst there was a mix of ethnicities, the sample is not representative in terms of different ethnicities. Furthermore, a recruitment bias may exist given the self-selected sample, in that the young people and their parents who chose to take part may have more negative or positive experiences of getting the diagnosis, than those that did not respond to the invitation. Finally, thematic analysis is often used with larger samples

than this study's sample. Whilst this study's sample of seven young people is in keeping with the suggestions of six to ten participants for studies of this kind (i.e. doctoral studies) using interviews and thematic analysis (Braun & Clarke, 2013), it could be argued that the study's aims might not have been achieved with the sample size obtained.

Whilst the young people were generally able to offer valuable reflections on their experiences, some could not remember much from their assessment, or when they first found out about their diagnosis. It is possible some may have struggled to articulate these experiences, or perhaps been too young to remember them fully, or that their later experiences after disclosure held greater significance for the young people, considering that this is what they talked about.

### **Future Research**

Further research of this kind on larger samples of autistic young people, with greater diversity in the sample characteristics noted in the limitations, would help understand if the themes identified here fit the experiences of other young people. However, it is not clear from this study whether there is an optimum age for young people to find out they have autism, which future research may want to consider. This study's young people were all told about their diagnosis soon after it was formally diagnosed, and mostly had positive perceptions of autism and themselves. Other research has however found that experiencing a disclosure delay can have negative effects, including rejecting the diagnosis once it is disclosed (Huws & Jones, 2008; Mogensen & Mason, 2015). Although causal links cannot be made, the speed of disclosure might have an influence on an individual's sense of self, and feelings about autism.

Furthermore, it remains unclear who is best placed to tell a young person about their diagnosis. However, this study suggests it might be the types of conversations that young people have with people after diagnosis, and what is covered in these, that may be more important and helpful. Further exploration of these experiences may help clarify this.

### **Conclusion**

This study suggests that young people's experiences of receiving their ASD diagnosis are multifaceted, and that it is a process in which their understanding for the diagnosis, the thought given to it, and their feelings towards it changed with time as they made sense of it, helping them become more self-aware and self-accepting. Whilst getting the diagnosis had meant most of the young people reflected on ways they, and their future, differed to non-autistic people, they had relatively positive views about this. Receiving their diagnosis led to greater support for some young people, and whilst some spoke of how the diagnosis could help others understand them more, and was accepted by others, some talked about a need for greater awareness to improve people's understanding for autism. These findings have indicated particular issues for professionals and parents to consider in how they talk about the diagnosis with a young person, and future research may help illuminate whether there is an optimum age for a young person to find out, and who is best placed to tell them.

## **Chapter Four: Integration, Impact, and Dissemination Summary**

### **Integration**

This section considers the thesis as a whole. The relationship between the systematic review and empirical study will be discussed, and methodological reflections are made on the process of conducting the empirical study.

### ***Role of the Systematic Review***

The review aimed to synthesis the current knowledge on the experiences of receiving an ASD diagnosis from the perspective of the individual with the diagnosis. No restrictions were placed on the ages of participants, as the aim was instead to gain an overall understanding of the existing literature. Preliminary literature searches during the proposal development, prior to the review, suggested these experiences in young people were under-researched. The review was useful in identifying studies where participants discussed experiences relating to getting their diagnosis despite this not being the study's objective. Furthermore, it helped clarify the research gap, and provide a rationale for the study.

### ***Integration of Systematic Review and Empirical Study Findings***

There are similarities and differences between the findings that emerged in the review and study. Comparisons between the papers should be made with caution, given the differing samples. Only 26 of the 218 participants in the review were younger than 18, with many only diagnosed in adulthood, whereas the study interviewed seven young people aged between 12 and 15.

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Some of the main similarities relate to how getting a diagnosis can impact an individual's perception of themselves. The diagnosis often introduced feelings of being 'different', and provided individuals with a new framework through which to understand their experiences in the context of their autism. This self-awareness could lead to greater acceptance of themselves and their differences, removing any previously held shame or blame. Furthermore, it emerged in both papers that receiving a diagnosis could impact on how others interacted with them, either fostering understanding or highlighting inaccurate knowledge of autism and any related stigma.

Finally, the experience of receiving a diagnosis seemed to change over time for people in both papers. However, whilst both noticed an initial negative reaction could develop over time into acceptance, the study found additional changes. The young people sometimes thought about their diagnosis increasingly as they got older. It may have seemed less important to them because of their age, or because they were too young to really understand it at the time; two young people reflected this on. Perhaps priorities change with developmental capability, and so young people spend more time thinking about, and trying to make sense of their diagnosis as time passes.

One of the main differences is in the study's theme of *Making Sense of the Diagnosis*. Some young people knew nothing about autism on diagnosis, with the uncertainties attached to this lack of understanding leading some to feel weird, upset, confused, or scared it might be something bad. This was not found in the review. The review synthesised studies mostly exploring adults' experiences of getting their diagnosis, and it is possible such samples had more prior understanding of autism, compared to

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the young people in the study. Furthermore, the understanding the young people acquired about autism afterwards, led to experiences of relief, as they re-evaluated their previous worries in the context of this knowledge. Whilst experiences of relief were captured within the review, this seemed to be the result of the diagnosis giving individuals an explanation for their experiences or differences.

Whilst there are differences in the labels given to themes in both papers, they encapsulate similar issues. For example, whilst a theme dedicated to *Reactions to Diagnosis* did not emerge in the study, young people's reactions were embedded within the *Making Sense of the Diagnosis* theme, as they spoke about the feelings they experienced when they first found out about the diagnosis, and after they understood its meaning. A strength of the study was giving young people an opportunity to reflect on how they were told about their diagnosis, and how they made sense of this, which was not captured within the review studies.

It is important to reflect on the similarities between the papers, and why this might be. Given the focus of the papers was the same, but within different aged samples, it is understandable there may be parallels in samples' experiences. Qualitative research holds an element of subjectivity, in that themes emerged through my interactions with the data, and interpretations of these. The similarities may arise because of my style of searching both data sets for patterns and any assumptions I may have made. Already having identified the review's themes before analysing my study's findings may have had an influence; efforts were made to minimise this through second coder checks, but coder checks when conducting the review's synthesis would have further strengthened this reflexivity.

### ***Methodological Reflections***

#### *Ethical approval process.*

Autistic young people's experiences are typically under-represented within qualitative research (DePape & Lindsay, 2015), and the previous relevant research had either mostly focused on gaining adults' experiences of getting their diagnosis, or on parents' experiences of getting their child's diagnosis, rather than directly from the young person themselves. Assumptions that autistic young people cannot reflect on their experiences and engage in verbal interviews may feed into this paucity. I faced these challenges during the ethics application process, as the committee were not confident it was appropriate to interview young people in this manner. However, I was able to challenge these assumptions by providing multiple examples of studies, which had successfully interviewed autistic children and provided meaningful results, on a range of issues across different ages. This highlights that whilst researchers are in a position of power whilst conducting studies, they can face challenges in accessing populations. I am pleased to have given these young people a voice about their experiences, and all of them appeared to value this opportunity and enjoyed talking about their experiences. Furthermore, the level of articulation demonstrated by some of this study's 12 and 13-year-olds might be useful in helping challenge future assumptions of this kind.

I also had to narrow the target age range from the previous proposal of 9-16 year olds to 12-16 year olds, as the ethics committee felt the former was too developmentally diverse to provide meaningful results. Whilst I was successful in defending the concept of the study, and advocating for this marginalised and under-represented group of individuals, I felt disappointed that this modification partly fed into the



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current state of research where younger children struggle to get their voices heard. This is an area that future research should focus on.

### *Recruitment.*

Recruitment was initially slow, and I kept momentum by maintaining regular contact with the service, and gaining updates on the numbers of letters sent out, and the response rate from these. Recruitment picked up and I was able to recruit seven participants; a further three participants had shown interest but changed their mind before meeting me. Although recruiting more participants would have strengthened the sample size in preparation for publication, a final sample of seven was felt adequate given it met the recommended 6-10 participants for thematic analysis studies of this kind (Braun & Clarke, 2013).

I reflected in my journal on how I could only access young people through their parents. Parents needed to be interested in the research, or think it was a good idea for their child, before discussing the invitation letter with them. Therefore, other young people may have wished to participate given the opportunity, but were unable to (or unaware) due to their parents' decision for them not to participate. Furthermore, when recruiting self-selected samples, there is a risk of recruiting those who have had either extreme positive or negative experiences of getting the diagnosis, or who have certain views on the diagnosis. This might explain why no participants appeared to reject their diagnosis, like other research has found (Huws & Jones, 2008).

I adopted a flexible approach during recruitment, being aware some young people may find it anxiety provoking meeting someone new, which may impact on their

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ability to reflect on, and talk about, their experiences. The young people were offered an introductory meeting with me to build rapport and minimise possible anxieties before deciding if they wanted to take part. I was also flexible about where I met the young people to help them feel comfortable, and all but one asked me to visit them at home.

### *Recruited sample.*

Given the gender ratio in autism is 4:1, with more boys than girls diagnosed (Loomes, Hull, & Mandy, 2017), I had modest expectations about recruiting girls. I was pleased to have recruited one girl, although her experiences may not fit with that of other girls. Not all girls may have had a lengthy diagnostic process that this young person experienced, although they reflected that it can sometimes be harder to diagnose ASD within girls than boys. Future research would be strengthened by larger samples with a greater number of girls.

Additionally, although qualitative studies do not aim to make generalisations to wider populations, it should be noted that this study represents the experiences of a particular group of autistic young people. Participants were predominately high-functioning, and all attended mainstream schools. Young people with differing levels of functioning, or who attend more specialist schools, may have different experiences and reflections on their diagnosis. Furthermore, all but one of the participants were diagnosed within the same London borough, and therefore young people's experiences of receiving diagnoses in other locations may differ to those in this study.

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### *Use of interviews, and service user consultation.*

I gained service user feedback on an interview schedule draft from a 12-year-old who met the study's criteria. This proved useful as it highlighted some unclear questions and suggested rewording. Two main questions were reworded (e.g. changing 'Do you remember finding out that you have autism?' to 'Do you remember the first time someone told you that you have autism?'), and minor changes were made to possible prompt questions. The young person did not feel any particular issues should be omitted from the interview, nor think of additional things to cover.

I was mindful that this was an articulate young person, and that others may find some questions more challenging. However, using a semi-structured interview allowed for flexibility, in adapting questions according to each individual. For example, I found that whilst one young person struggled with questions involving the word 'feelings', they could describe their experiences when asked about their thoughts, such as, "What thoughts went through your mind when you found out that you have autism?"

Some of the main questions in the interview schedule are not open-ended (e.g. "Do your friends think/know that you have autism?"), which could have arguably impacted on the richness of the data I obtained. However, I was mindful that some autistic young people may struggle with open-ended questions, and might have found an interview process anxiety provoking. Closed-ended questions were used as a way to introduce a different aspect of their experiences to the previous questions they had been asked. I always ensured I followed on from closed-questions with more exploratory open-ended questions on that particular issue, which could be adapted according to each young person.

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I was also aware of the power dynamic between the young people and me, and tried to minimise this by giving them the choice of where the interview took place, and where they wanted me to sit in the room. I also adapted my interview style to make them feel comfortable. For example, I spoke with one young person whilst we both looked at the floor, as they found looking in people's eyes uncomfortable.

Some of the experiences the young people spoke about, may be linked to, or perhaps influenced by, their parents' experiences of getting the diagnosis. For example, one young person asked for the recorder to be turned back on after going to tell their parent in the other room that the interview had finished, and talked about feeling misunderstood by professionals because their family had to seek a second opinion after the first service did not feel they had autism. Furthermore, simply receiving the invitation letter may have prompted a conversation between the young person and their parent, thinking back to when they got their diagnosis, and what they remembered about this. Future research interviewing both parents and young people separately may be interesting to see if there are similarities or differences in parent-child experiences. However, this study aimed to only interview the young people, to ensure their voices were heard and not overshadowed by their parent's perspectives, as has been the case in other autism research (see McLaughlin & Rafferty, 2014 for a review).

### *Qualitative analyses.*

Member checks are recommended within qualitative research to enhance the study's credibility, as they allow the researcher to check whether their interpretations of the findings fit with the participants' experiences (Kornbluh, 2015). Due to time

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constraints it was not possible to take a draft of the themes back to participants for their thoughts. I acknowledge this would have strengthened the study, although a review of published qualitative literature found no evidence that member checks improved the credibility of research (Thomas, 2017).

### *Personal reflections.*

I have had an interest in autism since my first psychology job eight years ago, and feel that whilst the condition can create challenges for individuals, it also brings strengths to their personality. I chose this project as I am passionate about helping children, and considering ways to best support autistic children when getting their diagnosis. I was also drawn to an approach prioritising young people's voices over adults, as has typically been the case within research in this population.

Given the active role of researchers in qualitative research, it is possible my previous experiences and views of autism influenced the research and the themes that emerged. For example, my questions considered that there may be both positive and negative aspects of receiving a diagnosis. Whilst interviews were tailored according to individual's responses, the questions asked impact on the data it gathers, although attempts were made to minimise this. Consulting with a service user on developing the interview schedule helped to ensure I captured topics that felt relevant to a young autistic person. Furthermore, coding checks by an external researcher during analysis helped to ensure that codes were not solely developed based on my own experience and knowledge of the area. This second coder was someone with minimal autism experience, and it was useful to compare codes from an outsider's perspective.

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Throughout the interviews I was struck that even children as young as 12 had reflected on the possible disruptions to their perceived life trajectory, in relation to getting a job, and it highlighted to me that the possible impact of a diagnosis for young people should not be under-estimated.

### **Impact**

This study's findings have potential implications for several different groups of beneficiaries. These will be discussed according to each group, along with plans for disseminating the findings to achieve this.

### *Autistic young people*

This project would not have been possible without the young people who took part, and this will be further acknowledged when the findings are disseminated back to them and their parents. This will be done through a feedback sheet summarising the findings in lay language. The young people may benefit from this by seeing how their experiences may relate to those of the other participants. Furthermore, participating in the research and talking about their experiences, may have empowered the young people to talk about their autism.

This research may also benefit other young people finding out they have autism. Hearing about young people's experiences may help them gain insight into their own, by making comparisons or noticing similarities. Professionals could share these findings with young people using the aforementioned summary sheet.

### *Healthcare professionals*

Given that healthcare professionals have the role in feeding back a diagnosis following a diagnostic assessment, whether that is directly to young people, or to their parents, the findings have several possible clinical implications. Autism assessments in adulthood may arise because an individual is seeking help themselves, while children are assessed when others, like parents, have raised concerns. Although it is important for professionals to be sensitive to parents' anxieties, this study highlights the needs of young people during the assessment process. The majority of this study's young people were diagnosed between the ages of 9 and 11. Parents may choose not to tell their child why they are being assessed for different possible reasons, such as not wanting to worry them. However, this study suggests that this could have a negative effect in some cases. Professionals could share what this study has found, to help parents think about how they want to explain the assessment to their child, and whether they would like any support from professionals in planning this.

Of significance, it is important for professionals to view the receipt of a diagnosis by a young person as a process, which may take time and need support so they can make sense of their experiences. Depending on their age, young people may not choose to think about the diagnosis much at first, needing time to develop this curiosity. Professionals are in a position to help young people foster the development of a positive perception of autism, and of themselves. This study suggests the current recommendations of offering a follow-up appointment 6 weeks after the initial feedback may be too rigid (NICE, 2017), and perhaps should be offered as and when a young person wants to explore the diagnosis further.

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It is important for professionals to consider the level of understanding that a young person has about autism, as it appears potentially to influence their feelings. For example, those that lacked an understanding at diagnosis reported feeling scared about what it might mean for them. Professionals need to find a way to communicate a diagnosis in a developmentally appropriate way to young people, or prepare parents for how to do this in the future. This study suggests that young people benefitted from transparent conversations where autism was explained to them in terms of their strengths as well as challenges, or how it may affect them. Like this study's sample, it may also be helpful for professionals to use tools such as books or websites to help facilitate these conversations, or signpost parents to tools they can use when disclosing the diagnosis later on.

This study is likely to initially impact the professionals within the service I recruited from. I have disseminated the findings back to this service, and the discussions that followed this revealed one way they will be changing their practice given the findings: to include a statement in the initial letter to parents encouraging them to think about how they would explain the appointment to their child, and that they could contact staff if they want help around this. I have also been asked to present the findings to the recruitment borough's Autism Steering Group. Furthermore, I plan to contact other clinical teams that may benefit from this research, such as other services specialising in assessments of suspected autism.

Furthermore, the National Autistic Society (NAS) has a platform for professionals working in Autism: Network Autism (NAS 2018b). The research will be posted



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within specialist interest groups about diagnosis, and once published, will be added to their directory of autism research.

### *Parents of children diagnosed with ASD*

This study's findings are likely to be important to, and potentially impact, parents of children who are diagnosed with ASD. Whilst the findings are only based on the experiences of a small number of young people, and do not resolve the issue that there are no consistent recommendations for parents about how to talk to their children about their diagnosis, parents may benefit from knowing about these young people's experiences before talking to their child. For example, it may help them reflect on their understanding of autism, and whether they would benefit from speaking with professionals, or attending a psychoeducational group, to ensure they have an adequate knowledge before talking to their child. It may also help them make a decision about how they feel best to tell their child. For example, in cases where parents are aware their child may struggle with uncertainty, or have become worried about things they do not understand in the past, they might consider introducing the concept of autism gradually before informing the child that they have it. Parents may also take from this study, that there are likely to be several conversations about the diagnosis with their child over time, as the child takes time to process it, or becomes curious to learn more.

Whilst the recruiting service plans to share this study's findings with parents of children being assessed in the future, disseminating the findings through additional points of support for parents would help maximise the study's potential impact. I have

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been asked to present the findings at the Special Parents Forum within the recruitment borough. Furthermore, The National Autistic Society (NAS) have advice for parents in relation to talking about the diagnosis with their child and may agree to help share my findings through publishing them on their website, or integrate them within relevant sections.

### *Professionals in school settings*

This study indicates that greater awareness for autism is needed within society, to help tackle the societal stigma. Dispelling this may help promote a better sense of self for young autistic people, allowing them to be more accepting of their diagnosis, and comfortable discussing it with others. The study's young people felt more education about autism was needed in schools. Research has found that information provided by teachers or professionals is more likely to produce positive changes in children's cognitive and behavioural attitudes towards autism, as opposed to that given by parents (Morton & Campbell, 2008), and that contact with autistic children may be more effective at achieving attitude change, than informative educational programmes (Campbell, 2006; Rosenbaum, Armstrong, & King, 1986). Professionals working in schools are in a position of power to help educate school children about autism, and given that contact with autistic children may be an effective way to create change, mainstream schools may benefit from linking with specialists schools to help their pupils develop an understanding of autism as a broad spectrum.

Special Educational Needs Coordinators (SENCOs) ensure that pupils with special educational needs receive the support they should get, and are potentially some of the

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professionals in schools with the greatest degree of understanding for autism. Communicating these results, and the young people's calls for further education in schools, to these professionals may lead to educational programmes being considered or further developed within their schools. SENCOs meet up within forums in each UK borough, to share understanding and develop their practice. I plan to ask the SENCO forum in the borough I recruited participants from, to present the study at their meeting. Following this, I would try to pursue links with SENCOs in other boroughs. This communication hopefully will lead to action in their schools and further dissemination of the findings through their contact with other professionals.

### **Dissemination**

In addition to those discussed in the impact section, there are further plans to disseminate the findings. The final paper will be submitted for publication within peer-reviewed journals. Those read by parents of autistic children, and professionals working with autism are likely to have the greatest impact on dissemination. Journals focussing on improving the quality of life of autistic people, in relation to their diagnosis, and the support they receive will be targeted. Relevant journals are:

- Autism
- Research in Autism Spectrum Disorders
- Journal of Autism and Developmental Disorders
- Good Autism Practice

Presenting at conferences will also be a useful way to disseminate the research.

Possible conferences include:

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- Autism Professionals Annual Conference, NAS
- Faculty for Children, Young People and their Families Annual Conference, British Psychological Society (BPS)
- Developmental Psychology Section Annual Conference, BPS

It may also be useful to contact NHS commissioners of child and adolescent services, and the committee members who developed the NICE (2017) *Autism Spectrum Disorder in under 19s: Recognition, Referral and Diagnosis* guidelines. Given the current NHS burden, there is often a pressure on services to complete assessments quickly, and this can mean individuals are discharged from services and left without support. Disseminating these findings might help illustrate that young people may instead require a timely and flexible approach to being supported in light of getting their diagnosis.

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**Appendices**

Appendix 1: Quality Assessment Tool

Appendix 2: NHS Health Research Authority, Research Ethics Committee Full  
Approval Letter

Appendix 3: NHS Trust R&D Approval

Appendix 4: Royal Holloway University of London, Self-Certification Certificate

Appendix 5: Guideline for staff in recruitment site approaching potential participants

Appendix 6: Invitation Letter

Appendix 7: Participant Information Sheet – Young Person Version

Appendix 8: Participant Information Sheet – Parent Version

Appendix 9: Young Person Assent Form

Appendix 10: Parent Consent Form

Appendix 11: Demographics Questionnaire

Appendix 12: Interview Schedule

Appendix 13: Example Coded Transcript Extract

Appendix 14: Additional Extracts from Thematic Analysis

Appendix 15: Extract from Reflective Journal

**Appendix 1: Quality Assessment Tool**

Adapted from the Critical Appraisal Skills Programme (CASP, 2018) and the Qualitative Research Quality Checklist (Saini & Shlonsky, 2012), and informed by a previous adaption of the CASP (Atkins et al., 2008), and general issues related to evaluating qualitative research (Mays & Pope, 2007).

Studies were given one of three ratings:

- Met Criterion, if they were deemed to be high quality in relation to the specified issue, or if there was a very clear reference to the criterion issue
- Did Not Meet, if there was no reference to the criterion issue within the study
- Unclear, if the study had some reference to the criterion issue, but it remained unclear, or the references were of poor quality

<u>Appraisal Question</u>	<u>Areas of Consideration</u>
Screening Question: Is the study qualitative, or reports qualitative findings?	
1. Was there a clear statement of the aims of the research?	<ul style="list-style-type: none"> <li>- Is the goal of the research clear?</li> <li>- Is it clear why this research is thought to be important?</li> <li>- Has the relevance of this research been discussed?</li> </ul>
2. Is a qualitative methodology appropriate?	<ul style="list-style-type: none"> <li>- Is the research aiming to interpret or illuminate the actions and/or subjective experiences of research participants?</li> <li>- Is a qualitative approach the correct methodology for meeting this gap in the research?</li> </ul>

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<i>Study Design</i>	
3. Was the research design appropriate to address the aims of the research?	<ul style="list-style-type: none"> <li>- Has the chosen research design been justified? For example, has the researcher been clear how they decided on their particular method?</li> <li>- Does this method and justification fit with the research aims?</li> </ul>
<i>Study Setting</i>	
4. Is the study context clearly described?	<ul style="list-style-type: none"> <li>- Is it clear what setting the study took place in?</li> </ul>
<i>Sampling Procedures</i>	
5. Is the recruitment strategy clearly described?	<ul style="list-style-type: none"> <li>- Has it been explained how participants were approached and selected?</li> <li>- Have they discussed their eligibility criteria?</li> <li>- Have they discussed other aspects of recruitment, such as if applicable, why some participants chose not to take part?</li> <li>- Have the characteristics of the sample been reported, to allow the reader to assess the transferability of these findings?</li> </ul>
6. Was the recruitment strategy appropriate to the aims of the research?	<ul style="list-style-type: none"> <li>- Has it been explained why the participants they selected were the most appropriate to provide access to the type of knowledge sought by the study?</li> </ul>
<i>Data Collection</i>	
7. Has the data collection method been clearly described?	<ul style="list-style-type: none"> <li>- Is it clear how data was collected? For example, semi-structured interviews, focus groups, etc.</li> <li>- Has the method of data collection been made explicit? For example, discussing the interview schedule, where/how interviews were conducted, whether a topic guide was used, etc.</li> <li>- If the methods of data collection were modified after starting the study, has the reason for this been clearly explained, and is it clear what the modifications were?</li> <li>- Is it clear what form the data was collected in?</li> </ul>

## YOUNG PEOPLE'S EXPERIENCES OF RECEIVING AN ASD DIAGNOSIS

	(E.g. tape recordings, notes, etc.)
	- If applicable, has data saturation been discussed?
8. Was the data collected in a way that addressed the research issue?	<ul style="list-style-type: none"> <li>- Has the setting for data collection been justified?</li> <li>- Has the researcher justified the methods they have chosen for data collection?</li> </ul>
<i>Reflexivity</i>	
9. Has the role of the researcher been clearly described?	<ul style="list-style-type: none"> <li>- Has the researcher critically examined their own role, potential bias and influence during:                             <ul style="list-style-type: none"> <li>a) Formulation of the research questions</li> <li>b) Data collection, including sample recruitment and choice of location</li> </ul> </li> <li>- How the researcher responded to events during the study and whether they considered the implications of any changes in the research design.</li> <li>- Did the researcher use a reflexive diary during data analysis, and their interpretations of the data?</li> </ul>
<i>Ethical Issues</i>	
10. Have ethical issues been taken into consideration?	<ul style="list-style-type: none"> <li>- If there are sufficient details of how the research was explained to participants, for The reader to assess whether ethical standards were maintained</li> <li>- If the researcher has discussed issues raised by the study (e.g. issues around informed consent or confidentiality, or how they have handled the effects of the study on the participants during and after the study</li> <li>- If approval has been sought from the ethics committee</li> </ul>
<i>Data Analysis</i>	
11. Was the analysis suited to the research question?	- Has the chosen method of analysis been justified in relation to the research and methodology?
12. Were the steps in	- Is there a clear audit trail of the individual steps

## YOUNG PEOPLE'S EXPERIENCES OF RECEIVING AN ASD DIAGNOSIS

data analysis clearly described?	taken during data analysis?
13. Have credibility checks been conducted?	<ul style="list-style-type: none"> <li>- Have multiple coders been used to assess researcher consensus? (Triangulation).</li> <li>- Were member checks carried out?</li> </ul>
14. Are quotes used to support themes or concepts derived from the data?	<ul style="list-style-type: none"> <li>- Are the themes/findings they present support by quotes?</li> </ul>
<i>Findings</i>	
15. Is there a clear statement of findings?	<p>If the findings are explicit:</p> <ul style="list-style-type: none"> <li>- Has attention been given to the discussion of negative cases, such as contradictory findings?</li> <li>- Are the findings discussed in relation to the original research question?</li> </ul>
16. Are the claims supported by the data found?	<ul style="list-style-type: none"> <li>- Do the claims they make, fit the data that has been presented/discussed?</li> </ul>



# YOUNG PEOPLE'S EXPERIENCES OF RECEIVING AN ASD DIAGNOSIS

## Appendix 2: NHS Health Research Authority, Research Ethics Committee Full

### Approval Letter



Health Research  
Authority

London - Camden & Kings Cross Research Ethics Committee

Jarrow Business Centre  
Rolling Mill Road  
Jarrow  
NE32 3DT

Telephone: 0207 104 8086

**Please note:** This is an acknowledgement letter from the REC only and does not allow you to start your study at NHS sites in England until you receive HRA Approval

16 August 2017

Miss Jasmine Anilmis  
9 Rojack Road  
Forest Hill  
London  
SE23 2DF

Dear Miss Anilmis

**Study title:** Young people's (aged 12-16 years) experiences of receiving a diagnosis of Autism Spectrum Disorder?  
**REC reference:** 17/LO/1215  
**Protocol number:** N/A  
**IRAS project ID:** 224496

Thank you for your correspondence on 16<sup>th</sup> August. I can confirm the REC has received the documents listed below and that these comply with the approval conditions detailed in our letter dated 03 August 2017

#### Documents received

The documents received were as follows:

<i>Document</i>	<i>Version</i>	<i>Date</i>
Other [Services for Additional Support Document]	Version 1	15 August 2017

#### Approved documents

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

<i>Document</i>	<i>Version</i>	<i>Date</i>
Evidence of Sponsor insurance or indemnity (non NHS Sponsors only) [Sponsor (RHUL) professional indemnity insurance policy schedule]	V1	27 February 2017

## YOUNG PEOPLE'S EXPERIENCES OF RECEIVING AN ASD DIAGNOSIS

Interview schedules or topic guides for participants [Interview Schedule]	Version 3.0	25 June 2017
IRAS Application Form [IRAS_Form_29062017]		29 June 2017
Letters of invitation to participant [Invitation to Take Part Letter]	Version 2.0	25 June 2017
Letters of invitation to participant [Guideline for approaching potential participants]	Version 2.0	25 June 2017
Letters of invitation to participant [Thank you for your interest letter (follow-up to phone call)]	Version 2.0	25 June 2017
Non-validated questionnaire [Demographics Questionnaire (for parents to complete)]	Version 2.0	25 June 2017
Other [REC Outcome Letter - Unfavourable Opinion]		05 June 2017
Other [Cover letter outlining changes made from unfavourable opinion]		25 June 2017
Other [Services for Additional Support Document]	Version 1	15 August 2017
Participant consent form [Parent Consent Form]	Version 2.0	22 June 2017
Participant consent form [Young Person Assent Form]	Version 2.0	22 June 2017
Participant information sheet (PIS) [Parent Participant Information Sheet]	Version 2.0	22 June 2017
Participant information sheet (PIS) [Young Person Participant Information Sheet]	Version 3.0	25 June 2017
Referee's report or other scientific critique report [Peer Review: Provisional Approval (1)]	1	09 December 2016
Referee's report or other scientific critique report [Responses to peer review feedback (1)]		12 January 2017
Referee's report or other scientific critique report [Peer Review: Provisional Approval (2)]	2.0	30 January 2017
Referee's report or other scientific critique report [Responses to peer review feedback (2)]		09 February 2017
Referee's report or other scientific critique report [Peer Review: Approval]		21 February 2017
Research protocol or project proposal [Research Protocol]	5.0	23 June 2017
Summary CV for Chief Investigator (CI) [Summary CV for Chief Investigator]		24 April 2017
Summary CV for supervisor (student research) [Summary CV for academic supervisor]		26 April 2017
Summary CV for supervisor (student research) [CV for Principal Investigator (and field supervisor)]		14 April 2017
Summary CV for supervisor (student research) [CV for key investigator (also field supervisor)]		24 April 2017

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.

<b>17/LO/1215</b>	<b>Please quote this number on all correspondence</b>
-------------------	---

Yours sincerely



**Christie Ord**  
**REC Manager**

E-mail: [nrescommittee.london-camdenandkingscross@nhs.net](mailto:nrescommittee.london-camdenandkingscross@nhs.net)

Copy to: *Ms Annette Lock*  
*Miss Erin Sheehan, Noclor*

# YOUNG PEOPLE'S EXPERIENCES OF RECEIVING AN ASD DIAGNOSIS

## Appendix 3: NHS Trust R&D Approval



1<sup>st</sup> Floor, Bloomsbury Building  
St Pancras Hospital  
4 St Pancras Way  
London, NW1 0PE  
Tel: 020 3317 3045  
Fax: 020 7685 5830  
Email: [contact.noclor@nhs.net](mailto:contact.noclor@nhs.net)  
[www.noclor.nhs.uk](http://www.noclor.nhs.uk)

19 September 2017

Miss Jasmin Almiyas  
4th Floor, East Wing  
St. Pancras Hospital  
4 St. Pancras Way,  
London  
NW1 0PE

Dear Miss Almiyas,

**Employer:** Camden and Islington NHS Foundation Trust  
**Accountable to:** Dr Kate Theodore

As an existing NHS employee you do not require an additional honorary research contract with this NHS organisation. We are satisfied that the research activities that you will undertake in this NHS organisation are commensurate with the activities you undertake for your employer. Your employer is fully responsible for ensuring such checks as are necessary have been carried out. Your employer has confirmed in writing to this NHS organisation that the necessary pre-engagement checks are in place in accordance with the role you plan to carry out in this organisation. This confirms your right of access to conduct research through the trust(s) identified in the box below, for the purpose and under the terms and conditions set out in page 2 & page 3.

<b>Study Title:</b> Young People's Experiences of Receiving a Diagnosis of ASD - Version 2		
<b>R&amp;D reference:</b> 224496		
<b>REC reference:</b> 17/LO/1215		
<b>Letter of access duration:</b>	<b>Start date:</b> 19/09/2017	<b>End date:</b> 20/09/2018
Central and North West London NHS Foundation Trust		
<i>If any information on this document is altered after the date of issue, this document will be deemed INVALID</i>		

Yours sincerely,

Mabel Salli  
Research Management & Governance Manager

Page 1 of 3

NCLET011T - 3.0.0 - 23/07/15 - Letter of access for university employee  
It is the researcher's responsibility to provide their substantive employer with a copy of this document

# YOUNG PEOPLE'S EXPERIENCES OF RECEIVING AN ASD DIAGNOSIS



1<sup>st</sup> Floor, Bloomsbury Building  
St Pancras Hospital  
4St Pancras Way  
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Fax: 020 7685 5830  
Email: [contact.noclor@nhs.net](mailto:contact.noclor@nhs.net)  
[www.noclor.nhs.uk](http://www.noclor.nhs.uk)

As an existing NHS employee you do not require an additional honorary research contract with this NHS organisation. We are satisfied that the research activities that you will undertake in this NHS organisation are commensurate with the activities you undertake for your employer. Your employer is fully responsible for ensuring such checks as are necessary have been carried out. Your employer has confirmed in writing to this NHS organisation that the necessary pre-engagement checks are in place in accordance with the role you plan to carry out in this organisation. You have a right of access to conduct such research as confirmed in writing in the letter of permission for research from this NHS organisation. Please note that you cannot start the research until the Principal Investigator for the research project has received a letter from us giving permission to conduct the project.

You have a right of access to conduct such research as confirmed in writing in the letter of permission for research from this NHS organisation. Please note that you cannot start the research until the Principal Investigator for the research project has received a letter from us giving permission to conduct the project.

You are considered to be a legal visitor to **relevant trust(s)** premises. You are not entitled to any form of payment or access to other benefits provided by this NHS organisation to employees and this letter does not give rise to any other relationship between you and this NHS organisation, in particular that of an employee.

While undertaking research through **relevant trust(s)**, you will remain accountable to your employer but you are required to follow the reasonable instructions of your nominated manager **Angela Williams, R&D Manager NoCLoR** in this NHS organisation or those given on her/his behalf in relation to the terms of this right of access.

Where any third party claim is made, whether or not legal proceedings are issued, arising out of or in connection with your right of access, you are required to co-operate fully with any investigation by this NHS organisation in connection with any such claim and to give all such assistance as may reasonably be required regarding the conduct of any legal proceedings.

You must act in accordance with the **relevant trust(s)** policies and procedures, which are available to you upon request, and the Research Governance Framework.

You are required to co-operate with the **relevant trust(s)** in discharging its duties under the Health and Safety at Work etc Act 1974 and other health and safety legislation and to take reasonable care for the health and safety of yourself and others while on **relevant trust(s)** premises. Although you are not a contract holder, you must observe the same standards of care and propriety in dealing with patients, staff, visitors, equipment and premises as is expected of a contract holder and you must act appropriately, responsibly and professionally at all times.

If you have a physical or mental health condition or disability which may affect your research role and which might require special adjustments to your role, if you have not already done so, you must notify your employer and the **relevant trust(s)** prior to commencing your research role at the Trust.

You are required to ensure that all information regarding patients or staff remains secure and strictly confidential at all times. You must ensure that you understand and comply with the requirements of the NHS Confidentiality Code of Practice

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# YOUNG PEOPLE'S EXPERIENCES OF RECEIVING AN ASD DIAGNOSIS



1<sup>st</sup> Floor, Bloomsbury Building  
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Email: [contact.noclor@nhs.net](mailto:contact.noclor@nhs.net)  
[www.noclor.nhs.uk](http://www.noclor.nhs.uk)

([https://www.gov.uk/government/uploads/system/uploads/attachment\\_data/file/200146/Confidentiality\\_-\\_NHS\\_Code\\_of\\_Practice.pdf](https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/200146/Confidentiality_-_NHS_Code_of_Practice.pdf)) and the Data Protection Act 1998. Furthermore you should be aware that under the Act, unauthorised disclosure of information is an offence and such disclosures may lead to prosecution.

**The relevant trust(s)** will not indemnify you against any liability incurred as a result of any breach of confidentiality or breach of the Data Protection Act 1998. Any breach of the Data Protection Act 1998 may result in legal action against you and/or your substantive employer.

You should ensure that, where you are issued with an identity or security card, a bleep number, email or library account, keys or protective clothing, these are returned upon termination of this arrangement. Please also ensure that while on the premises you wear your ID badge at all times, or are able to prove your identity if challenged. Please note that this NHS organisation accepts no responsibility for damage to or loss of personal property.

We may terminate your right to attend at any time either by giving seven days' written notice to you or immediately without any notice if you are in breach of any of the terms or conditions described in this letter or if you commit any act that we reasonably consider to amount to serious misconduct or to be disruptive and/or prejudicial to the interests and/or business of this NHS organisation or if you are convicted of any criminal offence. You must not undertake regulated activity if you are barred from such work. If you are barred from working with adults or children this letter of access is immediately terminated. Your employer will immediately withdraw you from undertaking this or any other regulated activity and you **MUST** stop undertaking any regulated activity immediately.

Your substantive employer is responsible for your conduct during this research project and may in the circumstances described above instigate disciplinary action against you.

If your circumstances change in relation to your health, criminal record, professional registration or suitability to work with adults or children, or any other aspect that may impact on your suitability to conduct research, or your role in research changes, you must inform the NHS organisation that employs you through its normal procedures. You must also inform your nominated manager in this NHS organisation.

# YOUNG PEOPLE'S EXPERIENCES OF RECEIVING AN ASD DIAGNOSIS

## Appendix 4: Royal Holloway University of London Ethics Self-Certification

### Certificate



#### Ethics Review Details

You have chosen to self certify your project.	
Name:	Anilmis, Jasmine (2015)
Email:	PCVA045@live.rhul.ac.uk
Title of research project or grant:	Young people's (aged 12-16 years) experiences of receiving a diagnosis of Autism Spectrum Disorder
Project type:	Royal Holloway postgraduate research project/grant
Department:	Psychology
Academic supervisor:	Dr. Kate Theodore
Email address of Academic Supervisor:	Kate.Theodore@rhul.ac.uk
Funding Body Category:	No external funder
Funding Body:	
Start date:	04/09/2017
End date:	04/06/2018

#### Research question summary:

How do young people (aged 12-16years) perceive their experience of receiving a diagnosis of Autism Spectrum Disorder?

#### Research method summary:

This is a phenomenologically-informed qualitative study, exploring within a group of 12-16 year olds their experiences of receiving a diagnosis of with Autism Spectrum Disorder.

Participants will be recruited from an NHS service, which provide assessments and diagnoses of children who may have ASD or related social communication difficulties. Two separate participant information sheets (PIS) have been developed; for parents/legal guardians, and for the young people. Prior to the PIS and assent form being given to the young person, the recruiter/lead researcher will check with the parents that the child has been informed that they have a diagnosis of ASD. If it becomes apparent that the diagnosis has not been disclosed to the child, then the recruitment process for that individual will immediately stop, so that no emotional distress is caused for the child and/or parents.

Given this is a small-scale educational project, that will use interviews to collect data, and will employ thematic analysis as the method for analysing data, this study will aim to recruit and interview 6-10 participants (Braun and Clarke, 2013).

Semi-structured interviews will be used, and carried out in a place that is familiar and comfortable for the young person. The choice will be given to both the young person and the parent(s) on whether they would like the parent(s) to be present for the interview. Additionally, time will be spent at the start of the interview, to build rapport with the young person by discussing their interests/other topics. Furthermore, given the possible social interaction and communication difficulties in this sample, in addition to the possibility of learning difficulties for some individuals, appropriate adjustments will be made for each participant; e.g. taking regular breaks, and using drawings to support engagement.

The interviews will be recorded then transcribed verbatim, and analysed using thematic analysis.

#### Risks to participants

Does your research involve any of the below?

Children (under the age of 16),

Yes

Participants with cognitive or physical impairment that may render them unable to give informed consent,

No

Participants who may be vulnerable for personal, emotional, psychological or other reasons,

Yes

# YOUNG PEOPLE'S EXPERIENCES OF RECEIVING AN ASD DIAGNOSIS

Participants who may become vulnerable as a result of the conduct of the study (e.g. because it raises sensitive issues) or as a result of what is revealed in the study (e.g. criminal behaviour, or behaviour which is culturally or socially questionable),

Yes

Participants in unequal power relations (e.g. groups that you teach or work with, in which participants may feel coerced or unable to withdraw),

No

Participants who are likely to suffer negative consequences if identified (e.g. professional censure, exposure to stigma or abuse, damage to professional or social standing),

No

Details,

The possible ethical issues raised have been discussed at an NHS Research Ethics Committee panel, who have given full ethical approval for this study to take place. Please see attached document.

## Design and Data

Does your study include any of the following?

Will it be necessary for participants to take part in the study without their knowledge and/or informed consent at the time?,

No

Is there a risk that participants may be or become identifiable?,

No

Is pain or discomfort likely to result from the study?,

No

Could the study induce psychological stress or anxiety, or cause harm or negative consequences beyond the risks encountered in normal life?,

Yes

Does this research require approval from the NHS?,

Yes

If so what is the NHS Approval number,

Are drugs, placebos or other substances to be administered to the study participants, or will the study involve invasive, intrusive or potentially harmful procedures of any kind?,

No

Will human tissue including blood, saliva, urine, faeces, sperm or eggs be collected or used in the project?,

No

Will the research involve the use of administrative or secure data that requires permission from the appropriate authorities before use?,

No

# YOUNG PEOPLE'S EXPERIENCES OF RECEIVING AN ASD DIAGNOSIS

Will financial inducements (other than reasonable expenses and compensation for time) be offered to participants?,

No

Is there a risk that any of the material, data, or outcomes to be used in this study has been derived from ethically-unsound procedures?,

No

Details,

## Risks to the Environment / Society

Will the conduct of the research pose risks to the environment, site, society, or artifacts?,

No

Will the research be undertaken on private or government property without permission?,

No

Will geological or sedimentological samples be removed without permission?,

No

Will cultural or archaeological artifacts be removed without permission?,

No

Details,

## Risks to Researchers/Institution

Does your research present any of the following risks to researchers or to the institution?

Is there a possibility that the researcher could be placed in a vulnerable situation either emotionally or physically (e.g. by being alone with vulnerable, or potentially aggressive participants, by entering an unsafe environment, or by working in countries in which there is unrest)?,

Yes

Is the topic of the research sensitive or controversial such that the researcher could be ethically or legally compromised (e.g. as a result of disclosures made during the research)?,

No

Will the research involve the investigation or observation of illegal practices, or the participation in illegal practices?,

No

Could any aspects of the research mean that the University has failed in its duty to care for researchers, participants, or the environment / society?,

No

Is there any reputational risk concerning the source of your funding?,

No



# YOUNG PEOPLE'S EXPERIENCES OF RECEIVING AN ASD DIAGNOSIS

Is there any other ethical issue that may arise during the conduct of this study that could bring the institution into disrepute?,

No

## Details,

The possible ethical issues raised have been discussed at an NHS Research Ethics Committee panel, who have given full ethical approval for this study to take place. Please see attached document.

Also, lone worker policy (RHUL and local NHS trust) in place.

## Declaration

By submitting this form, I declare that the questions above have been answered truthfully and to the best of my knowledge and belief, and that I take full responsibility for these responses. I undertake to observe ethical principles throughout the research project and to report any changes that affect the ethics of the project to the University Research Ethics Committee for review.

Certificate produced for user ID, PCVA045

Date:	25/08/2017 13:08
Signed by:	Anilmis, Jasmine (2015)
Digital Signature:	Jasmine Anilmis
Certificate dated:	8/25/2017 1:42:25 PM
Files uploaded:	REC Approval Letter.pdf Assent form (young people) V2.doc Consent form (parent) V2.doc PIS young person Version 3.docx PIS parent Version 2.docx Final IRAS Form for R&D.pdf

**Appendix 5: Guideline for staff in recruitment site approaching potential**

**participants**

**Guideline for Approaching Potential Participants**

Thank you for helping me (Jasmine Anilmis, Trainee Clinical Psychologist) recruit participants. I have outlined below the steps involved for this study's recruitment.

**Step 1: Identifying potential participants**

When performing searches of open and closed cases on the system, please identify potential participants based on the following inclusion and exclusion criteria.

*Inclusion criteria:*

- The young person is aged between 12-16 years, with a confirmed ASD diagnosis.
- The young person has previously been told about their diagnosis (although you may not have this information at this stage, and will need to confirm at steps 3 and 5 onwards)
- The young person uses verbal communication and has a level of cognitive functioning that allows them to engage in an interview. (Please use your clinical judgement, for example do you feel they could focus within an interview, and answer open-ended questions?)
- The young person has good spoken English, so that they can engage in an interview.

*Exclusion criteria:*

- If they are younger than 12 years, or older than 16 years
- The ASD diagnosis has not been disclosed to the young person
- If their level of spoken English, or verbal communication and/or cognitive functioning, is deemed to be below that will allow them to reflect on their experiences of receiving their diagnosis.
- If you/the service, or their parent deem this child to be at risk through participating; e.g. if they are currently psychologically distressed, or are highly anxious around new people.

As information on the service's database may not be up-to-date, and/or new information may arise throughout the recruitment process, it is important to keep these criteria in mind throughout all of the steps. If at any stage it becomes apparent that the young person does not meet this study's criteria, please explain this to the parent/young person, and thank them for their time/interest.

**Step 2: Invitation to take part letter**

Once potential participants have been identified, please post the 'Invitation to take part' letter to the parents of potential participants. These will have been prepared for you by Jasmine.

**Step 3: Follow-up phone call after sending letter**

Please allow two weeks after posting the letter before phoning the parents, this is to allow time for the family to think about whether they might be interested in the study. This telephone call is to briefly explain the purpose and set-up of the study.

**It is key that the contacting clinician checks with the parents that the young person is already aware of their autism diagnosis.**

Please refer to the participant information sheets (parent, and young person versions) for full information on the study, of which Part 1 is more relevant for this step. However, for quick reference, key information on the purpose of this study, and what it would involve for the young person is summarised below.

***What is the study about?***

Although there has been some research asking adults about their experience of receiving an autism diagnosis, many people with autism are diagnosed when they are a child or adolescent, and yet very little is currently known about younger people's experiences. This study would like to try and understand how a group of 12-16 year olds found out they had autism, and what this was like for them.

***Why are we doing this study?***

We feel that this research may be useful in thinking about how professionals can support families after they have received an autism diagnosis, and the findings may help to develop recommendations for parents on how and when to tell their child about the diagnosis.

This is a small-scale study, which hopes to really understand the experiences of each child involved, and we hope to recruit 6-10 participants in total.

***What would taking part involve?***

If both you and your child choose to take part one of the researchers will meet with your child to carry out an interview, asking questions about their experiences of receiving their autism diagnosis. The interview will involve a mixture of some questions that we feel would be useful to ask everyone that takes part, but also some questions that may flow from what your child has

said in response to other questions. It is likely that the interview will last different lengths of time depending on the child and the questions that come up through speaking with them, but we think that it will last no longer than one hour.

Taking part in this study will in no way impact on the care that you and your child may be currently receiving, or receive in the future, from NHS services.

Outcome of telephone contact:

If the parents are interested in finding out further information on the study, or are interested to take part, AND the young person meets the study's eligibility criteria, please add their details to the list of interested participants/families and ask if they are happy for their name and contact details to be passed on to the study's chief investigator; who is someone working outside of the service but linked with them. If they agree to this, please notify Jasmine and say that someone will soon be in contact to further explain the study.

**Step 4: Follow-up letter**

Where you have spoken with a family, and they are interested in taking part (step 3), please follow this up by posting the 'Thank you for your interest' letter. This letter includes a copy of the Participant Information Sheet, so that families can look at this before being contacted again, if they choose to do so.

**Step 5 onwards:**

Provided that the family have given consent to be contacted by the study's chief investigator (someone working outside of the service), the rest of the communication and recruitment (talking through the participant information sheets and obtaining informed consent) will be handed over to Jasmine.

Thank you again for your help with this. Please don't hesitate to get in contact if you have questions about the study, or this process.

For any questions, or updates about interested potential participants, you can contact me on [Jasmine.Anilmis.2015@live.rhul.ac.uk](mailto:Jasmine.Anilmis.2015@live.rhul.ac.uk).

**Appendix 6: Invitation Letter**



Royal Holloway, University of London  
Department of Clinical Psychology  
Egham, Surrey, TW20 0EX  
Tel: 01784 414012

---

*Invitation to Take Part in a Research Study*

***Young People's Experiences of Receiving an Autism Diagnosis***

***What is the study about?***

We are hoping to talk with a small number of 12-16 year olds, to try and understand how they found out they had autism, and what this was like for them. Other studies have spoken about these experiences with adults, however very little is known of younger people's experiences.

***What would taking part involve?***

We will do this by talking to the young people individually, asking questions about their experiences of receiving their autism diagnosis.

***Why are we doing this study?***

This study may help services develop recommendations for parents on how and when to tell their children about the diagnosis, as well as how professionals can support families following a diagnosis.

***Taking Part:***

If you and your child are interested in finding out more information about taking part in this study, then please contact [Assistant Psychologist's Name] on [email address] or [telephone number].

**Appendix 7: Participant Information Sheet – Young Person Version**



Royal Holloway, University of London  
Department of Clinical Psychology  
Egham, Surrey, TW20 0EX  
Tel: 01784 414012

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## Information Sheet for Young People

### **Young People's Experiences of Receiving an Autism Diagnosis**

We are asking whether you would be interested in taking part in a research study.

Before you decide if you would like to take part, it is really important that you understand what the study is about, why the study is being done and what it would involve for you. So please read and think about this sheet carefully. You can also talk to your family and friends about this if you want.

If something isn't clear or you have more questions, you can ask your parents to call us, and we can discuss it with you and your parents. Thank you for reading this.

#### **Part 1:**

#### ***Why are we doing this research?***

This research is being done to try and understand what it's like for young people with autism to find out about their diagnosis.

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

You have been invited because you are between 12 and 16 years old, and have been given an autism diagnosis.

We are hoping to talk to 6-10 young people with autism.

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

No, you don't. It is your choice whether you want to take part and you can always change your mind.

## YOUNG PEOPLE'S EXPERIENCES OF RECEIVING AN ASD DIAGNOSIS

### ***What will happen to me if I take part?***

Someone from our team will visit you and your parents at your home. This will be split into two visits.



In the first visit you and your parents will have the opportunity to ask any more questions you might have.



In the second visit you and at least one of your parents sign a form to say that you are both happy for you to take part in the study.



Then we will ask you questions about how you found out that you were given an autism diagnosis. This will probably last for about an hour. We would record our conversation.



When we have finished speaking to the other young people in the study, we will let you and your parents know what we have found out.

### ***Is there anything to be worried about when taking part?***

## YOUNG PEOPLE'S EXPERIENCES OF RECEIVING AN ASD DIAGNOSIS

We do not think that taking part in the study will upset you. But if you do become upset while we are talking, we can stop the interview. We can talk to you and your parents about what help you need.

### ***What do I do if I don't want to take part in the research anymore?***

Just tell your parents and the person who visits your house that you don't want to take part anymore. You can stop taking part at any time. You don't have to give a reason. **It is YOUR choice.**

### ***Will taking part in the study help me?***

The study will not help you right now, but it may help us to understand more about what it's like to be given a diagnosis of autism. This may help other young people in the future. You may also enjoy talking to us about your experiences.

WHO SHOULD I ASK IF I HAVE FURTHER QUESTIONS?
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If you have any questions, talk to your parents first. You can also contact the research team at Royal Holloway: Jasmine Anilmis by telephone on 01784 414012

**Thank you for reading so far. If you are still interested please go to Part 2 on the next page.**



**Part 2: Further Information**

**This is more detailed information that you need to know if you are taking part.**

***What happens when the research project stops?***

The results of the study will be written up so that people can read about it, but they won't know that you were in the study. We will also let you and your parents know the results of the study.

We would delete the recording of your interview straight away, but other information may be kept for five years. This information will not have your name in it.

***What if something goes wrong?***

If there is a problem you should talk to your parents first, or the person visiting your home.

***Will my information be kept private? Will anyone else know that I am taking part?***

We will tell the staff at the [ ] service if you want to take part in this study. They may also share information about you with us, like your address and diagnosis.

Anything you tell us will be kept private. We may however have to speak to other people if we worry about you or your family's safety.

***Who is organising and funding the research?***

This research is being organised by Royal Holloway, University of London, with the support of the [ ] service.

***Who has reviewed this study?***

Before any research is allowed to go ahead, it has to be checked by a group of people called the Research Ethics Committee. They make sure that the research is being carried out in a safe way. This study has been reviewed by the Camden and Kings Cross Research Ethics Committee.

**Thank you for your time and thinking about taking part in the study.**

**Appendix 8: Participant Information Sheet – Parent Version**



Royal Holloway, University of London  
Department of Clinical Psychology  
Egham, Surrey, TW20 0EX  
Tel: 01784 414012

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Information Sheet for Parents

**Young People's Experiences of Receiving an Autism Diagnosis**

We'd like to invite your child to take part in our research study. Joining the study is entirely up to you and your child, but before you decide we would like you to understand why the research is being done and what it would involve for your child. The lead researcher will go through this information sheet with you, to help you decide whether or not you would like to take part, and answer any questions you may have. We estimate this should take about 10-20 minutes.

Please feel free to talk to others about the study if you wish.

The first part of the Participant Information Sheet tells you the purpose of the study and what will happen to you if you take part.

Then we give you more detailed information about the conduct of the study.

Do ask if anything is unclear.

**Part 1:**

***Explanation: Purpose of this research***

Many individuals with autism are diagnosed when they are a child or adolescent. There has been some research asking adults about their experience of receiving a diagnosis of autism, however very little is known of younger people's experiences. We would like to try and understand how a group of 12-16 year olds found out they had autism, and what this was like for them.

## YOUNG PEOPLE'S EXPERIENCES OF RECEIVING AN ASD DIAGNOSIS

We feel that this research may be useful in thinking about how professionals can support families after they have received an autism diagnosis, and the findings may help to develop recommendations for parents on how and when to tell their child about the diagnosis.

This is a small-scale study, which hopes to really understand the experiences of each child involved, and we hope to recruit 6-10 participants in total.

### ***What would taking part involve?***

If both you and your child choose to take part, one of the researchers will meet with your child to carry out an interview, asking questions about their experiences of receiving their autism diagnosis. We want your child to feel as comfortable as possible, so we are happy to visit your home for this. The interview will involve a mixture of some questions that we feel would be useful to ask everyone that takes part, but also some questions that may flow from what your child has said in response to other questions. It is likely that the interview will last different lengths of time depending on the child and the questions that come up through speaking with them, but we think that it will last no longer than one hour.

Taking part in this study will in no way impact on the care that you and your child may be currently receiving, or receive in the future, from NHS services.

If you agree for your child to take part in this study, the clinical team may provide the researchers with relevant information from your child's notes. This would only be shared if required, and specifically related to the study, for example to get an address, age, or confirm clinical information.

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

Although taking part will not necessarily benefit you or your child directly, it will increase our knowledge of what it was like for young people who were given a diagnosis of autism. In the future, this may help professionals support other families after their child has been diagnosed with autism, which may include recommendations for the parents on when and how to inform their child of their diagnosis.

There is also the chance that your child may enjoy talking to us about their experiences.

### ***What are the possible disadvantages and risks of taking part?***

Before the interview starts, we would offer you and your child the choice of whether you would like to be present for the interview. Although we think it is

unlikely, and the questions have been designed to avoid this, there is a chance that your child may find taking part stressful or distressing. If this was to happen then the interview would be stopped straight away, and we would let you know if you are not already in the interview. We may also speak with a clinician within the [ ] service in case your child may need further support.

## **Part 2: Further Information**

### ***What if something goes wrong?***

If you have a concern about any aspect of this study, you should ask to speak to the researchers [Jasmine Anilmis, 01784 414012] or study supervisor [Dr. Alex Fowke, telephone number removed], who will do their best to answer your questions. If you remain unhappy and wish to complain formally, you can do this by contacting the [ ] Service Manager [ ].

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

Your decision to take part in this research is entirely voluntary, and you or your child can change your minds at any stage. If you decline the invitation for your child to take part, or you withdraw their participation later on, this will not affect the care that you do/will receive from NHS services.

If you withdraw from the study after your child has been interviewed, we will not include their interview in our analyses, or in the write-up of the findings.

### ***Will my information be kept confidential?***

The researcher will record their meeting with your child, on an encrypted device. The interview will be transcribed soon after the meeting, and the recording will be deleted. Your child will be given a unique code, which will be attached to their answers for the interview questions. Any identifiable details, such as your child's name, will be kept separate from what they say in the interview. Only the research team will have access to your child's information and their interview responses. Although the audio recordings will be deleted once they have been transcribed, other information relating to your child taking part in this study will be stored securely for up to five years for auditing purposes.

We also have a duty of care to keep you and your family safe. Therefore if we become concerned your child or someone else is at risk of harm, we will need to share this information with other professionals to ensure we are providing the best care. Where possible we will always try and let you know about this

before speaking to other people. This is in line with the Central and North West London NHS safeguarding policy.

***What will happen to the results of this study?***

We will let you know what we have found once the study is finished. This will either be through holding a feedback session for participants and their families, or through a sheet summarising the findings for you.

The findings will be written up as part of a doctoral piece of research, however they will also be submitted to scientific journals that publish autism research. The findings may also be presented at a professional conference.

Your child and your family will not be identifiable from any report or publication placed in the public domain.

***Who is organising this research study?***

This research is being organised by Royal Holloway, University of London, with the support of the [ ] service.

***How have the public been involved in this study?***

A young person with an autism diagnosis was involved in reviewing materials such as the young person Participant Information Sheet, and the interview questions.

***Who has reviewed this study?***

All research in the NHS is looked at by an independent group of people, called a Research Ethics Committee, to protect your interests. This study has been reviewed and given favourable opinion by the Camden and Kings Cross Research Ethics Committee.

***Further information and contact details***

Jasmine Anilmis (Trainee Clinical Psychologist)

[Jasmine.Anilmis.2015@live.rhul.ac.uk](mailto:Jasmine.Anilmis.2015@live.rhul.ac.uk)

01784 414012

Dr. Alex Fowke (Study Supervisor, Clinical Psychologist, Royal Holloway University of London)

[Contact details]

**Appendix 9: Young Person Assent Form**

IRAS ID: 224496

Participant Identification Number:

ASSENT FORM for Young People – V2 22/06/2017

**Young People's Experiences of Receiving an Autism  
Diagnosis**

**Name of Researcher:** Jasmine Anilmis

Thank you for thinking about taking part in this study. The study must be explained to you before you agree to take part. If you have any questions please ask before you decide whether to join in. You will be given a copy of this form to keep.

Please tick the boxes, if you agree and the answer is 'yes':

1. I have read the information sheet for Young People dated 25.06.2017 (version 3) and someone has explained it to me and answered my questions.
  
2. I know that I can change my mind about joining in anytime, and I don't have to say why.
  
3. I know what I say is private unless it is about somebody being hurt.
  
4. I am happy for the staff at the [     ] service to know I am taking part in this study.

YOUNG PEOPLE'S EXPERIENCES OF RECEIVING AN ASD DIAGNOSIS

5. It is OK for the staff at the [    ] service to share information about me with the research team. This may be things like my address, or about my diagnosis.
6. It is OK to record the meetings with me.
7. I understand the research team will write up my interview without my name in it, and will then delete the recording.
8. I know that the results of the study will be written up for other people to read, but they won't know that I was in the study.
9. It is OK to keep information of me taking part in the study for up to five years.
10. I want to join in with the study.

If any answers are 'no' or you don't want to join in, don't write your name.

If you do want to join in, write your name on the line.

Young person's name: \_\_\_\_\_ Date: \_\_\_\_\_

11. I have explained the study and answered any questions.

Name of researcher \_\_\_\_\_

Date \_\_\_\_\_ Signature \_\_\_\_\_

**Appendix 10: Parent Consent Form**

IRAS ID: 224496

Participant Identification Number:

**CONSENT FORM – V2 22/06/2017**

Title of Project: **Young People's Experiences of Receiving an Autism Diagnosis?**

**Name of Researcher:** Jasmine Anilmis

Please initial boxes

1. I confirm that I have read the information sheet dated 22.06.2017 (version 2) for the above project, and one of the researchers has talked to me about it. I have had enough time to think about it, and ask questions.
2. I understand that taking part is voluntary, and that my child and I are free to withdraw at any time without giving any reason, and without my child's medical care or legal rights being affected.
3. I am willing for the researcher to let my child's clinical team know that my child is taking part in the study.
4. I am willing for the researcher to contact my child's clinical team with any information relevant to you and your child's safety, should this become apparent while they are taking part in the study.
5. I give permission for the clinical team to provide the researchers with relevant information from my child's clinical notes, if required (for example, to get an address, age, or confirm clinical information).
6. I am willing for my child's meeting with the researcher to be audio-recorded. The interview will be transcribed soon after the meeting, and the recording will be deleted.
7. I agree to anonymous quotes from my child's interview being used within the write-up and publication of this study's findings. Any information that may identify your child will be removed from these.
8. I understand that information relating to my child taking part in this study will be stored securely for up to five years.



YOUNG PEOPLE'S EXPERIENCES OF RECEIVING AN ASD DIAGNOSIS

9. I agree for my child to take part in the above study.

\_\_\_\_\_  
Name of parent/carer                      Date                      Signature

10. I have explained the study to this parent/carer, and answered their questions honestly and fully.

\_\_\_\_\_  
Name of researcher taking consent                      Date                      Signature

**Appendix 11: Demographics Questionnaire**



Royal Holloway, University of London  
Department of Clinical Psychology  
Egham, Surrey, TW20 0EX  
Tel: 01784 414012

IRAS ID: 224496

Participant Identification Number:

**DEMOGRAPHICS QUESTIONNAIRE – V2 25/06/2017**

Title of Project: **Young people's (aged 12-16 years) experiences of receiving a diagnosis of Autism Spectrum Disorder?**

Thank you to agreeing for your child to take part in the above study. We kindly ask you to please fill in the following information:

**General Information**

1. Today's date: \_\_\_\_\_

2. Your child's age at time

of interview (*years and months*): \_\_\_\_\_

3. Your child's gender: \_\_\_\_\_

4. Your child's ethnicity: \_\_\_\_\_

**Information about Autism Diagnosis**

1. How old was your child when they were diagnosed?

\_\_\_\_\_

## YOUNG PEOPLE'S EXPERIENCES OF RECEIVING AN ASD DIAGNOSIS

2. What diagnosis were they given?

*e.g. Autism Spectrum Disorder/Autism Spectrum Condition/Asperger's Syndrome/Autism/Pervasive Developmental Disorder-Not Otherwise Specified/Other (please specify)*

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3. Does your child know that they have autism?

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4. How old were they when they found out?

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5. Did you seek any support around how to talk to your child about having autism? (please explain briefly)

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### **School Information**

1. What type of school does your child attend? (please tick as appropriate)

Mainstream school without additional support
Mainstream school with additional support*
* Please specify any additional information
Specialist school for children with autism
Other specialist school for children with special educational needs
Other (please specify):

**Interests**

*It may be helpful for Jasmine to know a little more about your child before they meet for the interview, so she can try to put your child at ease when they meet:*

1. Does your child have any things/people/places/activities that they particularly like to do, or talk about? (please explain)

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2. Is there anything else about your child that you think may be useful for Jasmine to know before they meet for the interview?

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## Appendix 12: Interview Schedule

Opening Question: I have planned to use the word 'autism' in the questions, but some people use other words like ASD/Autism Spectrum Disorder. I wondered what word/term you like to use to describe autism?

*Then use the young person's preferred term throughout the interview.*

### **Key**

#### **Main Question**

Possible Prompts/Follow-Up Questions (dependant on participant's response)

#### **9) What do you think autism (or substitute term) is?**

- Can you tell me more about that?
- Can you give me examples of that?

#### **10) Can you remember the first time someone told you that you have autism (or substitute term) (If no, go to Q7)**

- If they don't remember, explore process of knowing/finding out more: conversations with people? What they remember of this.

#### **11) How did you find out that you have autism (or substitute term)?**

- When was that?
- Where were you?
- Who told you/who were you with?
- What was that like for you?
- Had you heard of autism (or substitute term) before?
- Would you like anything to have been different about the way you found out you have autism?
- Did you get enough information? Would you have liked more/less?

**12) What was it like for you to find out that you have autism (or substitute term)?**

- How did you feel? (Try to elicit thoughts, feelings, reactions, if possible).
- For those that are struggling to articulate was this was like for them: Children often react differently to finding out they have autism, some people feel sad, some people angry, some happy. How did you feel?
- For those that are struggling to articulate was this was like for them: If it is hard to say how you felt/what you thought/what you did, can you draw me a picture of it? What did you draw? Why? What's happening in the picture?

**13) Have you spoken to anyone about it? What's it been like to talk to them?**

- Parents? Teachers? Friends? Professionals?
- What did you say to them?
- What did you like about what they said?
- Anything you didn't like about what they said?
- Did they say anything helpful to you?
- Did they say anything unhelpful to you?
- What was helpful/unhelpful?

**14) Do you think you have autism (or substitute word)?**

- Why don't you think you have autism?

**15) What does having autism (or substitute word) mean to you?**

- Can you tell me more about that?

**16) Do your friends think/know (depending on response to Q6) that you have autism (or substitute term)?**

- What do your friends think about that?
- How did you tell them/how did they find out?
- Why did you tell them/why not?
- How did you friends react? / How do you think they might react?

## YOUNG PEOPLE'S EXPERIENCES OF RECEIVING AN ASD DIAGNOSIS

- Did they act any different when they found out? In a good way? In a bad way?
- Has this changed anything?
- Are you pleased you told them?
- Is there anyone else you might tell? If 'yes', who would you tell? Is there anyone you wouldn't tell? Why not?
- What do you hope may happen if you tell them? / If they express worries about telling others: What worries you about doing this?

**14) Only ask to those who responded 'Yes' to 'Do you think you have autism?: Do you think autism (or substitute term) will affect what you do in the future?**

- Are there things about the future that you think might be the same for you and people without autism?
- Are there things that you think might be different?

**15) Is there anything good about having autism (or substitute term)? Is there anything bad about having autism (or substitute term)?**

- What types of things?
- Can you think of an example?

**16) Depending on young person's age/ability to answer such a question: If someone asked for your advice about how to tell someone that they have autism (or substitute word), what would you tell them?**

- Are there things you would tell them definitely not to do?

**Closing questions:**

**17) If I could tell people one thing about autism (or substitute term), what would you want me to tell them?**

- Is there anything else you would want to tell other young people just finding out they have autism?

**18) Only ask to those who responded 'Yes' to 'Do you think you have autism?': If you could summarise what it means to have autism in one sentence, what would you say?**

**Closing script:** Thanking the young person, and checking in with how the young person found the interview; whether they have any questions; explaining what will happen next, discussing any follow-up that may be required; whether they want a copy of the study results and how they want this, etc.





YOUNG PEOPLE'S EXPERIENCES OF RECEIVING AN ASD DIAGNOSIS

<p>in secondary I met X (SEN teacher). So it basically did take a year.</p> <p>R: OK. So you felt a bit weird at first [referring back to participant's earlier comment in the transcript]. What other feelings did you feel along that time when you were learning about it?</p> <p>P: I felt so confused because it was complicated finding out what it was.</p> <p>R: OK, so it felt confusing at times?</p> <p>P: Yer.</p> <p>R: Any other feelings?</p> <p>P: Erm...I'm trying to think...erm I was slightly determined because I wanted to find out what it properly was.</p> <p>R: Ah that's interesting. So you were confused but you were like 'no, I'm going to really find out about this'.</p> <p>P: Yer.</p> <p>R: Then how did you feel once you'd started to find out about it?</p> <p>P: Erm...I kind of felt relieved because autism apparently isn't' extremely bad. As X (SEN teacher said), it's nothing to be ashamed of. Just really relieved.</p> <p>R: So you felt relived after hearing that.</p> <p>P: Yer.</p> <p>R: Did you feel a bit bad about it before then?</p> <p>P: Erm, I was just scared it might be something bad.</p>	<p>Further learning through SEN teacher</p> <p>Confusing. Difficulties understanding diagnosis/complicated</p> <p>Curious – wanting to know more and learn about diagnosis</p> <p>Felt relieved after learning about autism.</p> <p>Previous worries (before understanding it) that diagnosis might be something bad.</p> <p>Worries about the unknown.</p>	<p><b>Making Sense of the Diagnosis</b> <i>The Unknown</i></p> <p><b>Making Sense of Diagnosis</b> <i>Process of Learning</i></p> <p><b>Making Sense of the Diagnosis</b> <i>Relief with Understanding</i></p> <p><i>The Unknown</i></p>
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**Appendix 14: Additional Extracts from Thematic Analysis**

Experiences during Assessment	Making Sense of the Diagnosis	Impact of Diagnosis on Self	Impact of Diagnosis on Self in Society	Interaction with Others
<p><b>P06:</b> “It was kind of like every like year, we’d have to go like twice, to another room opposite and we’d have to do like erm, fixing puzzles, answering questions .... <b>R:</b> Did you know why they were asking you those questions at the time? <b>P06:</b> No. They were still a little unsure on the subject of whether I had autism or not. <b>R:</b> OK. <b>P06:</b> They were kind of like ‘err, let’s try another one’. <b>R:</b> OK. So did you know that they’d thought autism might be a possibility at that point? <b>P06:</b> No I was completely unaware.”</p>	<p><u><i>The Unknown</i></u> <b>R:</b> “Did you feel anything else? <b>P06:</b> No, not, I mean upset at the beginning would be a word, but it wouldn’t be that bad after I understood what it was. <b>R:</b> What made you upset at the start? <b>P06:</b> I didn’t know what it was. <b>R:</b> Ah OK. <b>P06:</b> So I had no idea what it was, so I was pretty upset. Honestly, I only get upset if I don’t know what’s going on.”  <u><i>Process of Learning about Autism</i></u> <b>P03:</b> “She [mother] told me what it does, like how it affects you socially. And how it makes you stand out,</p>	<p><u><i>Self-awareness</i></u> <b>P01:</b> “I’m not sure if this is really my autism or not, but I really think of things in a different way than most people would I think.”  <u><i>Self-acceptance</i></u> <b>P03:</b> “When I got told about you know what happens, I then felt more comfortable doing, it made me more comfortable not looking in people’s eyes. <b>R:</b> So finding out made you more comfortable about things? <b>P03:</b> Yes because most people would say it’s really really weird behaviour...like you know what I’m doing now...when I keep ‘err-ing’ and stuff, I was always trying to stop that. But now I</p>	<p><u><i>Difference</i></u> <b>P01:</b> “All it does is, it makes you a little bit different from other people.”  <b>P03:</b> “...you can’t change being different, but you can accept it.”  <u><i>Thinking Ahead</i></u> <b>P06:</b> “My friends have all types of different dreams. Doctors, bus drivers, YouTuber’s. But I don’t really fall into that category if I’m honest with you... I think autism has affected that I’m way more creative than most people.”</p>	<p><u><i>Others Understand you more</i></u> <b>P07:</b> “I’d like people to know because then they could understand... I know that autism affects you socially and how you are talking to people. Maybe if they sort of recognise that with me, rather than thinking that I’m just like that, they might think ‘oh that’s why [name] might not be as easy to talk to as someone else”  <u><i>Acceptance from Others</i></u> <b>P05:</b> “People know I have autism and they all tolerate it... They all accept me for who I am. They have no problems with autism.”  <u><i>Poor Understanding in Others</i></u> <b>P06:</b> “We’d seen a video about one girl who went onto CBBC I</p>

YOUNG PEOPLE’S EXPERIENCES OF RECEIVING AN ASD DIAGNOSIS

	<p>and what it does, like how it makes you not want to look in people’s eyes.”</p> <p><b>R:</b> “Was anything helpful about the information that was given to you? Or things that people have done to help you understand?”</p> <p><b>P07:</b> Probably erm, sort of going over what it does was probably the best thing really. Yer.”</p> <p><i>Perceptions of Autism</i></p> <p><b>P05:</b> “Some people have different types of autism with different symptoms. So I don’t think there is really one...I think people with autism have different like, different things. Some people are more, have higher functioning, some can barely talk properly, so it really depends. It’s just, yer like a spectrum of a different kind of brain.”</p>	<p>know that I can do it, so I’m happy about that.</p> <p><b>R:</b> Ah. So you were almost trying to change things before? Trying to stop yourself from doing things?”</p> <p><b>P03:</b> Yer and I would be upset with myself, and I was thinking ‘I need to help myself, to teach myself how to stop it’.</p> <p><b>R:</b> So you used to get upset by some of the things before, but now how do you feel about that?”</p> <p><b>P03:</b> I just know, that they’re normal.”</p> <p><i>Support after Diagnosis</i></p> <p><b>P06:</b> “... I had help before, but after the diagnosis was put down they were finally able to get me the help I needed for that [school work].”</p> <p><b>P05:</b> “I’m often not listening in class and get distracted.</p>	<p><i>Responsibility to Educate Others</i></p> <p>No additional extracts as subtheme only relates to one participant.</p>	<p>think a few years back, talking about autism, and they [friends] were asking if that was all true. I said ‘it’s part of it, but autism affects people in different ways because we’re not all the same’.... The video was missing like the vital part that autism affects people in different ways... And there’s kind of like a stereotypical build up ever since the Donald Trump incident where vaccines apparently cause autism. No they don’t. And essentially that broke out, and everyone, there’s a bunch of videos that went out on the Internet not too long ago which were essentially showing an autistic kid freaking out... And one of those things that it’s kind of like it’s not true. First of all it affects people in so many different ways. I could be like him, but I could be different in my own right.”</p>
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YOUNG PEOPLE'S EXPERIENCES OF RECEIVING AN ASD DIAGNOSIS

	<p><b>P06:</b> “Autism is both a good thing and a bad thing, but embrace the good things and accept the bad things.”</p> <p><i>Relief with Understanding</i>  <b>R:</b> “You said that when you didn’t understand what it was, you felt a bit upset. But then after you’d had that conversation with dad and you went on the Internet together, how did you feel about it then?”  <b>P06:</b> That at least I knew what it was.  <b>R:</b> And how did that make you feel? Knowing what it was?  <b>P06:</b> Better. Better for sure.”</p> <p><i>Changing with Time</i>  <b>P01:</b> “Because the thing is, I’m not sure, maybe because I was much younger I didn’t really care that much</p>	<p>People with autism find it difficult to listen to things that they do not enjoy, do not prefer listening to. Like in Maths I do because it’s school, but it’s not an interest so it’s hard to listen.  <b>R:</b> How do cope with that in class then? How do you manage that?  <b>P05:</b> I get help from my key teachers.”</p>	<p><i>Fears of Others Knowing</i>  <b>P07:</b> “I’m not saying it’s like a nasty school or anything, but I think a lot of how teenagers are, really it’s not something I’d want to tell people. And I don’t feel close enough to anyone to really have faith that they’d keep it, or that they’d really need to know. So I haven’t really thought...well I have thought of speaking about it, but I haven’t sort of thought that’s a good idea to do that.  <b>R:</b> What’s making you, what’s kind of stopping you then?  <b>P07:</b> Err...probably, maybe sort of being made fun of because of it. Things like that. But it’s mostly that really. Or that, also that I wouldn’t want people to think that I’m...look at me in a different way because I’ve told them, rather than how they’d look at me before. Because now I’ve told them, they’ve realised ‘oh there’s something wrong with him’. I wouldn’t want to</p>
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YOUNG PEOPLE’S EXPERIENCES OF RECEIVING AN ASD DIAGNOSIS

	<p>really.”</p> <p><i>Reflections based on Experiences of Receiving a Diagnosis</i></p> <p><b>P07:</b> “...it would have been nicer to know more about it, and to sort of understand how to deal with it. Because they tell you what it is, and then that’s really it... they don’t tell you if it’s bad or good, or what you can do to be better at dealing with it.”</p>			<p>get into that with anybody.”</p> <p><i>More Awareness Needed</i></p> <p><b>R:</b> “What would make it easier for you to tell people?”</p> <p><b>P07:</b> Probably...if erm...if maybe other people understand it more...</p> <p><b>R:</b> Do you think there’s ways they could be helped to understand?</p> <p><b>P07:</b> Erm...maybe learning about issues of autism sort of thing, maybe learning about stuff like that a bit more.”</p>
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**Appendix 15: Extract from Reflective Journal**

At the end of data collection

Looking back at my entry after the first interview, I noted that I was a little surprised a 13-year-old had already been thinking about the possible impact their diagnosis may have on the job they get in the future. Having now finished the interviews, the majority of the young people also spoke about this. I'm not sure I was necessarily thinking about jobs at that age. Their future and employment is something these young people had already started to think about, in light of their diagnosis. It's important for adults not to minimise the potential impact of telling a young person about their diagnosis, and to consider this may be an issue they want to talk about. I wonder if this is perhaps also something that may have been talked about with their parents at some point. For example, I know one participant made a reference to the type of job that their mother thinks they should do. Again, this is something to think about, in that it can be difficult to tease apart what are the young people's thoughts and experiences, and what are those of their parents. Although, can they really be teased apart? To some extent, those around us influence our experiences. People's experiences are therefore potentially very much linked, or perhaps embedded, within those of other people. This might especially be the case in a parent-child relationship, where the young person is still discovering who they are and developing their individual identity.