A Study into the Lived Experiences of Receiving an Autism Diagnosis

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A thesis submitted in partial fulfilment of the requirement for the award of Doctor of Clinical Psychology

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Declaration

I, the author, confirm that the Thesis is my own work. I am aware of the University's Guidance on the Use of Unfair Means (www.sheffield.ac.uk/ssid/unfair-means). This work has not previously been presented for an award at this, or any other, university.

Word Count

Section One: Systematic literature review

Excluding references and tables	7,686
Including references and tables	12,718
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Section Two: Empirical Study

Excluding references and tables	8,000
Including references and tables	11,140
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Total Word Count

Excluding references and tables	15,686
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Overall Abstract

Receiving an autism diagnosis has a significant impact on an individual and people close to them. Qualitative research provides an in-depth exploration of individuals' experiences. A literature review was conducted to identify and evaluate the qualitative literature about individuals' experiences of the autism diagnostic process, in the UK. Six databases were searched, and twenty-six studies met the criteria for the review. Data were analysed using Thematic Synthesis. Results revealed dissatisfaction with the diagnostic process, including a distressing, deficit focus to assessments and professionals' limited knowledge of autism. Themes also illustrated the process of negotiating self-identity, misconceptions of autism and post-diagnosis support. For many participants, the diagnosis facilitated self-understanding. The results highlight the importance of autism training for all professionals and the benefits of peer support.

A research study was also conducted. Autistic women tend to experience barriers to diagnosis. Research also suggests mental health issues commonly co-occur with autism. There are strong links between self-compassion and mental health, but there is minimal research exploring autistic individuals' experiences of self-compassion. The study aimed to explore if receiving an autism diagnosis influences women's experiences of self-compassion. Eleven autistic women who received their diagnosis in adulthood participated in semi-structured interviews. Data were collected and analysed using Interpretative Phenomenological Analysis. Results revealed several barriers to self-compassion, including misconceptions of autism, social rejection, and unhelpful thinking styles. Themes explored social expectations, the process of self-understanding and relationships. Most participants reported their diagnosis facilitated self-compassion, which for many was a new way of self-relating, compared to self-criticism pre-diagnosis. The findings highlight the importance of early identification in girls and women, to reduce self-criticism associated with late diagnosis. The results relate to Neff's (2003) definition of self-compassion and suggest potential benefits of self-compassion interventions to improve autistic women's well-being.

Acknowledgements

I would like to firstly thank my research supervisors, Dr Megan Freeth, Professor Andrew Thompson and Dr Georgia Rowse. I have appreciated your continued interest and support throughout the research process. Megan, thank you for always been so approachable and responsive. It has been inspirational to work alongside you, learning from your knowledge and passion for autism research. Andrew, thank you for continuing to support this research after securing a new role in Cardiff. I have really appreciated your guidance about qualitative research, especially your knowledge of Interpretative Phenomenological Analysis. Georgina, thank you for your continued encouragement and insightful guidance, particularly your suggestions from an examiner's perspective.

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A huge thank you to my participants – without you, this research would not be possible. I was overwhelmed by your willingness to take part and incredibly grateful for you all choosing to share your experiences. I sincerely hope this research adds to the understandings of autistic women's experiences and that research in this area continues to develop.

To my fellow trainee and friend, Poppy Siddell, thank you for helping me keep perspective and always making me laugh. To my fabulous friends outside the course, thank you for your endless encouragement and motivational talks! Thank you to my wonderful family and partner Joe Langan; I could not have done this without your emotional support and faith in me.

Table of Contents

Section One: Systematic Literature Review

A thematic synthesis of autistic individuals’ experiences of the diagnostic process for autism in the UK

Abstract

Objectives

This review aimed to systematically identify, appraise and synthesise qualitative research concerning individuals' experiences of the autism diagnostic process in the UK. Qualitative research provided an in-depth exploration of how the autism diagnosis process impacts individuals' sense of self and relationships with others. Participants of all ages and gender were included to consider the influence on individuals' experience.

Design and Methods

Six databases were systematically searched for qualitative studies exploring autistic individuals' experiences of the autistic diagnostic process in the UK. Twenty-six studies, were included, assessed for quality (using the CASP appraisal tool), and analysed using Thematic Synthesis. Included studies were published between 2007-2021 and included more than 528 participants.

Results

Three super-ordinate themes were identified; *'Negotiating Self-identity'* (distressing assessment process; conflicting emotions towards diagnosis; neurodiversity; self-reflection and self-kindness); *'Feeling Misunderstood'* (autism is misunderstood; social challenges; mental health impact and misdiagnosis); and *'Support Post-Diagnosis'* (increased support and understanding; connection and validation).

Conclusions

Participants reported limited understanding from professionals, creating barriers to assessment and appropriate support. The process of negotiating and adjusting to an autism diagnosis is presented as dynamic, with a range of emotional responses. In many cases the diagnosis facilitated self-understanding and a non-judgemental approach to difficulties.

Practitioner Points

- Findings highlighted the need for autism training for professionals and the benefits of peer support.
- Clinicians to recognise strengths during typically deficit-focused assessment process.
- Future research to consider how ethnicity may impact autistic individuals' experiences.

Keywords

Autism; ASC; Thematic Synthesis; Qualitative; Diagnosis; UK; Systematic Review.

Introduction

Autism Spectrum Condition (ASC)[1], also known as autism, is a lifelong neurodevelopmental condition that affects how individuals perceive the world, including social communication, social interaction, behaviour, and interests (American Psychiatric Association, 2013). The autism diagnostic process varies between countries (Zaroff & Uhm, 2012) and as a result, it is important to investigate country specific issues when attempting to improve services. In the UK, there is an increase in adults seeking autism diagnosis, this heightened demand is highlighted by the national initiative to develop diagnostic clinics for adults with undiagnosed autism (National Institute of Clinical Excellence Guidelines [NICE], 2012). Qualitative methods are growing in popularity in autism research (MacLeod, 2019) and this approach attempts to provide in-depth understandings of lived experiences. Existing research has highlighted that receiving an autism diagnosis has a significant impact on an individual and people close to them (Midence & O'Neill, 1999; Punshon et al., 2009). This meta-synthesis aims to identify themes evident in the literature about autistic individuals' experiences of the autism diagnostic process in the UK, to provide theoretical and in particular clinical and practical insights into this experience. To our knowledge, this is the first thematic synthesis exploring autistic individuals' lived experiences of the diagnostic process for autism.

Prevalence statistics for ASC vary between countries, some of this variation is explained by age at diagnosis and diagnostic methods (Parner et al., 2011). An NHS survey concluded that the prevalence of autism in the UK was 1.1% (Brugha et al., 2012). However, research suggests the number of people diagnosed with autism is still lower than estimates of prevalence would suggest (Parkin et al., 2016). The National Institute for Health and Clinical Excellence (NICE, clinical guideline CG142, 2012) states that difficulties related to autism are present in childhood and continue into adulthood. NICE and Scottish

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[1] Autistic individuals prefer the term ASC compared to autism spectrum disorder, which is the diagnostic term (Kenny et al., 2015).

Intercollegiate Guidelines Network (SIGN, clinical guideline 145, 2016) recommend considering formal assessment tools as part of the diagnosis process (e.g., Autism Diagnostic Interview- Revised). The Diagnostic Statistic Manual of Mental Disorders (DSM-5, 2013) replaced distinct diagnoses including ‘Asperger syndrome’ with the collective term ‘autism spectrum disorder’, to streamline the diagnostic criteria and reflect the range of difficulties that people may experience. The International Classification of Diseases (ICD-10, 2004) is the most commonly used diagnostic manual in the UK. The revised edition, ICD-11 (2020) takes a similar approach to the DSM-5 (2013) and includes the overarching category of ‘autism’. Given the difference in autism diagnosis process between countries, this meta-synthesis exclusively investigates autistic individuals’ experiences of the diagnostic process in the UK. In addition, a recent scoping review found that most qualitative studies exploring the experience of receiving an autism diagnosis in adulthood were conducted in the UK (Huang et al., 2020).

Crane et al. (2016) reported that over half of the parents surveyed within the UK were dissatisfied with the diagnostic process and post-diagnostic support was limited. Similarly, research exploring parents’ experiences of their children receiving an autism diagnosis describe various challenges accessing services and balancing the demands of family life, with little respite (Hastings & Johnson, 2001; Vasilopoulou & Nisbet, 2016). Research also suggests that parents undergo a range of adjustment experiences in response to their child’s autism diagnosis, including some examples of personal growth in resilience and strength (Myers et al., 2009). A recent qualitative review reported that parents’ experiences of the diagnosis process for their children in the UK varied; authors developed third-order constructs relating to parents’ needs during the process: consideration of parents’ emotional needs, need for information to promote understanding and need for strong relationships with professionals (Legg & Tickle, 2019).

Compared to parents’ experiences, existing research about autistic adults’ experiences of the diagnostic process is more mixed (Crane et al., 2018). Jones et al. (2014)

UK-based survey of 128 autistic adults reported that 40% were dissatisfied, while 47% were satisfied with their experience of the diagnostic process. This survey highlighted dissatisfaction with post-diagnostic support. Satisfaction with post-diagnostic support is a predictor of satisfaction with the overall autism diagnostic process, for adults (Jones et al., 2014) and in parent survey findings (e.g., Crane et al., 2016). Most research exploring the diagnostic experience has been conducted with adult participants (Punshon et al., 2009). However, there are a few studies exploring children or adolescents' perspectives (e.g., Saggers et al., 2011). The existing literature reports a range of experiences of the autism diagnostic process; it is important to explore the research more thoroughly, from autistic individuals' perspectives, utilising a meta-synthesis approach. Synthesising research with both children and adult participants may reveal differences in experience related to the age of diagnosis. In addition, research suggests that the experience of autism differs between females and males (Gould, 2017; Lai & Baron-Cohen, 2015). Research also suggests autism diagnosis and autistic traits are common in the transgender population (de Vries at al., 2010). Synthesising research without restrictions on gender categories may reveal more detail about the gender differences in the diagnostic experience. Understanding gender differences and lifespan issues have been identified as priority areas for research by autistic adults (Pellicano et al., 2014). The clinical implications of the review will be considered and identify areas for improvement in UK practice.

There is a range of existing qualitative reviews investigating experiences of autism. A recent thematic synthesis explored siblings' lived experiences of autism; the findings described the impact of the diagnosis on family roles and family challenges, while also describing positive experiences of sibling connection (Leedham et al., 2020). DePape and Lindsay's (2016) meta-synthesis presents the experiences of autistic individuals across multiple areas of their life and how these experiences vary according to their developmental stage. This current review aims to synthesis and critically appraise qualitative research exploring the lived experiences of the diagnosis process in the UK, for autistic individuals of all ages.

A narrative review of autism diagnosis in the UK for adults and children, was published in 2018; this focused exclusively on clinical guidance documents, rather than individuals' lived experiences (Hayes et al., 2018). Similarly, existing reviews on adult autism diagnosis tend to focus on evaluating screening measures and diagnostic tools (Baghdadli et al., 2017; Falkmer et al., 2013; Hirota et al., 2018). A recent scoping review exploring the experience of autism diagnosis in adulthood presented qualitative and quantitative research findings. The review highlighted the emotional impact of diagnosis in adulthood, limited formal support and inconsistencies in access and processes (Huang et al., 2020). Qualitative evidence synthesis provides themes that explore the diversity of experiences. This meta-synthesis will provide an in-depth understanding of lived experiences of autistic individuals' experiences of the diagnostic process in the UK. Findings will reveal how an autism diagnosis impacts individuals' sense of self and relationships with others.

Given the nature of a scoping review, the Huang et al. (2020) review was very broad, limiting the discussions of the specific themes identified. This current review adopts a thematic synthesis approach, which allows researchers to preserve the core content of qualitative data while ensuring themes are derived via a rigorous and detailed coding process. This review aims to synthesis the literature to provide a deeper understanding of autistic individuals' experiences of the diagnostic process for autism in the UK. The thematic synthesis will identify gaps and limitations in the literature and consider clinical implications. The review aims to provide clinicians insight into the experiences of the diagnostic process in the UK and inform clinical practice.

Review aims:

1. To systematically identify the qualitative research that investigates autistic individuals' lived experience of the diagnosis process for autism in the UK.

2. To critically appraise qualitative research that investigates autistic individuals’ experiences of the diagnosis process for autism in the UK.
3. To generate a thematic synthesis of the themes evident in the literature on autistic individuals’ experiences of the diagnosis process for autism in the UK.

Review questions:

1. What are autistic individuals’ experiences of the diagnostic process for autism in the UK?
2. How does an autism diagnosis impact individuals’ sense of self and relationships with others?
3. Does receiving an autism diagnosis in childhood (under 18 years) compare to the lived experience of receiving the diagnosis in adulthood?
4. Are there gender differences in the experiences of the diagnostic process for autism in the UK?

Method

The protocol for this systematic review was registered on the prospective register PROSPERO (reference: CRD42020204383). The PRISMA (Preferred Reporting Items for Systematic Reviews and Meta-Analyses) guidelines (Moher et al., 2009) were utilised, excluding items not applicable for qualitative research (items 13, 20, 21).

Booth et al. (2018) structured methodology review identified seven (RETREAT) criteria for selecting qualitative evidence synthesis approaches. After considering these criteria, Thematic Synthesis (Thomas & Harden, 2008) was deemed the most appropriate method for this review as it is the most accessible form of synthesis. Thematic synthesis can be used across various epistemologies (Cruzes & Dyba, 2011) and applicable to synthesising studies with contrasting methodologies (Barnett-Page & Thomas, 2009).

This meta-synthesis aims to provide clinicians insight into the experiences of the autism diagnostic process and inform clinical practice. The analytical themes produced by Thematic Synthesis (Thomas & Harden, 2008) may be more appropriate when informing policy and practice, than other meta-synthesis approaches that are better suited to exploring areas of literature with broader review questions (Thomas & Harden, 2008). In addition, thematic synthesis presents a clear link between primary study findings and conclusions, presenting the transparency valued in systematic reviewing.

Search Strategy

The SPICE (Setting, Perspective, Intervention/ Interest, Comparison, Evaluation) mnemonic was utilised to develop the review question and search strategy (see table 1). The SPICE framework for defining the scope of systematic reviews may be especially useful for qualitative questions (Booth, 2004).

Table 1

Key elements of research question identified with SPICE tool.

Criteria	**Description**
Setting	United Kingdom
Perspective	Autistic individuals (all ages)
Intervention/ Interest	Experiences of the diagnostic process
Comparison (if relevant)	Potentially time since diagnosis/ gender
Evaluation	Attitudes, feelings, experiences captured in themes.

The databases Web of Science, PsycINFO, PsycARTICLES, Medline (all via OvidSP), Scopus, CINAHL (via EBSCO) were systematically searched in October 2020. Relevant synonyms and wildcards were used to increase the likelihood of locating relevant studies across the six databases. No restrictions were made on date limits during the searches to obtain all relevant articles from this area of research. Searches were limited to English only texts due to no translation ability. Authors were contacted for two of the studies as it was not possible to locate the full text; there was no response within two weeks to one of these requests.

Search terms were combined with Boolean operators: (Autis* Spectrum OR Autis* OR Asperger* OR Pervasive Developmental Disorder) AND (Lived experience* OR Qualitative) OR (lived experience* OR Qualitative method) AND (diagnosis). Names of specific qualitative methods were included in the search terms e.g., Big Q research, to ensure rigor of the systematic searches (Dixon-Woods et al., 2001; Shaw, 2012). Additional qualitative search terms were also included in the searches, including interpretative phenomenolog*, template, content, narrative, discourse, grounded theory, thematic. Prior to the lead author conducting the searches, all the search terms, the search strategy and appropriate databases were discussed and agreed between all authors in supervision and guided by the Centre for Review and Dissemination Guidance (Centre for Review & Dissemination, 2009). An example search within Psychinfo (database) is included in Appendix A.

Study Selection

The following inclusion and exclusion criteria were applied to obtain relevant articles from the searches.

Inclusion criteria

- Samples include autistic individuals (both adults and children) residing in the UK.
- Articles including data from family members/ carers/ teachers/ colleagues will be included if the autistic individuals’ data is easily extractable. Only autistic people’s data will be analysed.
- Studies employed qualitative methods and analysis.

Exclusion criteria

- Articles not written in English.

- Sample including self-identified autistic individuals and unable to extract their data from the clinically diagnosed autistic participants.
- Non-UK samples.
- Studies with online recruitment from non-UK websites could not guarantee participants received their autism diagnosis in the UK.
- Systematic reviews, book chapters, non-peer reviewed articles e.g., blogs and conference papers.
- Carer/ family member experiences of the diagnostic process for autism in the UK.

Screening

Initially, all the identified articles were screened by title and abstract, with irrelevant studies excluded using the inclusion and exclusion criteria. Duplicates were removed and then the remaining studies were read in full; studies that did not meet the inclusion/ exclusion criteria were removed. Scopus was utilised to complete forward tracking citations on included studies.

Data Extraction

Data relevant to the review research questions were extracted from the included studies. An aggregative approach was adopted for the review, data extraction tables presented the studies in a common format to facilitate assimilation. Extracted data included: author, year, reported sample characteristics (gender, time since diagnosis, age, presence of comorbid mental health diagnosis, autism/ Asperger's diagnosis), recruitment, data collection and methodology, key findings and themes. All studies were required to be UK based; the country was included if specified. A completed data extraction table is included in Appendix B.

Assessment of Quality

The quality of the studies was assessed using the Critical Appraisal Skills Programme qualitative research checklist (Critical Appraisal Skills Programme, CASP, 2018). The CASP is a well-established quality assessment tool in qualitative literature

(Dixon-Woods et al., 2007). The CASP Qualitive checklist (Appendix C) includes ten questions to evaluate the validity of research, rigor of analysis, clarity of results and the value of findings. Thomas and Harden (2008) and many qualitative reviewers do not exclude studies based on quality appraisal (Hannes & Mecaitis, 2012; Gallacher et al., 2013). Therefore, all articles following appraisal and critique are included in the thematic synthesis. A random selection of 10 studies (approx. 38%) was appraised by a second reviewer, a Psychology undergraduate researcher, independent of this review. There were discrepancies on 12 out of 100 CASP checklist questions and included seven studies. The discrepancies were resolved via discussions between the two reviewers.

Data Synthesis

Data from the included studies were reviewed and narratively synthesised using the Thematic Synthesis (Thomas & Harden, 2008) approach to meta-synthesis of qualitative literature. Using the Thomas and Harden (2008) stages to thematic synthesis the process involved extracting verbatim text from the 'findings' or 'results' sections of each included studies and transferring into a Microsoft Excel spreadsheet to perform 'line by line' coding of the text. The extracted text included the participant quotes and the authors' descriptions and interpretations of the findings. Including the authors’ interpretations in the synthesis follows the stages suggested by Thomas and Harden (2008) and qualitative literature generally (Toye et al., 2014).

Codes were created to identify the content and meanings within each line for each of the included studies. A collection of themes were developed through this inductive process for each study. The complete collection of themes was then compared across the studies to create descriptive themes and grouped in a hierarchical structure. The final stage of the process was interpreting the themes further to produce a list of superordinate and subthemes relating to autistic individuals’ experiences of the diagnostic process for autism in the UK. The development of the themes and coding were discussed at every stage of the synthesis process with research supervisors, and any discrepancies were resolved via discussions.

Results

Summary of Included Studies

A total of 1,580 studies from the six databases were input into a reference management database (Rayyan), and one additional record was identified through forward citation. 209 duplicates were removed. Articles were screened by title and abstract; those that were clearly not relevant were excluded. Two authors screened all 1372 studies by title and abstract, decisions were assessed blindly, and any conflicts were resolved via discussions. The remaining 70 studies were read in full and eligibility was assessed by application of the inclusion and exclusion criteria. All authors agreed each stage of the study selection process. Most of the reasons for excluding articles were objective (see figure 1). Unanimous decisions from all authors were sought when discussing any ambiguous studies in relation to the inclusion/ exclusion criteria.

Forward and backward reference checking produced an additional three studies. Forward tracking citations were completed using Scopus and an additional original article was identified. On full-text review none of these articles met the review inclusion criteria.

Figure 1 shows the PRISMA diagram detailing the screening and identification process for the inclusion of papers for the review. Overall, 26 studies met the inclusion criteria, including 528 autistic participants.

Figure 1. PRISMA Diagram showing search strategy; adapted from Moher et al. (2009)

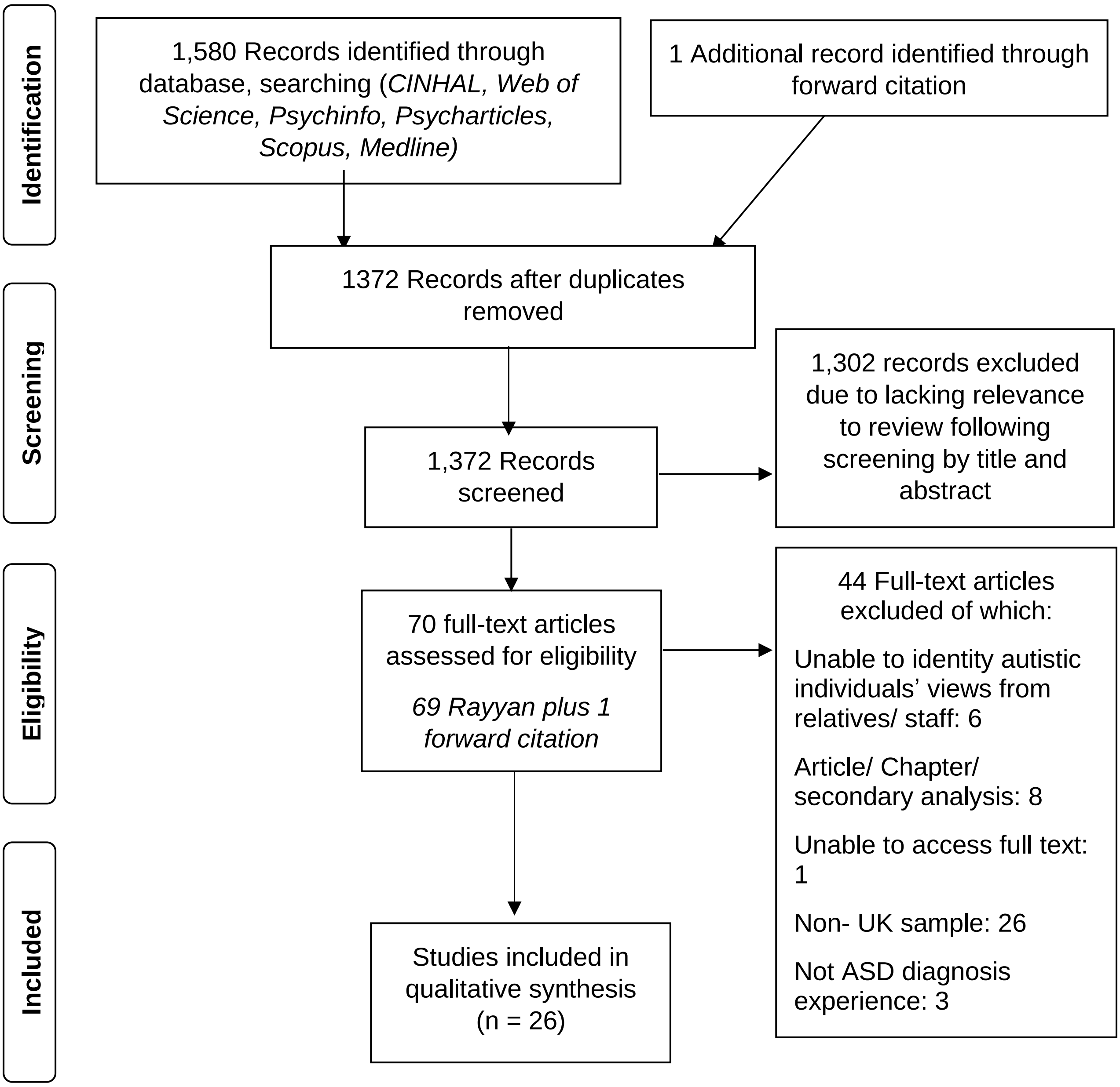


Table 2 presents summaries of the characteristics of the papers included in this systematic review. The studies range in publication dates from 2007 to 2021. Eighteen studies specified which UK country they were conducted, most reported England (N=14), and no authors specified Northern Ireland. Authors agreed in supervision discussions that only participants with a clinical diagnosis of autism could comment on the review's aim: autism diagnostic process in the UK. Therefore, samples including self-identified autistic individuals where the authors had not identified responses, thus preventing extraction of their data from the clinically diagnosed autistic participants, were excluded.

Most studies (n=20) collected data via interviews. The total number of clinically diagnosed participants across the studies totalled 528. One study did not report the number of focus group attendees; therefore the total number of participants included in the studies will be higher. From the studies that reported age, participants ranged in age from 9-71 years. Data regarding gender were available for 475 of the participants: 207 males, 267 females, and Mosely et al. (2020) reported one participant identifies as non-binary (Mosely et al., 2020). Powell and Acker (2016) reported 59% of the sample was male but did not confirm the remaining participants gender identities.

Most studies employed interpretative phenomenological analysis (n=10) or thematic analysis (n=9). Other approaches included framework analysis, open-ended exploration of lived experience account, multi-stage narrative analysis, ethnographic content analysis.

Quality Appraisal Results

Table 3 presents the critical appraisal summary of the included studies. Quality appraisal using the CASP checklist indicated that most studies achieved an overall moderate to good standard. Most studies did not meet the CASP criteria relating to relationship consideration and reflexivity (n = 11 did not meet; n = 8 unsure), limiting the transparency of the findings.

Table 2

Summary of study characteristics

Authors (Year)	Country	Participant characteristics	Recruitment	Data collection & Methodology	Key findings, themes
Bargiela et al. (2016)	U.K.	N= 14 autistic women	Via existing contacts in the research team, adverts on social media.	Semi-structured interview. Framework analysis.	Conflicts between ASC and a traditional feminine identity. Experiences of sexual abuse. Training would improve teachers' and clinicians' recognition of autism in women.
Ruiz Calzada et al. (2012)	U.K.	N=10 families, including 9 young people. Ages 9-16 years. 9 males. 6 diagnosed Asperger's, 3 high functioning Autistic Disorder	Specialist assessment clinic for high-functioning pervasive developmental disorder.	Semi-structured interviews 'Framework' approach	Advantages of diagnoses: increased understanding, practical support, and parental empowerment. Disadvantages: concerns around validity and stigma. Improvement of post-diagnostic services will improve the utility of autistic disorder and Asperger's disorder.
Camm-Crosbie et al. (2019)	U.K.	N= 200 autistic adults, 122 females, 77 males, 1 unreported. Aged between 18-67 years. Comorbid mental health diagnosis.	Online survey – recruited via local autism research database, charities, support groups, educational institutions, and social media.	Online survey Thematic analysis.	Overarching theme: individually tailored treatment and support was both beneficial and desirable. Recommendations for autism treatment pathways in mental health services.

Authors (Year)	Country	Participant characteristics	Recruitment	Data collection & Methodology	Key findings, themes
Crane et al. (2018)	England	N=30, 10 parents, 10 professionals. 10 autistic adults (9 Asperger syndrome), 6 women, 4 men. Age range 29-59 years. 9 participants diagnosed in adulthood.	Online survey	Semi- structured interview. Thematic analysis	Themes: the process of understanding and accepting autism, multiple barriers to satisfaction with the diagnostic process, inadequate post-diagnostic support provision.
Crane et al. (2021)	England	N=16; 9 participants had a formal diagnosis of ASD. Average age: 44.24 years, range from 18-71 years. 5 male, 11 female.	Online advertisements on autism interest group, local community website and word of mouth.	Brief questionnaire, Interviews immediately after the programme and 6 months later. Thematic analysis	*Motivation for attending the programme:* exploration of autism, empowerment, developing practical strategies and coping mechanisms. *Evaluation of the programme:* appreciation of the autistic-led nature of the programme, unity in diversity, developing a positive practical outlook on autism.
Dittrich & Burgess (2012)	England	N=255, 181 parents/ carers, 42 professionals, 30 people with autism diagnosis, or believed to have autism, 2 siblings.	Consultation via local autism partnership board.	Questionnaire. Ethnographic content analysis.	Recommendations for the council to take a life course approach to autism-related needs.

Authors (Year)	Country	Participant characteristics	Recruitment	Data collection & Methodology	Key findings, themes
Gaffney (2020)	England	N=6 autistic adolescent females, aged from 14-20 years old. Two participants were diagnosed in their teens, four participants were diagnosed under 11 years old.	Posters displayed in learning support departments in secondary schools.	Semi structured interviews. Interpretative phenomenological analysis	Some participants were unsure about the meaning of autism. Suggested that young people find autism diagnosis useful, but some reported the diagnosis can be harmful to personal identity.
Griffith et al. (2011)	Wales & England	N= 11 adults with Asperger syndrome, 7 males, 4 females. Ages ranged from 37-57 years.	Advertisements on websites of two autism charities and a Welsh research network.	Semi structured interviews. Interpretative phenomenological analysis	Themes: living with Asperger syndrome; employment issues; experiences with mainstream support; and future steps towards supporting adults with Asperger syndrome. Recommendations for tailored support for individuals.
Hickey et al. (2018)	England	N= 13, aged over 50 years. 10 male, 3 female	NHS adult autism diagnostic service, autism support and social groups in London.	Semi-structured interviews Thematic analysis	Themes: difference, life review and longing for connection. Highlight the need for improving access to diagnosis and reducing isolation.
Huws & Jones (2008)	Wales	N=9, 3 female, 6 males. Ages ranged from 16-21 years.	Specialist college for autism.	Semi structured interviews. Interpretative phenomenological analysis	The effects of the diagnosis or disclosure of diagnosis from the perspective of the person with autism be given greater consideration.

Authors (Year)	Country	Participant characteristics	Recruitment	Data collection & Methodology	Key findings, themes
Jones et al. (2013)	Wales	N= 9, 3 female, 6 males. Ages ranged from 16-21 years.	Specialist college for autism.	Semi structured interviews. Interpretative phenomenological analysis Secondary analysis by 'expert author'.	Complexity of interpersonal relationships, a desire to 'fit in' to a wider group, and a feeling of being regarded as 'different'. Expert author helped avoid a 'diagnostic overshadowing' interpretation of these findings.
Jordan et al. (2021)	England	N= 8, 7 males, 1 female, aged between 19-51 years old. Comorbid depression/ low mood.	Online advertisements in two university disability services and health and wellbeing department.	Semi structured interviews. Interpretative phenomenological analysis	Autism has made me the person I am', 'I can't function in the world' and 'It's like trying to do accounts on the futures market': Making sense of emotions. Findings highlight a need for specialist mental health provision for autistic adults.
Kanfiszer et al. (2017)	U.K.	N=7 autistic women diagnosed in adulthood. Three participants also had an intellectual disability. Comorbid mental health diagnoses. Aged between 20-59 years old.	Community mental health services, an inpatient service, community support group.	Semi structured interviews. Multi-stage narrative analysis.	Gender identity and social relationships. Participants drew upon notions of 'normalcy' in how they internalized a representation of the self. Nonconformity with cultural expectations of feminine results in questions around gender identity.

Authors (Year)	**Country**	**Participant characteristics**	**Recruitment**	**Data collection & Methodology**	**Key findings, themes**
Kock et al. (2019)	England	N= 8 autistic women diagnosed in adulthood (within 5 years prior to the study), aged between 20-40 years old.	Two specialist ASD diagnostic clinics and an advertisement in the National Autistic Society newsletter.	Semi structured interviews. Interpretative phenomenological analysis	Themes: “Response to the diagnosis and receiving more information about autism” , “Factors influencing dating behaviour”, “Sex and sexual experiences” and “Experience of intimate relationships as a person with autism
Leedham et al. (2020)	England	N=11 autistic women who received their diagnosis ages 40 years or older.	NHS adult autism diagnostic service	Semi structured interviews. Interpretative phenomenological analysis	Themes: a hidden condition, the process of acceptance, the impact of others post-diagnosis. Change in identity enabled greater acceptance and self-understanding, but painful to adjust at later stage of life.
MacLeod et al. (2018)	U.K.	N= 16, 10 males, 6 females.	Via student support departments at five higher education institutions.	Semi structured interviews. Interpretative phenomenological analysis	The autism diagnosis was perceived both as an aid to self-understanding and a cause of additional barriers. Recommendations for a more inclusive higher education curriculum and environment.
Markham (2018)	England	N=1 autistic woman	Review and commentary on the author’s lived experience of ASD diagnosis as a patient in	Open-ended exploration of lived experience account/ case study.	Encourage practitioners to be inclusive of patient perspective when completing diagnostic assessment.

			a secure, forensic hospital.		Recommends future research into the diagnostic assessment of females for ASD in secure, forensic hospitals.
Milner et al. (2019)	U.K.	N=22, 18 autistic females and 4 mothers of autistic females. 16 autistic females had a clinical diagnosis of autism, 2 were self-diagnosed. Ages ranged from 11-55 years.	Adverts on social media, word of mouth, through contacts at a secondary school and through a tertiary referral autism diagnostic clinic.	Group and individual discussions. Thematic analysis	Themes: fitting in the with the norm; potential obstacles for autistic women and girls; negative aspects of autism; the perspective of others; and positive aspects of having autism. Clinical implications: improved awareness, diagnosis and support for autistic women and girls.
Moseley et al. (2020)	U.K.	N= 17 (16 identified as cis gender women). 7 participants self-diagnosed autism.	Adverts on two Facebook support groups run by and for autistic people.	Semi structured interviews. Inductive thematic analysis guided by IPA.	Themes: covering the long journey of our participants to recognizing autism in adulthood; menopausal awareness and perceptions; symptoms and their impact; and ways that a neurodiverse menopause might differ from the norm.
Myles et al. (2019)	England	N= 8 autistic females aged 12-17 years old.	Contact with Special Educational Needs Coordinators in secondary and middle schools.	Semi structured interviews. Thematic analysis.	Themes: perceived peer acceptance; friendship and social competence. Autistic adolescent females are socially motivated to form friendships.

Authors (Year)	**Country**	**Participant characteristics**	**Recruitment**	**Data collection & Methodology**	**Key findings, themes**
Price et al. (2017)	England	N=10, 3 trainee medics doctors with Asperger syndrome.	Professional support unit for trainee doctors.	Semi-structured interviews. Thematic analysis.	Themes: the diagnosis as a double-edged sword, developing insight into problem, and the effect of disclosing the diagnosis. Highlighted widespread misunderstanding of Asperger's syndrome, and how fear of exposing weaknesses may prevent trainees seeking support.
Powell & Acker (2016)	England	N= 74 Average age 36.08 years, 59% male participants.	Adult Asperger syndrome diagnostic clinic	Opened ended questions on feedback form. Thematic content analysis.	Participants described relief the diagnosis, as it provided an alternative explanation for social and emotional difficulties. Externalizing blame from self to autism.
Pushon et al. (2009)	England	N=10, 7 male, 3 female. Age from 22-45 years. Age at Asperger's diagnosis ranged from 21-44 years.	Local service for adults with Asperger syndrome.	Semi structured interviews. Interpretative phenomenological analysis	Themes: negative life experiences; experiences of services (pre-diagnosis); beliefs about symptoms of Asperger syndrome; identity formation; effects of diagnosis on beliefs; effect of societal views of Asperger syndrome. Highlighted the importance of the societal view of Asperger syndrome. Recommendations for post diagnostic support.

Authors (Year)	Country	Participant characteristics	Recruitment	Data collection & Methodology	Key findings, themes
Stagg & Belcher (2019)	U.K.	N= 9, 5 female, 4 male, aged between 52-54 years old. Majority received their diagnosis within two years of the study.	Online autism forums and messages posted on a blog run by the second author.	Free-associative narrative interview. Thematic analysis.	Diagnosis was described as a positive and allowed for a reconfiguration of self and an appreciation of individual needs. Recommendations for identifying older adults with undiagnosed autism.
Rodgers et al. (2019)	England & Scotland	N=23 autistic adults 12 male, 11 female. Age range 18-64. Age of diagnosis range 2.5-62 years. Diagnosis: autism (n=2). Asperger's (n=16), ASD (n=6)	Autism charities and support groups.	Four focus groups. Transcripts analysed with thematic analysis	Overarching theme about the uncertainty about what the future may hold. Implications for social work practice. Lack of autism-specific knowledge identified as barrier to employment and health care.
Townson et al. (2007)	England	N=4 interview participants. Two focus groups but attendees not reported.	Attendance at autism conferences, local autism groups and email contact.	Interviews, focus groups and observations.	Themes: late diagnosis and lack of support services; unfortunate experiences within the system of care; feelings of not belonging and issues of identity; barriers to communication and sensitivity. Highlighted challenges of late diagnosis including impact on mental health and suggested the need for advocacy for autistic adults.

Table 3

Quality appraisal results

Authors (year)	Clear aims stated	Qualitative methodology appropriate	Research design appropriate	Recruitment strategy appropriate	Data collection appropriate	Relationship and reflexivity	Ethical considerations	Rigorous data analysis	Findings clearly stated	Value of research
Bargiela et al. (2016)	✓	✓	✓	✓	✓	?	✓	✓	✓	✓
Ruiz Calzada et al. (2012)	?	✓	✓	✓	✓	x	✓	✓	?	✓
Camm-Crosbie et al. (2019)	✓	✓	✓	✓	✓	✓	✓	?	✓	✓
Crane et al. (2018)	✓	✓	✓	✓	✓	x	✓	?	✓	✓
Crane et al. (2021)	✓	✓	✓	✓	✓	?	✓	✓	✓	✓
Dittrich & Burgess (2012)	✓	✓	?	?	?	?	?	?	?	✓
Gaffney (2020)	✓	✓	✓	✓	✓	?	✓	✓	✓	✓

Authors (year)	**Clear aims stated**	**Qualitative methodology appropriate**	**Research design appropriate**	**Recruitment strategy appropriate**	**Data collection appropriate**	**Relationship and reflexivity**	**Ethical considerations**	**Rigorous data analysis**	**Findings clearly stated**	**Value of research**
Griffith et al. (2012)	✓	✓	✓	✓	✓	x	✓	✓	✓	✓
Hickey et al. (2018)	✓	✓	✓	✓	✓	x	✓	✓	✓	✓
Huws & Jones (2008)	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓
Jones et al. (2013)	✓	✓	✓	✓	✓	✓	✓	✓	✓	?
Jordan et al. (2021)	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓
Kanfiszer et al. (2017)	✓	✓	✓	✓	✓	?	✓	✓	✓	✓
Kock et al. (2019)	✓	✓	✓	✓	✓	?	✓	?	✓	✓
Leedham et al. (2020)	✓	✓	✓	✓	✓	?	✓	✓	✓	✓
MacLeod et al. (2018)	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓
Markham (2018)	✓	✓	?	?	x	x	x	x	?	?
Milner et al. (2019)	✓	✓	✓	✓	✓	?	✓	✓	✓	✓

Authors (year)	**Clear aims stated**	**Qualitative methodology appropriate**	**Research design appropriate**	**Recruitment strategy appropriate**	**Data collection appropriate**	**Relationship and reflexivity**	**Ethical considerations**	**Rigorous data analysis**	**Findings clearly stated**	**Value of research**
Moseley et al. (2020)	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓
Myles et al. (2019)	✓	✓	✓	✓	✓	x	?	?	✓	✓
Price et al. (2017)	✓	✓	?	✓	✓	x	✓	?	✓	✓
Powell & Acker (2016)	✓	✓	?	✓	?	x	?	✓	✓	✓
Pushon et al. (2009)	✓	✓	✓	✓	✓	x	✓	✓	✓	✓
Stagg & Belcher (2019)	✓	✓	✓	?	✓	✓	✓	✓	✓	✓
Rodgers et al. (2019)	✓	✓	✓	✓	✓	x	✓	?	✓	✓
Townson et al. (2007)	✓	✓	x	x	?	x	x	x	✓	✓

Note ✓=yes; x = no; ?= unclear.

Thematic Synthesis

There were 57 codes in the ‘bank of codes’ (Appendix D) and 9 descriptive themes (Appendix E). Analysis of the data revealed three superordinate themes: *‘Negotiating Self-identity’*, ‘*Feeling Misunderstood’,* and *‘Support Post-Diagnosis’*. The identified themes summarise the themes across the included studies, the themes do not provide an exhaustive list of participants’ experiences. Participants’ quotes are provided to illustrate the themes and ‘…’ represents when quotes have been edited.

Table 4

Super-ordinate and Sub-themes

Super-ordinate themes	Sub-themes
Negotiating self-identity	Distressing assessment process
	Conflicting emotions towards diagnosis
	Neurodiversity
	Self-reflection and self-kindness
Feeling misunderstood	Autism is misunderstood
	Social challenges
	Mental health impact and misdiagnosis
Support post-diagnosis	Increased support and understanding
	Connection and validation

Negotiating self-identity

This super-ordinate theme describes how participants make sense of their autism diagnosis, how it relates to their identity and the range of emotional experiences involved.

Distressing assessment process. Stigma was reported as a barrier to seeking an assessment.

> *“Asperger syndrome was coming out into the world but they didn’t . . . they didn’t want a label” (Pushon et al., 2009, p. 274).*

Only one study described positive reflections on the assessment process:

> *"A couple of people with autism said they received an excellent service" (Dittrich & Burgess, 2012, p.299).*

Across the studies most participants reported feeling dissatisfied with the autism assessment and suggested the process was emotionally draining:

> *"I felt really scrutinised, I felt so vulnerable… it didn't feel very friendly, a bit soul destroying" (Crane et al., 2021, p.897).*

A participant in the Crane et al. (2018) study reflected on the age appropriateness of the assessment materials and suggested the assessment process felt patronising at times.

> *"I've spoken to a lot of people on forums who feel exactly the same way, that they're kinda aimed at children…I didn't particularly feel like a 40-year old being questioned." (Crane et al., 2018, p. 3767).*

Participants also reported the negative focus of the assessments*; "Nobody wants their negative side highlighted all the time" (Crane et al., 2018, p.3766)*, and feeling unsupported during the process:

> *"I found it quite traumatic…they [professionals] are dredging up old stuff…then you're just left to work all that out for yourself." (Crane et al., 2018, p. 3768).*

It is noteworthy that most of these reflections were from participants diagnosed in adulthood. Arguably, adults would be more acutely aware of the assessment process and potentially sought their diagnosis themselves. The experience of receiving an autism diagnosis in childhood may differ to assessments in adulthood, particularly if children are not fully informed of the process.

Some studies specifically explored women's experiences of the autism diagnosis process, similar reports of dissatisfaction and the emotional impact of assessments were reported:

> *“Negative experiences were reflected by the majority of the women... ‘We headed to the nearest café and cried, cried, cried for a day; […] it was the most awful, awful experience’” (Milner et al., 2019, p.2396).*

Participants also reflected on gender differences and the impact of compensatory behaviours on assessments.

> *“That’s the trouble with female ASD is in that time slot of whether they’re going to say yes or no to your diagnosis you could be performing or camouflaging” (Milner et al., 2019, p.2396).*

Conflicting emotions towards diagnosis. Most studies described a range of emotional responses to receiving an autism diagnosis. Often participants reported positive reactions:

> *“It really was like a sort of eureka moment … it was kind of a relief” (Stagg & Belcher, 2019, p.353).*

Similarly, some participants described the positive impact the diagnosis had on their sense of self and identity;

> *“I was happy . . . I feel validated . . . liberated.” (Powell & Acker, 2016, p.75).*

Interestingly, participants’ responses often related to relief that they were able to explain themselves to others and suggested previous experiences of discrimination:

> *“Yeah… [since the diagnosis]…I can like say to people if they say something that isn’t very nice - give a reason to them for why I am the way I am” (Kock et al., 2019, p.44).*

Comparatively, in some studies, positive feelings towards the diagnosis were juxtaposed with feelings of shock*: “I didn’t believe it at first, because I didn’t think I had that” (Huws & Jones, 2008, p.102)* and a sense of grief, reflecting how the diagnosis is lifelong:

> *“I am never going to be like one of these ‘normal’ people . . . ‘I am stuck being like this now.” (Pushon et al., 2009, p.278).*

These quotes describe participants feeling different due to their diagnosis and *“at first”* suggests stages of emotional responses to their diagnosis, reflecting the complexity of emotions involved. The literature also highlighted participants’ concerns about their diagnosis disclosure:

> *“Relieved at first but I am now starting to see how difficult it can be having AS, not least the disclosure issue” (Powell & Acker, 2016, p.75).*

A participant in Stagg and Belcher (2019) study alluded to regretting seeking his diagnosis:

> *“if I hadn’t bothered finding out what Asperger’s was, I would have just been this lonely person who just carried on. I sometimes wonder whether I should have, is it a bad thing to have had, the diagnosis.” (Stagg & Belcher, 2019, p.355).*

Participants that received their diagnosis in adulthood often described feelings of *“sadness for their pre-diagnosis self” (Leedham et al., 2020, p.140)*.

> *"…having to, psychologically, on your own, reassess your whole life. And at the age of 53 it’s going back a long way". (Hickey et al., 2018, p. 361).*

Participants reflected on past difficulties and suggested that their lives would have been improved with earlier diagnosis:

> *“…if I had known, and if people had helped me from earlier on, then life would’ve been a whole lot easier.’’ (Bargiela et al., 2016, p. 3286).*

Studies with younger participants more commonly reported feelings of anger or avoidance when asked to reflect on their feelings towards their diagnosis:

> *“if I had a choice between not existing and having this [diagnosis] I would choose not existing, because I hate it so much...” (Gaffney, 2020, p.142).*

Two studies described participants feeling “*indifferent*” to learning about their diagnosis: *“I’m not that interested [in the meaning of the diagnosis]” (Ruiz Calzada et al., 2012, p. 235).*

Two studies also described participants who disagreed with their autism diagnosis*:*

> *“Melody refuted the validity of her autism diagnosis as she did not see herself as different to peers”* (*Gaffney, 2020, p.142)*.

The literature highlights the range of emotional responses participants described in relation to their diagnosis, including validation, relief, grief, and anger, illustrating the individuality of the diagnostic experience.

Neurodiversity. In half the studies, participants compared themselves with the neurotypical “normal” and described efforts to meet societal expectations:

> *“….[when I] appear sort of normal, that is because of the years of actual effort that I’ve put into it.”(Leedham et al., 2020, p.141).*

Participants reflected on society’s intolerance of difference and experiences of rejection by deviating from the norm,

> “*for people with an ASC it is likely that they will be rejected by society because we don’t fit in … The idea of what normal … is shrinking [and] more and more people are being excluded from society” (Camm-Crosbie et al., 2019, p.1437).*

Participants discussed the non-social challenges associated with autism,

> *“my behaviour’s been quite bad because of autism… like having trouble with spelling and maths… and things like can’t do the job you exactly want to do like because of it.” (Jones et al., 2013, p.103).*

Comparatively, in over a quarter of studies, participants celebrated the strengths and unique qualities of autism;

> *“Ryan also attributed his positive personality traits, such as being ‘honest’ and ‘moralistic’, to being autistic.” (Jordan et al., 2021, p.1688).*

Participants reflected on the range of needs and experiences associated with autism, highlighting the individuality of experience. The heterogeneity in experience presents challenges for appropriate support.

> “*I feel ‘lost’… I am too high functioning for most ASD programming in my area, but not neurotypical enough to function well in conventional work and social situations. (Camm-Crosbie et al., 2019, p.1435).*

Self-reflection and self-kindness. Across the studies, participants reported that their diagnosis helped make sense of difficult past experiences, especially when the diagnosis was receiving in adulthood:

> *“Suddenly the first fifty years of my life made sense” (Hickey et al., 2018, p.361).*

In most of the studies, participants described developing greater self-understanding and feeling less critical towards themselves after receiving their autism diagnosis.

> *“…Now I understand why I’ve felt the way I have a lot of the time and why I’ve been the way I am a lot of the time as well.” (Leedham et al., 2020, p.140).*

Alongside self-understanding, participants described taking a non-blaming approach towards their differences,

“I feel better about myself because . . . I know it’s not my fault.” (Powell & Acker, 2016, p.77), often by externalising their autism, “*it’s just a symptom of a neurological condition and not something that is innately wrong with your character, that makes it a lot easier” (Crane et al., 2021, p.899)*.

In a quarter of studies, participants reported researching autism, both pre- and post-diagnosis, to develop their understanding. In some studies, participants' research developed a critical view of traditional theories of autism and highlighted misconceptions of autistic women:

> *"Having researched ASD, she spontaneously and firmly, rejected the Extreme Male Brain Theory (e.g. Baron-Cohen, 2002).'… I definitely don't have the extreme male brain … lots of other women I know and myself are living proof that we're definitely not extreme males …" (Kanfiszer et al., 2017, p. 665).*

Feeling misunderstood

This super-ordinate theme explores participants' interpretations of how autism is conceptualised in society and considers the impact on their well-being.

Autism is misunderstood. Across the studies, participants reflected on experiences of feeling misunderstood by others and related this to society's limited understanding of autism, often underpinned by unhelpful stereotypes of autism,

> *"I'll always remember my special needs teacher saying I'm too poor at maths to be autistic." (Bargiela et al., 2016, p.3286)*.

The experience of feeling misunderstood negatively impacted participants' self-esteem, social experiences, and employment opportunities. In some studies, the participants spoke about wanting to improve other people's understanding of autism by educating others or participating in research.

> *"I don't think they know what Asperger's syndrome is [laughs] but I have told them anyway… She said I was staring at her and I said 'Sorry, I have got Asperger syndrome' and she went 'You must be clever then'. (Pushon et al., 2009, p.280).*

The studies reported limited understandings from professionals, at times creating barriers to assessment and a scarcity of appropriate post-diagnostic support, particularly for adults:

> *"When I went to my GP I said, 'Could you refer me to somebody, because I'd like to look into getting a diagnosis for Asperger syndrome.'…he said, 'Asperger's, isn't that something that kids get?' Which really, really shocked me, I stood up, and said 'What happens to those children, do they not grow into adults?" (Griffith et al., 2012, p.541).*

Social challenges. Across the studies, participants reflected on social challenges, feeling different from peers and experiences of victimisation:

> *"I got bullied because I was different" (Jones et al., 2013, p.139).*

Participants also reported dismissive responses from others following their diagnosis disclosure:

> "'*You don't have autism, you're perfect. There's nothing wrong with you.'….he thinks I'm his perfect little girl….who's got nothing wrong with her, so I can't talk to him about if I've had a bad day." (Leedham et al., 2020, p.141).*

Gender differences were raised by participants in two studies, including "masking". Participants also suggested the social challenges and expectations were greater for autistic women than autistic men:

> *"Boys are more content to be themselves… whereas the girls really want to fit in, um, and I think that makes them unhappier…I think it's harder, much harder as a girl because girl peers are less forgiving of other girls. The girls seem to be very tolerant of the boys with autism and almost mother them" (Milner et al., 2019, p.2394).*

Mental health impact and misdiagnosis. A fifth of studies reported participants accessing mental health services, highlighting the co-occurrence of mental health issues,

> *"… I become very easily depressed and that is because I have Asperger's – because I haven't got the protection." (Griffith et al., 2012, p.537).*

Participants also expressed frustrations towards the inappropriate mental health misdiagnoses they received before their autism diagnosis. One participant in Leedham et al. (2020) described the power imbalance between professionals imposing unhelpful mental health diagnoses:

> *"I was almost convinced that they wanted to be right and I'd actually buried some deep trauma and I had no memory of it and I started questioning the whole – like everything." (Leedham et al., 2020, p.139).*

Some studies discussed the validation participants felt when their autism diagnosis replaced previous mental health diagnoses:

> *"For years and years everything has been put down to anxiety and depression. Everything from the last 30 years made sense, it just all fitted in and it made sense" (Stagg & Belcher, 2019, p.353).*

This quote highlights the potential for diagnostic overshadowing, where professionals hold a reductionistic view on an individual's behaviours, in these participants' experiences, neglecting the possibility they could be autistic. Similarly, a participant in Macleod et al. (2018) reflected on attempting to understand her anxiety, "AS" refers to Asperger's Syndrome.

> *"Would somebody classed as normal do the same thing… Is my anxiety AS or is my anxiety what a normal person would have." (Macleod et al., 2018, p.690).*

Support post-diagnosis

This super-ordinate theme explores the helpful responses and supportive outcomes that some participants experienced after receiving their autism diagnosis.

Increased support and understanding. Despite some participants reporting post-diagnostic support is limited, over a quarter of studies suggested that participants found increased support following diagnosis disclosure:

> *"Several participants experienced tailored and helpful support, with many describing supportive adaptations at work" Leedham et al., 2020, p.141)*.

Including statutory services, *"It helped me get help from social services" (Powell & Acker, 2016, p.77)*, and increased understanding from others:

> *"After getting the diagnosis mom … explained all of my stresses…I then passed them [exams] which proved it was the environment rather than my learning skills" (MacLeod et al., 2018, p.689).*

Connection and validation. Many studies reported that participants found increased understanding from autistic people and joined autism groups following their diagnosis:

> *"…talking to each other about our experiences… you feel legitimised by other people having the same experiences, so it means you're not just one weird outpost" (Crane et al., 2021, p.898).*

A fifth of studies reported on the genetic aspect of autism. Participants suggested that recognising their shared family experiences developed greater understanding of individual needs and instigated some participants' autism assessments:

"The diagnosis process brought into light that my father and grandfather had quite similar developmental histories to me…It was also quite a bonding experience for the male line in my family…later on, my brothers went through a similar process." (Crane et al., 2018, p.3769).

Discussion

This review aimed to identify, appraise, and thematically synthesise the available qualitative literature to provide a detailed understanding of autistic individuals' experiences of the autism diagnostic process in the UK. Three super-ordinate themes were identified: *‘Negotiating self-identity’, ‘Feeling misunderstood’*, and *‘Support post-diagnosis’*.

The first super-ordinate theme, *‘Negotiating self-identity’,* describes how the autism diagnostic process impacts individuals’ sense of self and relationships with others and highlights this process is not linear. Dissatisfaction with the assessment process was widely reported and described as distressing, with limited support, and a deficit focus (e.g., Milner et al., 2019; Crane et al., 2021). This super-ordinate theme illustrates the diversity in emotions that participants experienced as part of their diagnostic process, including relief (e.g., Stagg & Belcher, 2019; Pushon et al., 2009), anger (e.g., Gaffney, 2020) and indifference (e.g., Powell & Acker, 2016). In many of the studies, participants reported developing self-understanding compared to their previous self-criticism. This finding is consistent with Leedham et al.’s (2020) research, where several autistic women suggested their diagnosis in adulthood facilitated a transition from self-criticism to self-compassion. Interestingly, Howes et al. (2020) reported that autistic traits are negatively correlated with self-compassion in men and women. Future research could explore autistic individuals’ experiences of self-compassion to develop understandings in this area. Reduced self-compassion may be explained by the social challenges commonly encountered by autistic individuals, also illustrated in this review. Dugdale et al.’s (in press) systematic review proposed that the social difficulties autistic individuals experience is related to their ‘minority status’ in society rather than autism. In half the studies, participants compared themselves with the neurotypical “normal”. This super-ordinate theme illustrates the process of adjusting to a new identity on the spectrum.

The second super-ordinate theme, *‘Feeling misunderstood’,* highlights participants’ experiences of the limited understanding of autism and the subsequent impact on well-being. Several participants reported common unhelpful stereotypes of autism; this is consistent with other research where stereotypes consistently present autistic individuals as “weird” (Treweek et al., 2019), adding to feeling not normal (e.g., Hickey et al., 2017). Participants of all ages reported multiple experiences of victimisation (e.g., Pushon et al., 2009; Jones et al., 2013); this is also consistent with previous literature (Treweek et al., 2019; Weiss & Fardella, 2018). Unsurprising, mental health difficulties were discussed; adult participants also referred to experiences of misdiagnosis (e.g., Stagg & Belcher, 2019; Leedham et al., 2020). Previous research suggests that autistic women's needs are commonly misattributed to different diagnoses (Attwood, 2007; Eaton, 2018). Research suggests mental health issues commonly co-occur with autism, with one study reporting that 79% of autistic adults met diagnostic criteria for a mental health condition (Lever & Geurts, 2016).

Inappropriate, 'one size fits all' approaches to support and limited understanding from professionals neglects the heterogeneity in autistic individuals' needs (e.g., Crane et al., 2018). Gender differences were also discussed about the diagnostic process; autistic women reported masking and camouflaging in social situations. Other research has described how these compensatory behaviours can be a barrier to autism diagnosis (Hull et al., 2017) and can negatively impact mental health (Bargiela et al., 2016). Participants in Milner et al. (2019) suggested that society was more accepting of autistic males, than autistic females. Acceptance of autistic males may be related to higher diagnosis rates in males, with approximately three times more males than females (Loomes et al., 2017), with women commonly reporting barriers to autism assessment (Lewis, 2017). This super-ordinate theme highlighted social challenges, gender differences and the impact these experiences can have on autistic individuals' mental health.

The third super-ordinate theme, '*Support post-diagnosis',* presents the beneficial outcomes that some participants experienced as part of the diagnosis process. Connection with others in the autistic community created a sense of validation and understanding that participants had not experienced pre-diagnosis (Bargiela et al., 2016). This theme is consistent with previous research, with newly diagnosed participants describing themselves as finding a new community post-diagnosis (Tan, 2018). Similarly, Crompton et al. (2020) highlighted the benefits of peer support for autistic adults and the need for autistic-led social activities. A fifth of studies reported on the genetic aspect of autism; this facilitated understanding of relationship needs (e.g., Kock et al., 2019) and instigated some participant's autism assessments (e.g., Pushon et al., 2009). Most participants described limited post-diagnosis support, however some participants reported increased understanding from friends, family, and employers (e.g., Leedham et al., 2020; MacLeod et al., 2018). This super-ordinate theme illustrates some positive outcomes post-diagnosis.

This review extends previous research findings by providing distinct themes and an in-depth account of the literature investigating autistic individuals' experiences of the diagnostic process in the UK.

Summary of Methodological Quality in Studies

Spencer and Ritchie (2011) proposed guiding principles for assessing the quality of qualitative research: contribution, credibility, and rigor. Most studies adhered to these principles, e.g., provided illustrative verbatim quotes defending the plausibility of identified themes. Similarly, most studies also provided valuable recommendations for clinical practice and clear rationales for their chosen methods. All studies were included in the synthesis regardless of quality.

The most common methodological limitation identified across studies was the limited reporting of reflexivity, however this is only an issue for interpretative approaches. Most authors provided a description of the epistemological standpoint of the study (e.g., Gaffney, 2020). When the epistemological standpoint was not reported, it was challenging to accurately evaluate the underpinning theory of the study.

Authors reported expert by experience involvement in developing interview questions (e.g., Leedham et al., 2020). In one study, Jones et al. (2013) employed an expert author for analysis. Service user involvement in autism research is important given the 'double empathy problem' (Milton, 2012), describing the possible mutual misunderstandings between neurotypical and autistic people, potentially threatening the authenticity of qualitative data.

Clinical Implications

This review highlights several clinical implications and suggestions to improve understandings of autism. Participants commonly reported limited understanding from professionals, creating barriers to assessment and appropriate support. Research with autistic women that received their diagnosis in adulthood suggested that their lives may have been different if they had received their diagnosis earlier, including prevention of mental health issues and social challenges (e.g., Bargiela et al., 2016; Leedham et al., 2020). These findings highlight the importance of early identification and support, especially for women. Dissatisfaction with the assessment process was also reported, consistent with previous research (Jones et al., 2014). These findings illustrate the need to review the current assessment process; involving autistic individuals in service development and evaluation could be a useful starting point. Most participants diagnosed in adulthood described the deficit focus of assessments (e.g., Crane et al., 2021; Milner et al., 2019); it is recommended that clinicians recognise personal strengths in the diagnostic process.

This review highlights the need for further training for professionals in primary care, mental health services, schools, and other agencies to support all individuals and reduce the unmet needs of autistic girls and women. Training and support should be provided by autistic individuals where possible, Crane et al. (2021) reported high levels of satisfaction from an autistic-led programme. This finding echoes participants' suggestions about educating others about autism and participation in research (Powell & Acker, 2016; MacLeod et al., 2018).

Connection and validation within the autistic community were commonly reported by participants (e.g., Bargiela et al., 2016; Crane et al., 2021), highlighting the benefits of peer support. With this knowledge, professionals should signpost to autism support groups. Caution is recommended to ensure professionals do not assume all autistic individuals will want to access this support.

The review emphasises the range in autistic individuals' experiences of the diagnostic process and the prejudice often reported. Promoting autism awareness in all settings and encouraging inclusion in society may support a move to celebrating difference. This finding is consistent with Dugdale et al.'s (in press) review, recommending that autistic adults would benefit from services that hold a narrative of 'difference', opposed to 'disability'. Future research could evaluate the efficacy of inclusion/ autism awareness strategies that challenge the 'disability' narrative.

Limitations and Future Research Directions

Participants varied in the time since their autism diagnosis, e.g., Hickey et al. (2018) reported an average six years before the study, Stagg and Belcher (2019) reported an average of two years before the study. Comparatively, Gaffney (2020) included participants that received their diagnosis before their 11th birthday. Four studies included participants under 16 years old, this suggests there is limited research exploring children's experiences of the diagnostic process for autism in the UK.

This time variation may have impacted the participants' experience of the diagnostic process. Similarly, the diagnostic process is unlikely to be consistent across service providers. The studies also varied in publication dates from 2007-2021, this includes the DSM-5 (2013) change to the diagnostic criteria, and there may have been inconsistencies in practice adapting to this revision.

Most studies were conducted in England (N=14) and no authors specified any recruitment from Northern Ireland. Further research in Northern Ireland, Scotland and Wales will provide greater detail about the autistic diagnostic process in the UK. Few studies reported participants' ethnicity; those that did (e.g., Hickey et al., 2018) described the participants as 'white'. Autistic individuals identifying from other ethnic backgrounds may report different experiences of the diagnostic process. The National Autistic Society (2014) report stated that ethnic minority communities face additional challenges to obtaining autism diagnoses and support. The report also highlighted the scarcity of research about ethnic communities' experiences of autism and this presents an important consideration for future research.

This review attempted to investigate how the experience of the autistic diagnostic process varied between childhood and adulthood. Younger participants commonly reported feelings of anger or avoidance when asked to reflect on their feelings towards their diagnosis (e.g., Gaffney, 2020). However, this review did not obtain sufficient data to answer this question clearly. Future research could attempt to explore these potential differences.

Only one study reported that three participants had a diagnosed intellectual disability (e.g., Kanfiszer et al., 2017). This presents limited developmental diversity across the data and highlights a need for future research to include participants with intellectual disabilities. This is consistent with previous research recommendations to understand how the experiences of autistic individuals vary by age, gender, symptom severity and socio-demographic factors (DePape & Lindsay, 2016).

Attempts were made to contact the authors of two articles as it was unclear whether both articles drew on the same data set (Jones et al., 2013, and Huws & Jones, 2008). No response was received, and this concern was discussed in supervision. The decision to include both studies was based on the different themes identified and the 2013 paper using an alternative form of analysis (secondary analysis by 'expert author').

Conclusions

This is the first meta-synthesis of autistic individuals' experiences of the diagnostic process in the UK. The findings can inform clinicians and policymakers about factors impacting autistic individuals' experiences. Factors include barriers to assessment, scarcity of appropriate post-diagnostic support and the impact of a deficit-focused assessment process on individuals' well-being. In response to the review question considering how an autism diagnosis impacts individuals' sense of self and relationships with others, findings present the process of adjusting to a new autistic identity as dynamic, with a range of complex emotional responses. In many cases, the diagnosis facilitated self-understanding and a non-judgemental approach to difficulties. Experiences of connection and validation from the autistic community supported participants' well-being. The findings from this review highlight wider societal issues around misconceptions of autism and the impact on mental health.

In response to the review question considering the influence of gender and the diagnostic process, autistic women reported limited professional understanding as barriers to assessment. There was insufficient data to conclude on the influence of non-binary categories of gender and the diagnostic process. There was also insufficient data to compare the lived experience of receiving an autism diagnosis in childhood or adulthood, further research exploring children's experiences of the diagnostic process for autism is needed. Recommendations are suggested to improve autism awareness and ways to address these misunderstandings employing a participatory approach to research, training, and service development.

References

American Psychiatric Association. (2013). *Diagnostic and statistical manual of mental disorders* (5th ed.). American Psychiatric Publishing.

Attwood, T. (2007). The pattern of abilities and development of girls with Asperger's syndrome. In T. Attwood, & T. Grandin (Eds.), *Asperger's and girls* (pp. 1-6). Texas, USA: Future Horizons.

Baghdadli, A., Russet, F., & Mottron, L. (2017). Measurement properties of screening and diagnostic tools for autism spectrum adults of mean normal intelligence: A systematic review. *European Psychiatry*, *44*, 104-124. https://doi.org/10.1016/j.eurpsy.2017.04.009

Bargiela, S., Steward, R., & Mandy, W. (2016). The experiences of late-diagnosed women with autism spectrum conditions: An investigation of the female autism phenotype. *Journal of Autism and Developmental Disorders*, *46*, 3281-3294. https://doi.org/10.1007/s10803-016-2872-8

Barnett-Page, E., & Thomas, J. (2009). Methods for the synthesis of qualitative research: a critical review. *BMC Medical Research Methodology*, *9*, 1-11. https://doi.org/10.1186/1471-2288-9-59

Baron-Cohen, S. (2002). The extreme male brain theory of autism. *Trends in Cognitive Science 6,* 248–254. https://doi.org/10.1016/S1364-6613(02)01904-6

Booth, A. (2004). Formulating answerable questions. In Booth, A & Brice, A (Eds) *Evidence Based Practice for Information Professionals: A Handbook.* (pp. 61-70) London: Facet Publishing.

Booth, A., Noyes, J., Flemming, K., Gerhardus, A., Wahlster, P., van der Wilt, G. J., Mozygemba, K., Refolo, P., Sacchini, D., Tummers, M., & Rehfuess, E. (2018). Structured methodology review identified seven (RETREAT) criteria for selecting qualitative evidence synthesis approaches. *Journal of Clinical Epidemiology*, *99*, 41-52. https://doi.org/10.1016/j.jclinepi.2018.03.003

Brugha, T., Cooper, S. A., McManus, S., Purdon, S., Smith, J., Scott, F. J., Spiers, N., & Tyrer, F. (2012). *Estimating the Prevalence of Autism Spectrum Conditions in Adults: Extending the 2007 Adult Psychiatric.* Retrieved from: https://data.gov.uk/dataset/e6871059-4f9c-4ab8-a21c-1be8e811a395/estimating-the-prevalence-of-autism-spectrum-conditions-in-adults-extending-the-2007-adult-psychiatric-morbidity-survey

Camm-Crosbie, L., Bradley, L., Shaw, R., Baron-Cohen, S., & Cassidy, S. (2019). 'People like me don't get support': Autistic adults' experiences of support and treatment for mental health difficulties, self-injury and suicidality. *Autism, 23,* 1431-1441. https://doi.org/10.1177%2F1362361318816053

Centre for Reviews and Dissemination. (2009). *Systematic reviews: CRD's guidance for undertaking reviews in health care.* York, UK: York Publishing Services Ltd.

Crane, L., Batty, R., Adeyinka, H., Goddard, L., Henry, L. A., & Hill, E. L. (2018). Autism diagnosis in the United Kingdom: Perspectives of autistic adults, parents and professionals. *Journal of Autism and Developmental Disorders*, *48*, 3761-3772. https://doi.org/10.1007/s10803-018-3639-1

Crane, L., Chester, J., Goddard, L., Henry, L. A., & Hill, E. L. (2016). Experiences of autism diagnosis: A survey of over 1000 parents in the United Kingdom. *Autism, 20,* 153–162. https://doi. org/10.1177/1362361315573636

Crane, L., Hearst, C., Ashworth, M., Davies, J., & Hill, E. L. (2021). Supporting newly identified or diagnosed autistic adults: an initial evaluation of an autistic-led programme. *Journal of Autism and Developmental Disorders, 51,* 892-905. https://doi.org/10.1007/s10803-020-04486-4

Critical Appraisal Skills Programme. (2018). *Qualitative research checklist.* Accessed 30 November 2020 https://casp-uk.net/wp-content/uploads/2018/01/CASPQualitative-Checklist-2018.pdf/.

Crompton, C. J., Hallett, S., Ropar, D., Flynn, E., & Fletcher-Watson, S. (2020). 'I never realised everybody felt as happy as I do when I am around autistic people': A thematic analysis of autistic adults' relationships with autistic and neurotypical friends and family. *Autism*, *24*, 1438-1448. https://doi.org/10.1177%2F1362361320908976

Cruzes, D. S., & Dyba, T. (2011, September). Recommended steps for thematic synthesis in software engineering. In *2011 international symposium on empirical software engineering and measurement* (pp. 275-284). IEEE.

De Vries, A. L., Noens, I. L., Cohen-Kettenis, P. T., van Berckelaer-Onnes, I. A., & Doreleijers, T. A. (2010). Autism spectrum disorders in gender dysphoric children and adolescents. *Journal of Autism and Developmental Disorders*, *40*, 930-936. https://doi.org/10.1007/s10803-010-0935-9

DePape, A. M., & Lindsay, S. (2016). Lived experiences from the perspective of individuals with autism spectrum disorder: A qualitative meta-synthesis. *Focus on Autism and Other Developmental Disabilities*, *31*, 60-71. https://doi.org/10.1177%2F1088357615587504

Department of Health. (2010). *"Fulfilling and rewarding lives" The strategy for adults with autism in England.* London: Department of Health

Dittrich, R., & Burgess, L. (2012). Improving autism services in Hampshire: a lifespan approach. *Journal of Integrated Care, 20,* 296-307. https://doi.org/10.1108/14769011211270747

Dixon-Woods, M., Fitzpatrick, R., & Roberts, K. (2001). Including qualitative research in systematic reviews: opportunities and problems. *Journal of Evaluation in Clinical Practice*, *7,* 125-133. https://doi.org/10.1046/j.1365-2753.2001.00257.x

Dixon-Woods, M., Sutton, A., Shaw, R., Miller, T., Smith, J., Young, B., Bonas, S., Booth, A. & Jones, D. (2007). Appraising qualitative research for inclusion in systematic reviews: a quantitative and qualitative comparison of three methods. *Journal of Health Services Research & Policy*, *12*, 42-47. https://doi.org/10.1258%2F135581907779497486

Dugdale et al. (in prep). A Thematic Synthesis of Autistic Adults Lived Experiences of Non-Familial Relationships.

Eaton, J. (2018). *A Guide to Mental Health Issues in Girls and Young Women on the Autism Spectrum. Diagnosis, Intervention and Family Support.* London, UK: Jessica Kingsley Publishers.

Falkmer, T., Anderson, K., Falkmer, M., & Horlin, C. (2013). Diagnostic procedures in autism spectrum disorders: a systematic literature review. *European Child & Adolescent Psychiatry*, *22*, 329-340. https://doi.org/10.1007/s00787-013-0375-0

Gaffney, J. C. (2020). 'It's Autism, It's Just a Name': Exploring the Impact of Autism Spectrum Diagnosis with Adolescent Females Using Interpretative Phenomenological Analysis. *Educational & Child Psychology*, *37*, 136-147.

Gallacher, K., Jani, B., Morrison, D., Macdonald, S., Blane, D., Erwin, P., May, C. R., Montori, V. M., Eton, D. T., Smith, F., Batty, D. G., & Mair, F. S. (2013). Qualitative systematic reviews of treatment burden in stroke, heart failure and diabetes: Methodological challenges and solutions. *BMC Medical Research Methodology, 13,* 1-10. http://doi.org/10.1186/1471-2288-13-10

Gould, J. (2017). Towards understanding the under-recognition of girls and women on the autism spectrum. *Autism, 21,* 703-705. http://doi.org/10.1177/1362361317706174

Greenhalgh, T., & Peacock, R. (2005). Effectiveness and efficiency of search methods in systematic reviews of complex evidence: audit of primary sources. *British Medical Journal, 331*, 1064-1065. https://doi.org/10.1136/bmj.38636.593461.68

Griffith, G. M., Totsika, V., Nash, S., & Hastings, R. P. (2012). ‘I just don’t fit anywhere’: support experiences and future support needs of individuals with Asperger syndrome in middle adulthood. *Autism*, *16*, 532-546. https://doi.org/10.1177%2F1362361311405223

Hannes, K., & Macaitis, K. (2012). A move to more systematic and transparent approaches in qualitative evidence synthesis: update on a review of published papers. *Qualitative Research*, *12*, 402-442. https://doi.org/10.1177%2F1468794111432992

Hastings, R. P., & Johnson, E. (2001). Stress in UK families conducting intensive home-based behavioural intervention for their young child with autism. *Journal of Autism and Developmental Disorders, 31,* 327–336. https://doi.org/10.1023/A:1010799320795.

Hayes, J., Ford, T., Rafeeque, H., & Russell, G. (2018). Clinical practice guidelines for diagnosis of autism spectrum disorder in adults and children in the UK: a narrative review. *BMC Psychiatry*, *18*, 1-25. https://doi.org/10.1186/s12888-018-1800-1

Hickey, A., Crabtree, J., & Stott, J. (2018). ‘Suddenly the first fifty years of my life made sense’: Experiences of older people with autism. *Autism*, *22*, 357-367. https://doi.org/10.1177%2F1362361316680914

Hirota, T., So, R., Kim, Y. S., Leventhal, B., & Epstein, R. A. (2018). A systematic review of screening tools in non-young children and adults for autism spectrum disorder. *Research in Developmental Disabilities*, *80*, 1-12. https://doi.org/10.1016/j.ridd.2018.05.017

Howes, A., Richards, G., & Galvin, J. (2020). A Preliminary Investigation into the Relationship Between Autistic Traits and Self-Compassion. *Psychological Reports*

https://doi.org/10.1177/0033294120957244

Huang, Y., Arnold, S. R., Foley, K. R., & Trollor, J. N. (2020). Diagnosis of autism in adulthood: A scoping review. *Autism*, *24*, 1311-1327. https://doi.org/10.1177%2F1362361320903128

Hull, L., Petrides, K.V., Allison, C., Smith, P., Baron-Cohen, S., Lai, M.-C., & Mandy, W. (2017). “Putting on my best normal”: Social camouflaging in adults with autism spectrum conditions.

Journal of Autism and Developmental Disorders, 47, 2519-2534. https://10.1007/s10803-017-3166-5

Huws, J. C., & Jones, R. S. (2008). Diagnosis, disclosure, and having autism: An interpretative phenomenological analysis of the perceptions of young people with autism. *Journal of Intellectual and Developmental Disability*, *33*, 99-107. https://doi.org/10.1080/13668250802010394

Jones, L., Goddard, L., Hill, E. L., Henry, L. A., & Crane, L. (2014). Experiences of receiving an autism spectrum disorder diagnosis: A survey of adults in the United Kingdom. *Journal of Autism and Developmental Disorders, 44,* 3033–3044. https://doi. org/10.1007/s10803-014-2161-3

Jones, R. S., Huws, J. C., & Beck, G. (2013). ‘I’m not the only person out there’: Insider and outsider understandings of autism. *International Journal of Developmental Disabilities, 59,* 134-144. https://doi.org/10.1179/2047387712Y.0000000007

Jordan, A. L., Marczak, M., & Knibbs, J. (2021). ‘I Felt Like I was Floating in Space’: Autistic Adults’ Experiences of Low Mood and Depression. *Journal of Autism and Developmental Disorders*, 51, 1683-1694. https://doi.org/10.1007/s10803-020-04638-6

Kanfiszer, L., Davies, F., & Collins, S. (2017). ‘I was just so different’: The experiences of women diagnosed with an autism spectrum disorder in adulthood in relation to gender and social relationships. *Autism*, *21*, 661-669. https://doi.org/10.1177%2F1362361316687987

Kock, E., Strydom, A., O’Brady, D., & Tantam, D. (2019). Autistic women’s experience of intimate relationships: the impact of an adult diagnosis. *Advances in Autism, 5,* 38-49. https://doi.org/10.1108/AIA-09-2018-0035

Lai, M. C., & Baron-Cohen, S. (2015). Identifying the lost generation of adults with autism spectrum conditions. *The Lancet Psychiatry, 2,* 1013-1027. https://doi.org/10.1016/S2215-0366(15)00277-1

Leedham, A., Thompson, A. R., Smith, R., & Freeth, M. (2020). ‘I was exhausted trying to figure it out’: The experiences of females receiving an autism diagnosis in middle to late adulthood. *Autism*, *24*, 135-146. https://doi.org/10.1177%2F1362361319853442

Legg, H., & Tickle, A. (2019). UK parents’ experiences of their child receiving a diagnosis of autism spectrum disorder: A systematic review of the qualitative evidence. *Autism*, *23*, 1897-1910. https://doi.org/10.1177%2F1362361319841488

Lever, A., & Geurts, H. (2016). Psychiatric Co-occurring Symptoms and Disorders in Young, Middle-Aged, and Older Adults with Autism Spectrum Disorder. *Journal Of Autism and Developmental Disorders*, *46*, 1916-1930. https://10.1007/s10803-016-2722-8

Lewis, L. F. (2017). A mixed methods study of barriers to formal diagnosis of autism spectrum disorder in adults. *Journal of Autism and Developmental Disorders, 47,* 2410-2424 https://10.1007/s10803-017-3168-3

Loomes, R., Hull, L., & Mandy, W. P. L. (2017). What is the male-to-female ratio in autism spectrum disorder? A systematic review and meta-analysis. *Journal of the American Academy of Child & Adolescent Psychiatry*, *56*, 466-474. https://doi.org/10.1016/j.jaac.2017.03.013

MacLeod, A. (2019). Interpretative phenomenological analysis (IPA) as a tool for participatory research within critical autism studies: A systematic review. *Research in Autism Spectrum Disorders*, *64*, 49-62. https://doi.org/10.1016/j.rasd.2019.04.005

MacLeod, A., Allan, J., Lewis, A., & Robertson, C. (2018). ‘Here I come again’: the cost of success for higher education students diagnosed with autism. *International Journal of Inclusive Education*, *22*, 683-697. https://doi.org/10.1080/13603116.2017.1396502

Markham, S. (2019). Diagnosis and treatment of ASD in women in secure and forensic hospitals. *Advances in Autism, 5,* 64-76. https://doi.org/10.1108/AIA-09-2018-0027

Midence, K., & O’Neill, M. (1999). The experience of parents in the diagnosis of autism: A pilot study. *Autism*, *3*, 273-285. https://doi.org/10.1177%2F1362361399003003005

Miles, O., Boyle, C., & Richards, A. (2019). The social experiences and sense of belonging in adolescent females with autism in mainstream school. *Educational and Child Psychology, 36,* 8-21.

Milner, V., McIntosh, H., Colvert, E., & Happé, F. (2019). A qualitative exploration of the female experience of autism spectrum disorder (ASD). *Journal of Autism and Developmental Disorders*, *49*, 2389-2402. https://10.1007/s10803-019-03906-4

Moher, D., Liberati, A., Tetzlaff, J., & Altman, D. G. (2009). Preferred reporting items for systematic reviews and meta-analyses: the PRISMA statement. *British Medical Journal*, *62*, 1006–1012. https://doi.org/10.1136/bmj.b2535

Moseley, R. L., Druce, T., & Turner-Cobb, J. M. (2020). Autism research is ‘all about the blokes and the kids’: Autistic women breaking the silence on menopause. *British Journal of Health Psychology, 26,* 709-726. https://doi.org/10.1111/bjhp.12477

Myers, B. J., Mackintosh, V. H., & Goin-Kochel, R. P. (2009). “My greatest joy and my greatest heart ache”: Parents’ own words on how having a child in the autism spectrum has affected their lives and their families’ lives. *Research in Autism Spectrum Disorders, 3,* 670–684. https://doi.org/10.1016/j.rasd.2009.01.004.

NICE. (2012). *Autism spectrum disorder in adults: Diagnosis and management.* London: National Institute for Health and Clinical Excellence. Retrieved from: https://www.nice.org.uk/guidance/cg142

Noyes, J., Booth, A., Flemming, K., Garside, R., Harden, A., Lewin, S., Pantoja, T., Hannes, K., Cargo, M., & Thomas, J. (2018). Cochrane Qualitative and Implementation Methods Group guidance series—paper 3: methods for assessing methodological limitations, data extraction and synthesis, and confidence in synthesized qualitative findings. *Journal of Clinical Epidemiology*, *97*, 49-58. https://doi.org/10.1016/j.jclinepi.2017.06.020

Parkin, E., Bate, A., Long, R., Gheera, M., Powell, A., & Bellis, A. (2016). Autism–overview of UK policy and services. *Briefing paper*. Retrieved from: https://www.base-uk.org/sites/default/files/knowledgebase/CBP-7172.pdf

Parner, E. T., Thorsen, P., Dixon, G., De Klerk, N., Leonard, H., Nassar, N., Bourke, J., Bower, C., & Glasson, E. J. (2011). A comparison of autism prevalence trends in Denmark and Western Australia. *Journal of Autism and Developmental Disorders*, *41*, 1601-1608. https:// 10.1007/s10803-011-1186-0

Pellicano, E., Dinsmore, A., & Charman, T. (2014). What should autism research focus upon? Community views and priorities from the United Kingdom. *Autism*, *18*, 756-770. https://doi.org/10.1177%2F1362361314529627

Petticrew, M., Egan, M., Thomson, H., Hamilton, V., Kunkler, R., & Roberts, H. (2008). Publication bias in qualitative research: what becomes of qualitative research presented at conferences?. *Journal of Epidemiology & Community Health*, *62*, 552-554. https:// http://dx.doi.org/10.1136/jech.2006.059394

Powell, T., & Acker, L. (2016). Adults' experience of an Asperger syndrome diagnosis: analysis of its emotional meaning and effect on participants' lives. *Focus on Autism and Other Developmental Disabilities*, *31*, 72-80. https://10.1177/1088357615588516

Price, S., Lusznat, R., Mann, R., Locke, R. (2017). Doctors with Asperger's: the impact of a diagnosis. *The Clinical Teacher, 16,* 19-22. https://doi.org/10.1111/tct.12743

Punshon, C., Skirrow, P., & Murphy, G. (2009). The 'not guilty verdict:' Psychological reactions to a diagnosis of Asperger syndrome in adulthood. *Autism*, *13*, 265-283. https://doi.org/10.1177%2F1362361309103795

Rodgers, J., Herrema, R., Garland, D., Osborne, M., Cooper, R., Heslop, P., & Freeston, M. (2019). Uncertain futures: Reporting the experiences and worries of autistic adults and possible implications for social work practice. *The British Journal of Social Work*, *49*, 1817-1836. https://doi.org/10.1093/bjsw/bcy117

Ruiz Calzada, L. R., Pistrang, N., & Mandy, W. P. (2012). High-functioning autism and Asperger's disorder: Utility and meaning for families. *Journal of Autism and Developmental Disorders*, *42*, 230-243. https:// 10.1007/s10803-011-1238-5

Saggers, B., Hwang, Y. S., & Mercer, K. L. (2011). Your voice counts: Listening to the voice of high school students with autism spectrum disorder. *Australasian Journal of Special Education*, *35*, 173-190. https://doi.org/10.1375/ajse.35.2.173

Shaw, R. L. (2012). Identifying and synthesizing qualitative literature. In D. Harper, & A. R. Thompson (Eds.). *Qualitative Research Methods in Mental Health and Psychotherapy* (pp. 9–22). West Sussex, UK: John Wiley & Sons Ltd.

Spencer, L., & Ritchie, J. (2011). In Pursuit of Quality. In D. Harper & A. Thompson (Eds.), *Qualitative Research Methods in Mental Health and Psychotherapy: A Guide for Students and Practitioners* (pp. 287–240). John Wiley & Sons Ltd. https://doi.org/10.1002/9781119973249.ch16

Stagg, S. D., & Belcher, H. (2019). Living with autism without knowing: receiving a diagnosis in later life. *Health Psychology and Behavioral Medicine*, *7*, 348-361. https://doi.org/10.1080/21642850.2019.1684920

Tan, C. D. (2018). "I'm a normal autistic person, not an abnormal neurotypical": Autism Spectrum Disorder diagnosis as biographical illumination. *Social Science & Medicine, 197,* 161-167. https://doi.org/10.1016/j.socscimed.2017.12.008

Thomas, J., & Harden, A. (2008). Methods for the thematic synthesis of qualitative research in systematic reviews. *BMC Medical Research Methodology*, *8*, 1-10. https:// 10.1186/1471-2288-8-45

Townson, L., Macauley, S., Harkness, E., Docherty, A., Dias, J., Eardley, M., & Chapman, R. (2007). Research project on advocacy and autism. *Disability & Society*, *22*, 523-536. https://doi.org/10.1080/09687590701427669

Toye, F., Seers, K., Allcock, N., Briggs, M., Carr, E., & Barker, K. (2014). Meta-ethnography 25 years on: challenges and insights for synthesising a large number of qualitative studies. *BMC Medical Research Methodology*, *14*, 1-14. https://doi.org/10.1186/1471-2288-14-80

Treweek, C., Wood, C., Martin, J., & Freeth, M. (2019). Autistic people's perspectives on stereotypes: An interpretative phenomenological analysis. *Autism*, *23*, 759-769. https://doi.org/10.1177%2F1362361318778286

Vasilopoulou, E., & Nisbet, J. (2016). The quality of life of children with autism spectrum disorder: A systematic review. *Research in Autism Spectrum Disorders, 23,* 36–49. https://doi.org/10.1016/j.rasd.2015.11.008

Weiss, J. A., & Fardella, M. A. (2018). Victimization and perpetration experiences of adults with autism. *Frontiers in Psychiatry*, *9*, 203. https://doi.org/10.3389/fpsyt.2018.00203

World Health Organization. (2004). The *International Statistical Classification of Diseases and Health Related Problems ICD-10: Tenth Revision. Volume 1: Tabular list* (Vol. 1). World Health Organization.

Zaroff, C. M., & Uhm, S. Y. (2012). Prevalence of autism spectrum disorders and influence of country of measurement and ethnicity. *Social Psychiatry and Psychiatric Epidemiology*, *47*, 395-398. https://10.1007/s00127-011-0350-3

Appendices

Appendix A: Search Strategy for Psychinfo Database October 2020

(Autis* OR Autis* Spectrum OR Asperger OR Pervasive Developmental Disorder) AND (Lived Experience* OR Qualitative OR Content OR thematic OR discourse OR narrative OR template OR grounded theory OR interpretative phenomenolog* OR conversation*) AND (Diagnosis)

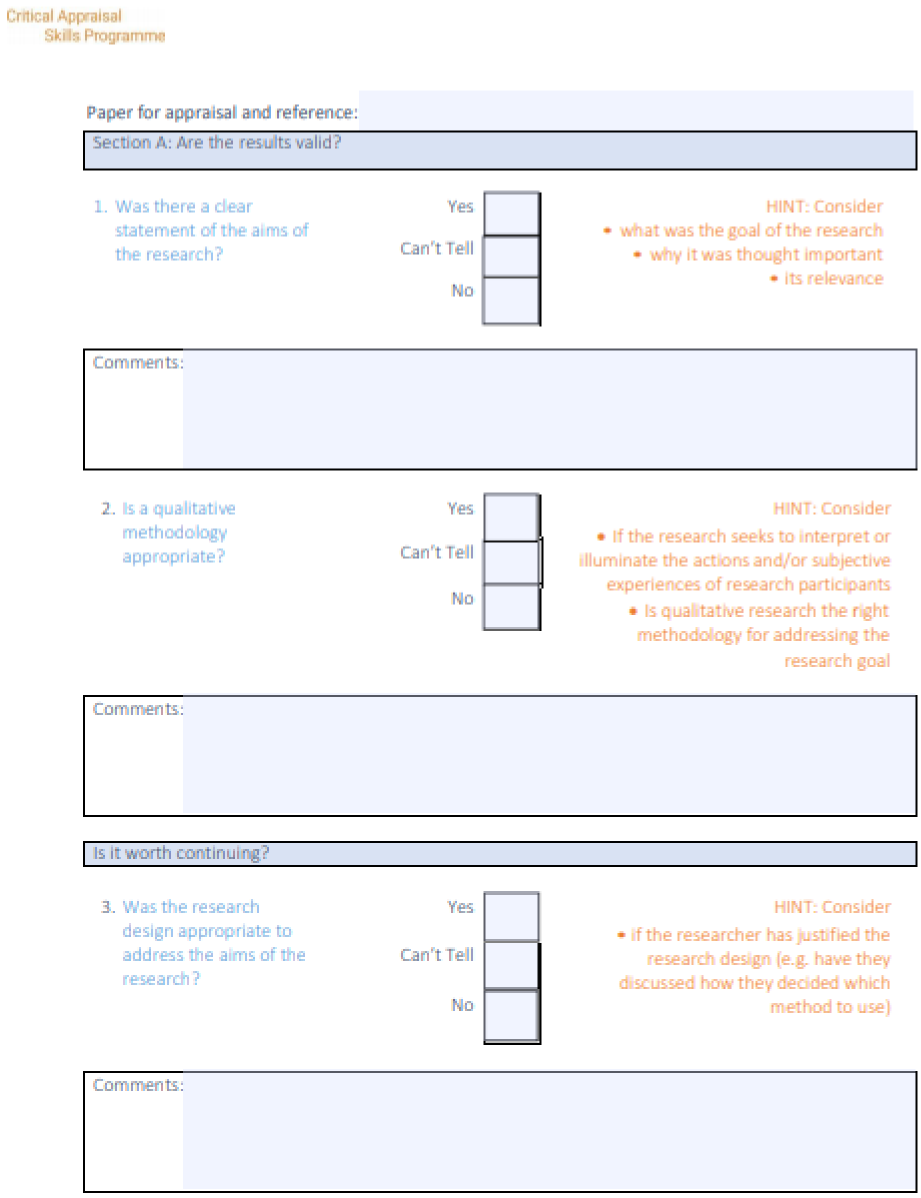
No date limits input.

Appendix B: Example Completed Data Extraction Table

Extraction field	**Information extracted**
Author, date, country	Hickey, Crabtree & Scott (2018) England
Participants and recruitment context	13 autistic adults, aged over 50 years. 10 male, 3 female. Information about the study was sent to 9 individuals via a NHS adult autism diagnostic service, 4 of whom contacted the authors to participate. The remaining 9 participants were recruited via autism support and social groups in London. All diagnosed in adulthood, average of 6 years prior to the study.
Study Design, Data Collection and Methodology (include theoretical background if stated)	Qualitative. Written consent obtained. Participants completed Hospital Anxiety and Depression Scale. Semi structure interviews – expert by experience involved in development of schedule. Transcripts analysed by first author: thematic analysis (Braun & Clarke, 2006). Credibility checks: independent coping of 4 transcripts and checking interpretation. Respondent validation with 7 participants.

Key themes and findings	Three overarching themes: difference, life, review, and longing for connection. Highlight the need for improving access to diagnosis and reducing isolation. Results similar to young age groups in terms of lived experiences and need for greater support.
Limitations	Lack of verified autism diagnoses for majority of participants. Individuals with intellectual disabilities were excluded. All participants received their diagnosis in adulthood – transferability to other groups may be limited. Potential bias in recruitment (support and social groups). Challenges of semi-structured interview format for individuals with communication differences.

Appendix C: CASP Qualitive Checklist



Critical Appraisal
Skills Programme

Paper for appraisal and reference:

Section A: Are the results valid?

1. Was there a clear statement of the aims of the research?

Yes ☐
Can't Tell ☐
No ☐

HINT: Consider
- what was the goal of the research
- why it was thought important
- its relevance

Comments:

2. Is a qualitative methodology appropriate?

Yes ☐
Can't Tell ☐
No ☐

HINT: Consider
- If the research seeks to interpret or illuminate the actions and/or subjective experiences of research participants
- Is qualitative research the right methodology for addressing the research goal

Comments:

Is it worth continuing?

3. Was the research design appropriate to address the aims of the research?

Yes ☐
Can't Tell ☐
No ☐

HINT: Consider
- if the researcher has justified the research design (e.g. have they discussed how they decided which method to use)

Comments:

4. Was the recruitment strategy appropriate to the aims of the research?

Yes ☐
Can't Tell ☐
No ☐

HINT: Consider
- If the researcher has explained how the participants were selected
- If they explained why the participants they selected were the most appropriate to provide access to the type of knowledge sought by the study
- If there are any discussions around recruitment (e.g. why some people chose not to take part)

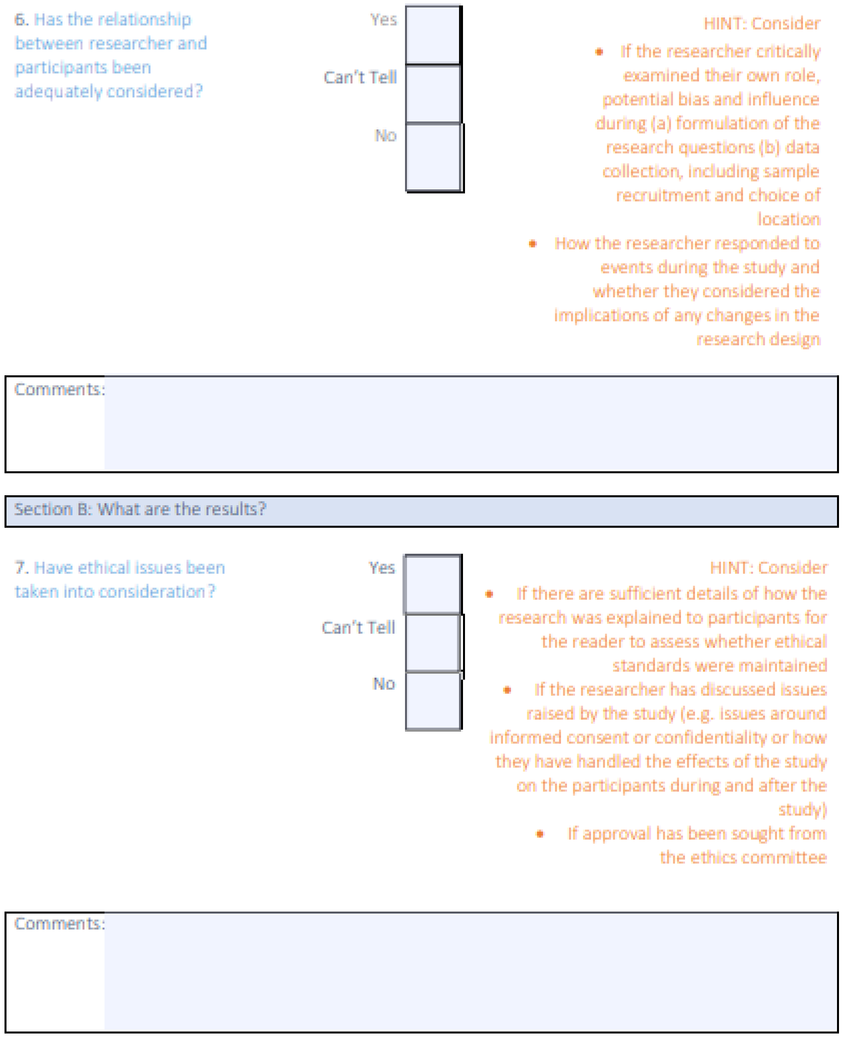
Comments:

5. Was the data collected in a way that addressed the research issue?

Yes ☐
Can't Tell ☐
No ☐

HINT: Consider
- If the setting for the data collection was justified
- If it is clear how data were collected (e.g. focus group, semi-structured interview etc.)
- If the researcher has justified the methods chosen
- If the researcher has made the methods explicit (e.g. for interview method, is there an indication of how interviews are conducted, or did they use a topic guide)
- If methods were modified during the study. If so, has the researcher explained how and why
- If the form of data is clear (e.g. tape recordings, video material, notes etc.)
- If the researcher has discussed saturation of data

Comments:



6. Has the relationship between researcher and participants been adequately considered?

Yes ☐
Can't Tell ☐
No ☐

HINT: Consider

- If the researcher critically examined their own role, potential bias and influence during (a) formulation of the research questions (b) data collection, including sample recruitment and choice of location
- How the researcher responded to events during the study and whether they considered the implications of any changes in the research design

Comments:

Section B: What are the results?

7. Have ethical issues been taken into consideration?

Yes ☐
Can't Tell ☐
No ☐

HINT: Consider

- If there are sufficient details of how the research was explained to participants for the reader to assess whether ethical standards were maintained
- 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)
- If approval has been sought from the ethics committee

Comments:

8. Was the data analysis sufficiently rigorous?

Yes ☐
Can't Tell ☐
No ☐

HINT: Consider
- If there is an in-depth description of the analysis process
- If thematic analysis is used. If so, is it clear how the categories/themes were derived from the data
- Whether the researcher explains how the data presented were selected from the original sample to demonstrate the analysis process
- If sufficient data are presented to support the findings
- To what extent contradictory data are taken into account
- Whether the researcher critically examined their own role, potential bias and influence during analysis and selection of data for presentation

Comments:

9. Is there a clear statement of findings?

Yes ☐
Can't Tell ☐
No ☐

HINT: Consider whether
- If the findings are explicit
- If there is adequate discussion of the evidence both for and against the researcher's arguments
- If the researcher has discussed the credibility of their findings (e.g. triangulation, respondent validation, more than one analyst)
- If the findings are discussed in relation to the original research question

Comments:

CASP
Critical Appraisal
Skills Programme

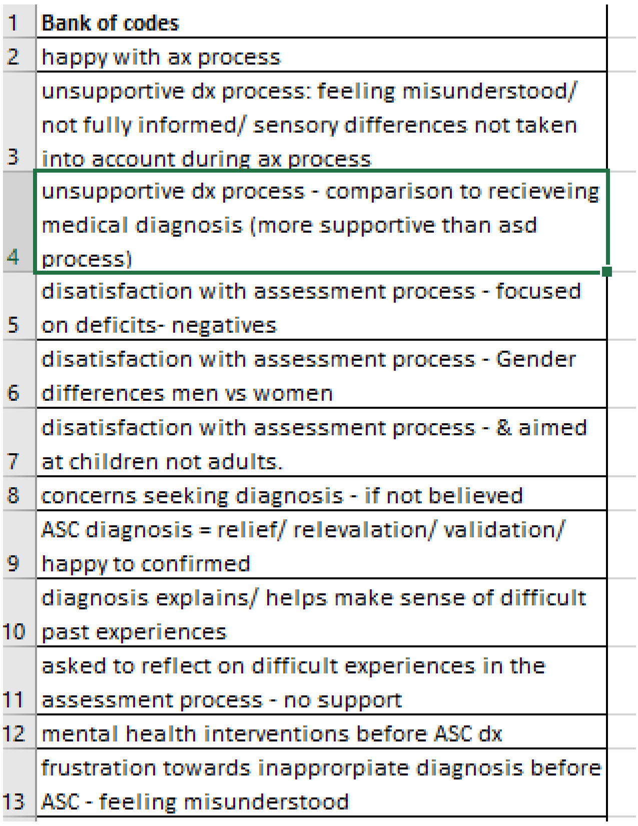
Section C: Will the results help locally?

10. How valuable is the research?

HINT: Consider
- If the researcher discusses the contribution the study makes to existing knowledge or understanding (e.g. do they consider the findings in relation to current practice or policy, or relevant research-based literature
- If they identify new areas where research is necessary
- If the researchers have discussed whether or how the findings can be transferred to other populations or considered other ways the research may be used

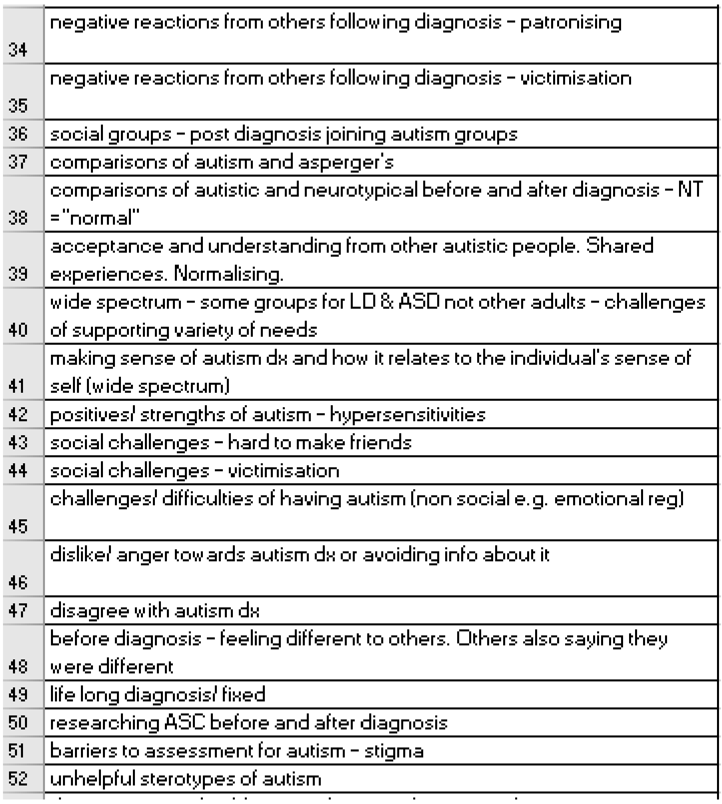
Comments:

Appendix D: Bank of Codes

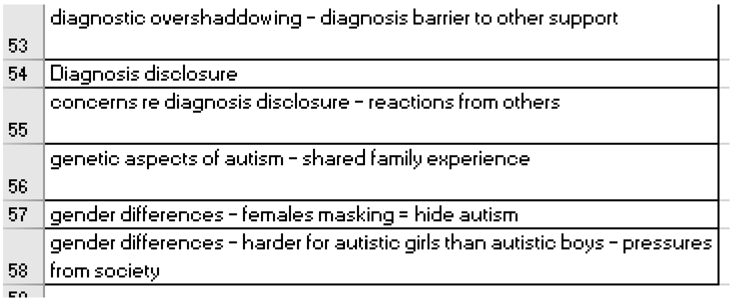


1	**Bank of codes**
2	happy with ax process
3	unsupportive dx process: feeling misunderstood/ not fully informed/ sensory differences not taken into account during ax process
4	unsupportive dx process - comparison to recieveing medical diagnosis (more supportive than asd process)
5	disatisfaction with assessment process - focused on deficits- negatives
6	disatisfaction with assessment process - Gender differences men vs women
7	disatisfaction with assessment process - & aimed at children not adults.
8	concerns seeking diagnosis - if not believed
9	ASC diagnosis = relief/ relevalation/ validation/ happy to confirmed
10	diagnosis explains/ helps make sense of difficult past experiences
11	asked to reflect on difficult experiences in the assessment process - no support
12	mental health interventions before ASC dx
13	frustration towards inapprorpiate diagnosis before ASC - feeling misunderstood

14	ASC diagnosis replaced other diagnosis (e.g. BPD)
15	mixed emotional responses to ASC diagnosis
16	difficulties/ sadness/ anger re late diagnosis
17	process of accepting diagnosis
18	shocked/ overwhelmed/ grief response to diagnosis
19	feeling indifferent to receiving the diagnosis
20	new understanding following diagnosis (learning about social etiquttes)
21	new self understanding following diagnosis
22	self acceptance/ reduced shame following diagnosis
23	non blaming for difficulties/ externalise autism
24	lack of understanding from others - feeling misunderstood
25	lack of understanding about autism/ asperger's
26	lack of professional support for autism - blanket approach not helpful, focused on children not adults
27	diagnosis = access to support
28	improved support from employer following diagnosis
29	improved support from services following diagnosis
30	wanting to improve other peoples understanding of autism - research/ teaching
31	increased understanding from others following diagnosis
32	limited post-dx support - not adult appropriate
33	negative reactions from family - not understanding

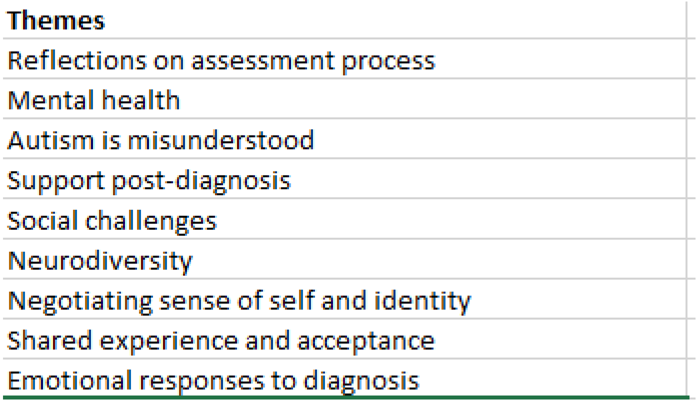


34	negative reactions from others following diagnosis – patronising
35	negative reactions from others following diagnosis – victimisation
36	social groups – post diagnosis joining autism groups
37	comparisons of autism and asperger's
38	comparisons of autistic and neurotypical before and after diagnosis – NT ="normal"
39	acceptance and understanding from other autistic people. Shared experiences. Normalising.
40	wide spectrum – some groups for LD & ASD not other adults – challenges of supporting variety of needs
41	making sense of autism dx and how it relates to the individual's sense of self (wide spectrum)
42	positives/ strengths of autism – hypersensitivities
43	social challenges – hard to make friends
44	social challenges – victimisation
45	challenges/ difficulties of having autism (non social e.g. emotional reg)
46	dislike/ anger towards autism dx or avoiding info about it
47	disagree with autism dx
48	before diagnosis – feeling different to others. Others also saying they were different
49	life long diagnosis/ fixed
50	researching ASC before and after diagnosis
51	barriers to assessment for autism – stigma
52	unhelpful sterotypes of autism

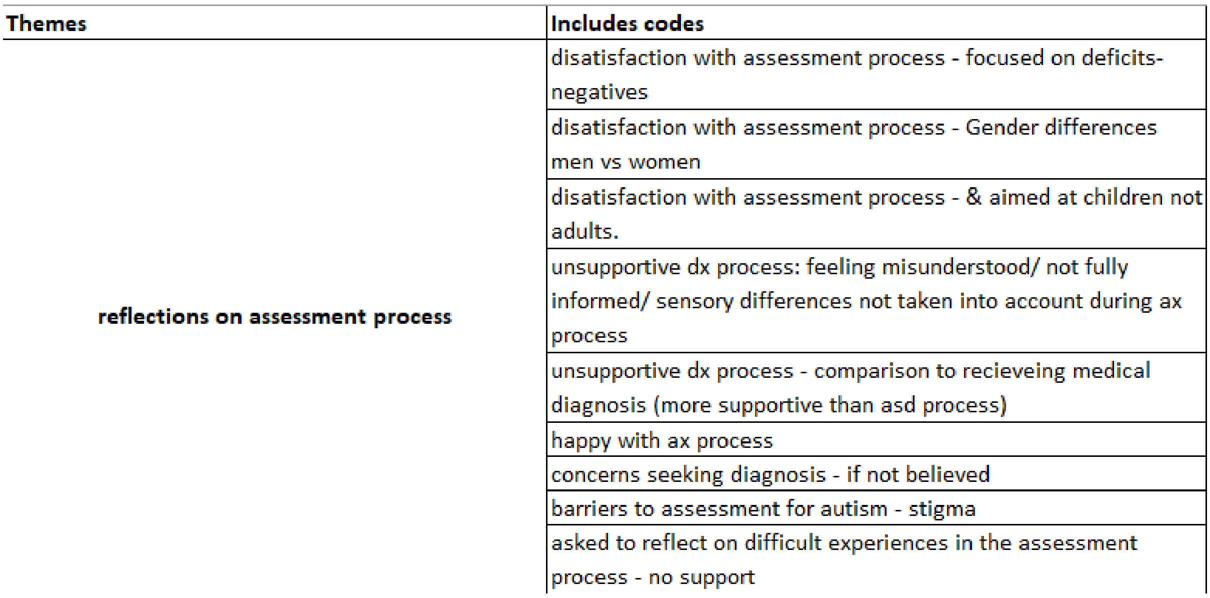


53	diagnostic overshaddowing – diagnosis barrier to other support
54	Diagnosis disclosure
55	concerns re diagnosis disclosure – reactions from others
56	genetic aspects of autism – shared family experience
57	gender differences – females masking = hide autism
58	gender differences – harder for autistic girls than autistic boys – pressures from society

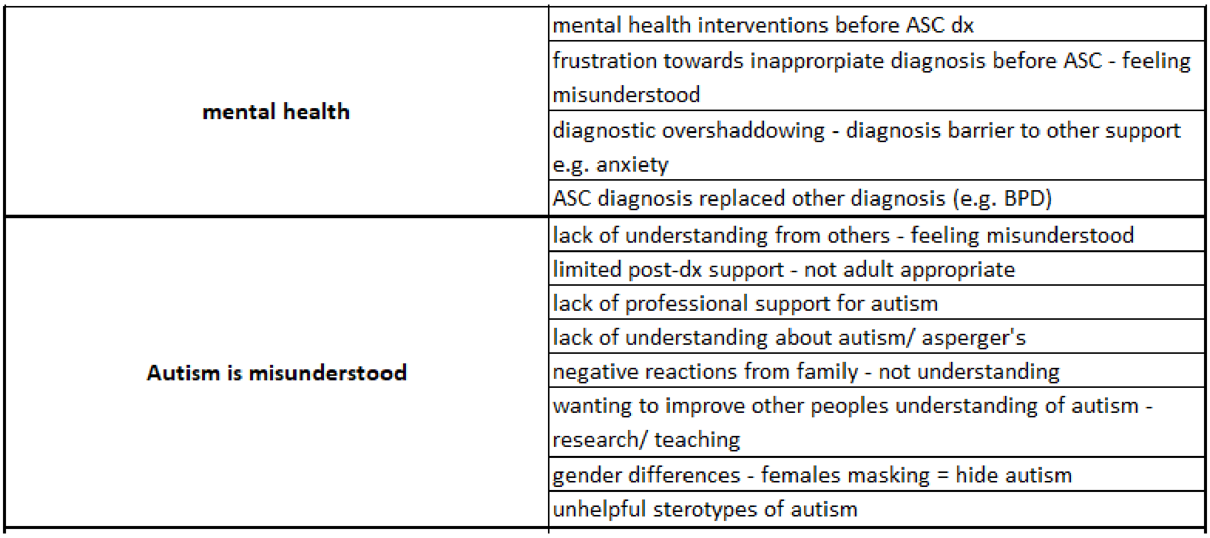
Appendix E: Descriptive Themes



Themes
Reflections on assessment process
Mental health
Autism is misunderstood
Support post-diagnosis
Social challenges
Neurodiversity
Negotiating sense of self and identity
Shared experience and acceptance
Emotional responses to diagnosis



Themes	Includes codes
reflections on assessment process	disatisfaction with assessment process - focused on deficits- negatives
	disatisfaction with assessment process - Gender differences men vs women
	disatisfaction with assessment process - & aimed at children not adults.
	unsupportive dx process: feeling misunderstood/ not fully informed/ sensory differences not taken into account during ax process
	unsupportive dx process - comparison to recieveing medical diagnosis (more supportive than asd process)
	happy with ax process
	concerns seeking diagnosis - if not believed
	barriers to assessment for autism - stigma
	asked to reflect on difficult experiences in the assessment process - no support



mental health	mental health interventions before ASC dx
	frustration towards inapprorpiate diagnosis before ASC - feeling misunderstood
	diagnostic overshaddowing - diagnosis barrier to other support e.g. anxiety
	ASC diagnosis replaced other diagnosis (e.g. BPD)
Autism is misunderstood	lack of understanding from others - feeling misunderstood
	limited post-dx support - not adult appropriate
	lack of professional support for autism
	lack of understanding about autism/ asperger's
	negative reactions from family - not understanding
	wanting to improve other peoples understanding of autism - research/ teaching
	gender differences - females masking = hide autism
	unhelpful sterotypes of autism

Support post diagnosis	improved support from employer following diagnosis
	improved support from services following diagnosis
	increased understanding from others following diagnosis
	diagnosis = access to support
Social challenges	negative reactions from others following diagnosis - patronising
	negative reactions from others following diagnosis - victimisation
	social challenges - hard to make friends
	before diagnosis - feeling different to others. Others also saying they were different
	Diagnosis disclosure
	concerns re diagnosis disclosure - reactions from others
	gender differences - harder for autistic girls than autistic boys - pressures from society (sociable, mothers)
	social challenges - victimisation

Neurodiversity	comparisons of autism and asperger's
	comparisons of autistic and neurotypical **before and after** diagnosis - NT ="normal"
	positives/ strengths of autism - hypersensitivities
	challenges/ difficulties of having autism (non social e.g. emotional reg)
	wide spectrum - some groups for LD & ASD not other adults - challenges of supporting variety of needs
	making sense of autism dx and how it relates to the individual's sense of self (wide spectrum)

Negotiating sense of self and identity	new self understanding following diagnosis
	self acceptance/ reduced shame following diagnosis
	non blaming for difficulties/ externalise autism
	process of accepting diagnosis
	new understanding following diagnosis (learning about social etiqutțes)
	diagnosis explains/ helps make sense of difficult past experiences
	researching ASC before and after diagnosis
Shared experience and acceptance	**acceptance and understanding from other autistic people. Shared experiences. Normalising.**
	social groups - post diagnosis joining autism groups
	genetic aspects of autism - shared family experience

Emotional responses to diagnosis	dislike/ anger towards autism dx or avoiding info about it
	disagree with autism dx
	difficulties/ sadness/ anger re late diagnosis
	feeling indifferent to receiving the diagnosis
	shocked/ overwhelmed/ grief response to diagnosis
	mixed emotional responses to ASC diagnosis
	ASC diagnosis = relief/ relevalation/ validation/ happy to confirmed
	life long diagnosis/ fixed

Section Two: Research Report

Autistic women's experiences of self-compassion and receiving their diagnosis in adulthood.

Abstract

Objectives

Research highlights strong links between self-compassion and mental health, but there is very limited research specifically exploring autistic individuals' experiences of self-compassion. The process of receiving a diagnosis on the autism spectrum can be complex and autistic women tend to experience several barriers to diagnosis. This study aims to investigate autistic women's experiences of receiving their diagnosis in adulthood and whether receiving their diagnosis has influenced their perception of self-compassion.

Design and Methods

This study employs Interpretative Phenomenological Analysis to explore if receiving a diagnosis of autism influences women's experiences of self-compassion. Eleven autistic women who received their diagnosis in adulthood participated in semi-structured interviews.

Results

Three super-ordinate themes were identified: *'Disconnect between the autistic self and experience of societal expectations'*, (the burden of conformity; autism is misunderstood; social challenges; mental health impact)*'*; *'Unmasking: the process of self-understanding',* (autonomy and self-compassion; validation and grief) and *'Impact on relationships',* (diagnosis disclosure dilemmas; connection and understanding).

Conclusions

Society's misconceptions of autism, and unhelpful thinking styles were presented as barriers to self-compassion. Most participants reported that their diagnosis provided greater self-understanding, facilitating self-compassion. Some participants also suggested their shared understanding of autism developed their compassion towards others.

Practitioner Points

- Findings highlighted the need for autism training for professionals to support early identification in girls and women to reduce the self-criticism associated with late diagnosis.
- Future research to consider how ethnicity may impact autistic individuals' experiences of self-compassion.

Keywords

Autistic women; ASC; Self-compassion; Autism Diagnosis; Interpretative Phenomenological Analysis.

Introduction

Autism Spectrum Disorder (ASD), also known as autism, is a lifelong neurodevelopmental condition that affects how individuals perceive the world. Autism is characterised by persistent difficulties in social communication, social interaction, along with restricted and repetitive behaviours (American Psychiatric Association, 2013). Research exploring the experience of being autistic[2] has been emerging in recent years (DePape & Lindsay, 2016). Existing research has highlighted that receiving an autism diagnosis has a huge impact on an individual and the lives of people close to them (Midence & O'Neill, 1999; Punshon et al., 2009).

Research suggests that females experience significant barriers to receiving an autism diagnosis compared to males (Lewis, 2017). Research is also dominated by findings from male samples. This study aims to add to the growing area of research exploring autistic women's experiences. Understanding gender differences and lifespan issues have been identified as priority areas for research by autistic adults (Pellicano et al., 2014). More research is needed to understand how the perspectives and experiences of autistic individuals varies by age, gender, symptom severity and socio-demographic factors (DePape & Lindsay, 2016). Research suggests that autistic females' needs are under recognized (Gould, 2017) and their support needs are often misunderstood and misattributed to different diagnoses (Attwood, 2007). Research also suggests autistic women may be missed earlier in life (Rutherford et al., 2016); therefore recruiting adult participants will provide further information of this group's experiences compared to research with younger samples. A barrier to diagnosis can be the use of compensatory strategies to 'mask' or 'camouflage' difficulties (Hull et al., 2017). These strategies can take significant cognitive and emotional effort and negatively impact mental health (Bargiela et al., 2016).

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[2] Autistic adults and family members favored identity-first terms e.g. 'autistic' or 'autistic person' (Kenny et al., 2016).

Mental health issues are common in autistic people, with one study reporting that 79% of autistic adults met diagnostic criteria for a mental health condition (Lever & Geurts, 2016). Depression and anxiety are most commonly reported (Strang et al., 2012), alongside high rates of social anxiety (Maddox & White, 2015) and suicidal ideation (Hirvikoski et al., 2016). Some research suggests the social challenges associated with autism could increase the risk of developing mental health issues e.g., autistic people and people with high autistic traits are reported to experience bullying (Bejerot & Mörtberg, 2009; Zablotsky et al., 2014) and non-acceptance from others (Cage et al., 2017; Sasson et al., 2017). These experiences may increase camouflaging behaviours and reduce self-acceptance. Similarly, higher autistic traits were associated with self-reported loneliness in autistic adults (Hedley et al., 2018), increasing the risk of depression and suicidality.

Qualitative findings from possibly autistic and autistic participants suggested that the similarities in symptom presentation between autism and some mental health diagnoses could lead to potential misdiagnosis (Au-Yeung et al., 2019). In addition, participants reported that healthcare professionals' limited understanding and awareness of autism contributed to their perceived misdiagnosis of mental health conditions (Au-Yeung et al., 2019). Fusar-Poli et al. (2020) reported gender differences in the mental health diagnoses autistic men and women received before their autism diagnosis in adulthood; men were identified to have "externalising" symptoms e.g., attention deficit hyperactivity disorder, conduct disorders, or psychoses. Whereas women received diagnoses with "internalising" behaviours: anxiety, depression, or personality disorders. Comparatively, research also described the potential for the diagnostic overshadowing of an autism diagnosis, whereby co-occurring mental health conditions are neglected (Matson & Williams, 2013). Research suggests autism acceptance contributes to mental health. Specifically, regression analyses revealed that autism acceptance from external sources and personal acceptance significantly predicted depression, but no relationship was found between autism acceptance and anxiety (Cage et al., 2017).

Self-compassion is defined by Neff (2003) as comprising three interrelated elements: self-kindness versus self-judgement, common humanity versus isolation, and mindfulness versus over-identification. Research suggests cultivating self-compassion and compassion for others promotes resilience, well-being, and social connection (Neff & Germer, 2017). Self-compassion research is rapidly growing due to its strong link with mental health (Barnard & Curry, 2011; Gilbert, 2009). Research reports that people who score high in self-compassion tend to score lower on measures of neuroticism and depression, and higher on measures of life satisfaction, social connectedness, and subjective well-being (Leary et al., 2007). Self-compassion can act as a buffer against anxiety symptoms after experiencing a stressor, even after controlling for self-esteem (Neff et al., 2007). Similarly, MacBeth and Gumley's (2012) meta-analysis reported a large effect size for the relationship between self-compassion and psychopathology; higher levels of self-compassion were associated with lower levels of mental health symptoms. Self-compassion is shown to support women's well-being in several ways through increasing empowerment, self-worth, positive body image and resilience, while also decreasing negative self-talk, stress, unhealthy interpersonal problems, and body dissatisfaction (Stevenson & Batts, 2016). Yarnell et al.'s (2015) meta-analysis reported a small, significant gender difference, stating that women tended to have less self-compassion than men, suggesting women are potentially at greater risk of mental health issues associated with lower self-compassion. Similarly, research suggests females ruminate over their problems more than males (Shors et al., 2017) and often prioritise the needs of others over their own (Yarnell et al., 2018).

There is limited research exploring self-compassion in autistic populations; a small number of studies explored self-compassion and parents of autistic children (Neff & Faso, 2015; Wong et al., 2016). Galvin et al. (2021) examined whether self-compassion is associated with autistic traits in a sample without a clinical diagnosis of autism. Their findings presented self-compassion as a partial mediator in the positive relationship between autistic traits and depressive/ anxiety symptomology. Based on these findings, Galvin et al. (2021)

suggest self-compassion could be a target for clinical intervention for people with high autistic traits experiencing depression and or anxiety. Arguably autistic women and women with subclinical autism may be more vulnerable to reduced self-compassion as they are more likely to internalise their difficulties (Bargiela et al., 2016; Mandy et al., 2012; Scherff et al., 2014). This research aims to explore autistic women's experiences of self-compassion to develop understandings in this area.

In a recent qualitative study, several autistic women reported that receiving their autism diagnosis in adulthood increased their sense of agency and acceptance of the self (Leedham et al., 2020). Other research reported that diagnosis was linked to feelings of relief, providing answers to questions participants had about themselves (Pushon et al., 2009). Research suggested self-esteem was positively associated with identifying with an autistic identity and this mediated an association with anxiety and depression (Cooper et al., 2017). Comparatively, difficult feelings associated with diagnosis, such as grief, are also reported in the literature (Portway & Johnson, 2005; Leedham et al., 2020).

Most of the literature focuses on the experiences of adolescents or the diagnostic experiences of children and their parents (Pakenham et al., 2004; Abbott et al., 2012). This study aims to provide valuable insight into the experiences of autistic women who have received their diagnosis in adulthood and whether the diagnosis influences their experience of self-compassion. There is no current research specifically exploring autistic individuals' experiences of self-compassion. Given the existing research reporting the relationship between self-compassion and mental health, this study has clinical implications for increasing understandings about autistic women's experiences of self-compassion and possibly ways to facilitate its development. The focus on diagnosis and how this may influence self-compassion will also contribute to understanding the value of the diagnosis in the autistic community. This study will contribute to the growing but limited research into autistic women's experiences, increasing understanding of the needs in this population. The findings may inform client-centred practices and policies in health care settings and potentially provide both positive and negative aspects of autism diagnosis.

Qualitative methods are growing in popularity in autism research and this approach was deemed appropriate to gain an in-depth understanding of experiences (MacLeod, 2019). Conducting semi structured interviews and employing interpretative phenomenological analysis (IPA, Smith, 1996) enables exploration of autistic women's experiences of self-compassion after receiving their diagnosis. The IPA analytic process is designed to give a voice to individual participants by providing an interpretative account of their experiences in their unique context (Larkin & Thompson, 2012). IPA attempts to equalise power between the researcher and interviewee by recognising the participant as an expert in their experience. It has been argued using IPA in autism research goes some way toward alleviating the 'double empathy problem' (Milton, 2012), which can discredit research in this area (Howard et al., 2019). The 'double empathy problem' (Milton, 2012) refers to the disconnect in social interactions and meaning making between people with different dispositional outlooks and life experiences. Milton (2012) argues that autistic and neurotypical people have mutual misunderstandings of each other. The 'double empathy problem' challenges the suggestion that social miscommunications are due to an empathy deficit in autism. Researchers report this is a two-way problem (Hacking, 2009) and can lead to misinterpretations and exclusion of autistic people's views in autism research.

Aims

To investigate autistic women's experiences of receiving their diagnosis in adulthood and whether receiving their diagnosis has influenced their perception of self-compassion.

Methodology

Design

This study employed a qualitative design, using an Interpretative Phenomenological Analysis (IPA: Smith et al., 2009) approach to data collection and analysis. IPA has an interpretative phenomenological epistemology. This approach permitted the exploration of the personal meanings and subjective interpretations of each participant's reality; specifically, individuals' lived experiences of self-compassion, and whether this has changed since receiving their autism diagnosis in adulthood.

IPA is an effective method for autism research (Griffith et al., 2012; MacLeod, 2019). The IPA approach gives a much-needed voice to autistic individuals (Humphrey & Lewis, 2008). Data were collected from semi-structured interviews. This approach to autism research is increasing in popularity to develop understandings of the lived experiences of autistic individuals (Ward & Webster, 2018; MacLeod, 2019; Treweek et al., 2019). IPA is an idiographic approach; it was decided, given the heterogeneous nature of the autistic population, that this focus on individual lived experience would be more appropriate than other qualitative approaches, e.g., Grounded Theory, which aims to reach a conceptual theory and therefore is less concerned with individual experience (Willig, 2008).

Ethics

Ethical approval was obtained via the Integrated Research Application System (IRAS, 275964) and from the local NHS Foundation Trust for governance (see appendix A for approval letters).

Participants

Twelve participants were recruited via purposive sampling and self-identified as to whether they met the study requirements. Due to recording issues with one interview, eleven participants' data were analysed. The inclusion criteria were:

- Received clinical autism diagnosis after their 18th birthday
- Cisgender female

Participants were excluded if they lacked the capacity to provide consent; unable to speak English; did not have access to the internet (due to COVID-19 restrictions, consent was obtained electronically).

See table 1 for demographic information. All names are pseudonyms to protect confidentiality. Some participants reported additional diagnoses including Dyspraxia, Depression and Anxiety.

Table 1

Participant demographics

Participant	Age at interview*	Age at diagnosis	Diagnosis	Ethnicity
Jessica	40-44	30-34	ASC as seen in Women and Girls	White British
Stacey	35-39	35-39	ASD	White British
Tara	55-59	50-54	AS	White
Melissa	45-49	20-24	Autism	White British
Karen	65-69	65-69	ASD	White British
Angela	60-64	55-59	ASD	White British
Debby	55-59	50-54	ASD	White British
Juliet	35-39	35-39	ASD	White British
Natasha	35-39	35-39	ASD (formally AS)	White British
Louise	35-39	35-39	ASD	White British
Sue	35-39	35-39	ASD	White British

Note. ASC= Autism Spectrum Condition; ASD = Autism Spectrum Disorder (American Psychiatric Association, 2013); AS= Asperger’s Syndrome, diagnostic description based on previous diagnostic criteria; ADHD = Attention Deficit Hyperactivity Disorder; DCD= Developmental Coordination Disorder; OCD = Obsessive Compulsive Disorder. *Exact ages are not reported to protect confidentiality.

There is no strict guidance on sample size in IPA studies, however samples are purposefully small (Thompson et al., 2011), published studies tend to range from one to fifteen participants.

Materials

The interview schedule was designed in line with methodological guidance and based on the aims of study (Larkin & Thompson, 2012: see table 2). The interview schedule was developed from research findings and interview questions from Leedham et al. (2020). Prompts were utilized to request further information and clarification. The interview was piloted with a peer independent to the research to familiarize the lead researcher with the questions before participant interviews.

Table 2

Interview schedule

Interview questions	**Prompts**
1. What was the exact diagnosis you were given	*What term(s) do you prefer to use to refer to your diagnosis, e.g. "autistic"/ "on the spectrum"? Sometimes people use different names to describe their diagnosis or to refer to themselves. Sometimes people have a preference.*
2. What does [insert the term the participant uses] mean to you? (or) How would you describe autism [or alternative preferred term] to someone?	
3. What effect has your diagnosis has on your life?	*Did you do anything as a result of receiving your diagnosis? Sometimes people say they feel different about themselves and things that have happened in the past. Is this right or is it something else? (options if needed "the diagnosis gave them a frame to see themselves in"/ "answered questions they had about themselves")*

4. What effect has receiving the diagnosis had on how you feel about yourself?	*How did you feel before receiving the diagnosis, then the day you received it, and how does that compare to how you feel now? Do you like yourself more or less?*
5. How do you act towards yourself in difficult times?	*How do you think about yourself in difficult times? How do you behave towards yourself in difficult times? Can you provide an example of a difficult time and then describe how you thought about yourself and behaved towards yourself at this time? Are there any differences in how you acted towards yourself before or after receiving your diagnosis?* *Has this changed over time since your diagnosis? If so, please could you explain how?* *How able do you feel to self-soothe or self-regulate? Or value yourself? What specifically do you to in order to self-soothe/value yourself?* *Is this different to how you felt before your diagnosis?*
6. Are there certain things that make it easier (or harder) to be kinder or more forgiving towards yourself?	
7. How do you feel the way you think and behave towards yourself compares with what other people experience?	*Is this different to how you felt before your diagnosis?*
8. Is there anything else you would like to share about how you feel towards yourself since receiving your diagnosis of [preferred term]?	

Service User Involvement

The lead researcher attended a monthly discussion group at a local NHS adult autism diagnostic service to gain feedback on the proposed research study. The group included nine autistic adults, both men and women, all diagnosed in adulthood. The group feedback informed the terminology used on the participant information sheets and the interview schedule. Two autistic adults were contacted from their details on the Sheffield Autism Research Lab (ShARL). They also reviewed the interview schedule and participant facing-information e.g., information sheet (appendix B), consent form (appendix C). These consultations provided advice regarding the accessibility of the language and terminology, consideration of ethical and methodological issues.

Procedure

Participants were recruited via a local NHS autism diagnostic service and the ShARL website. Staff at the NHS service provided research information flyers (appendix D) at diagnosis follow-up, and research information was also displayed on the ShARL website. Participants were asked to express their interest by recording their contact details on a secure online form. A participant information sheet and consent form were sent to participants that were eligible to take part. Participants were also provided the interview schedule if requested.

Due to COVID-19 restrictions, interviews were conducted via video call or telephone, depending on the participant’s preference. The interviews took place between the 21st of August and 5th November 2020. At the start of each interview, the limits of confidentiality (e.g., risk issues) were discussed. Audio from the interviews was recorded via an encrypted smart tablet. Interviews ranged between 37 and 96 minutes. Participants were debriefed at the end of the interviews. The lead author transcribed one interview and the remaining interviews were transcribed by an approved transcriber.

Data Analysis

Reflexivity

Reflexivity refers to an ability to “consider intersubjective dynamics between researcher and data” (Biggerstaff & Thompson, 2008). Phenomenological research explores how individuals make sense of their experiences and their perceptions of objects. Therefore, researchers are required to ‘bracket’ their preconceptions during analysis (Pietkiewicz & Smith, 2012). To support this process, the lead author kept a reflective diary during the research, recording emotions, personal thoughts, and non-verbal interactions with participants during interviews (see appendix E for an example entry). These notes provided critical reflections on the researcher’s influence on interpretations during analysis and ensured the results were drawn from the data. The lead researcher is a white British female in her early thirties, without a diagnosis of ASC. The lead researcher’s position and interpretations were discussed in supervision, including how their role as a trainee clinical psychologist may have influenced the experiences participants shared. The lead researcher also has experience working in a child and adolescent ASC diagnostic team. She has studied psychological theories of autism, self-compassion research and utilised Compassion Focused Therapy (Gilbert, 2009) in her clinical work.

Analysis

Transcripts were analysed using IPA guidance (Larkin & Thompson, 2012; Smith et al., 2009). The interviews were transcribed verbatim. Initially, transcripts were read while listening to audio recordings to ensure accuracy of transcribing and familiarity with the original data. During this early stage of analysis, exploratory comments were recorded on the right-hand margin. Transcripts were then read again and ‘line by line’ coding of the data was conducted, recording descriptive, linguistic, and conceptual comments in the right-hand margin. Next, while re-reading the transcripts, tentative emerging themes and possible interpretations were recorded on the left margin of transcripts. Then, individual data was organised into themes, creating conceptual maps using online software, Mind Manager (see appendix F). Comparisons of data across the transcripts identified overlapping concepts and exceptions. Clusters of themes were developed alongside psychological theory and research while remaining grounded in the participant's accounts. Clusters established a hierarchical relationship of super-ordinate and sub-ordinate theme categories.

Quality Control

Three supervisors and a peer trainee psychologist completed an audit of each stage of analysis for three transcripts to ensure a high standard of rigor (see appendix G for audit forms). Coding and interpretations were discussed in regular supervision to maintain focus and test the plausibility of interpretations. Other validation strategies such as member checking were deemed less appropriate given the interpretative stance of IPA and this process can be counter-productive in studies with more than one participant (Larkin & Thompson, 2012). The consolidated criteria for reporting qualitative research checklist (COREQ) were also considered to enhance the quality of the report.

Results

Analysis of the data produced three super-ordinate themes and several sub-themes; see table 3 for details. Participants' quotes are provided to illustrate each theme, missing data is represented by the use of '…' and additional explanation of points are included within '[ ]'. The themes do not provide an exhaustive account of participants' experiences; they provide an interpretation of several accounts (see appendix H for additional supporting quotes). Pseudonyms are used to protect participant's anonymity.

Table 3

Super-ordinate Themes and Sub-themes

Super-ordinate themes	**Sub-themes**
Disconnect between the autistic self and experience of societal expectations	The burden of conformity

	Autism is misunderstood
	Social challenges
	Mental health impact
Unmasking: the process of self-understanding	Autonomy and self-compassion
	Validation and grief
Impact on relationships	Diagnosis disclosure dilemmas
	Connection and understanding

Disconnect between the autistic self and experience of societal expectations

This super-ordinate theme explores participants' experiences of feeling different from society's neurotypical expectations, creating feelings of rejection, frustration and "*disconnect between me and society"* (Angela). Participants often reported feeling that autism is misunderstood and described common unhelpful stereotypes. All the participants recalled social challenges, including attempts to navigate social rules. Some participants reflected on the impacts of these experiences on their mental health.

The burden of conformity. Over half of the participants reflected on their autism diagnosis in comparison to societal norms and the pressure to conform to neurotypical expectations:

> *"being left-handed in a right-handed world… I've been in a neurotypical world and people have been trying to treat me and condition me as if I was neurotypical and I'M NOT!"* (Karen)

Karen suggests that she feels society wants to change or "*repair*" (Angela) her to be more neurotypical. "*Treat*" suggests something is wrong, requiring intervention, echoing traditional medical model narratives of autism. Other participants shared similar views stating they were often "*made to feel less*" (Debby) or "*broken*" (Sue, Juliet, Karen). During the interviews, Juliet and Melissa also reflected on Applied Behavioral Analysis (ABA), which controversially employs conditioning methods to change autistic children's behaviours. Understandably, most participants expressed disappointment and feeling "*frustrated at the world at large*" (Stacey) towards society's intolerance of difference and various rules:

> "*so many straight jackets and so much rigidity, most of it unspoken" (Angela).*

Angela's description illustrates her perception of societal expectations as vague, invasive, and restrictive. Participants also expressed feelings of confusion and injustice when reflecting on social rules. Reflections at the "*world*" emphasises the intensity of these feelings, suggesting the experience is relentless with little reprieve from the reminder of their felt differences. These descriptions also position participants as separate from the world rather than a part of it. 'Common humanity versus isolation' is one element of Neff's (2003) definition of self-compassion; these quotes illustrate the isolation the participants often reported. Similarly, Debby is the mother of three autistic children, and she described other people's distress as "*waves*" compared with "*tsunamis*" her family experience. This comparison positions her emotional pain as more intense and distinct to her personal experience, increasing her sense of isolation. Neff (2003) suggests neglecting the common humanity of distress is a barrier to developing self-compassion. Participants' descriptions of isolation and feeling different regarding their diagnosis potentially limit their resources for self-compassion.

Emotional intensity was commonly reported;

> *"I'm an emotional sponge..."* (Jessica).
>
> "We *feel more empathy…and become burnt out… neurotypical people just see things and they get on…"* (Louise).

These descriptions contrast with common misconceptions that autistic people do not experience empathy and add to the felt difference autistic women described compared to neurotypical others.

Participants varied in how they described their diagnosis; Karen expressed a sense of superiority, "*a gifted state*", whereas Melissa described autism as "*really disabling*". Some participants shared reflections on the Social Model of Disability (Oliver, 1983) and highlighted the importance of adaptations to best support their needs. Participants also described feeling different from others in relation to sensory differences. Some participants discussed the conflict between age-appropriateness and their preferred interests, highlighting a further disconnect with societal expectations.

Many participants described having different thinking styles, feeling that they tended to "*think very, very deeply on things* "(Juliet) or "*ruminate*" (Jessica) more than others, often about social situations. It is likely that these unhelpful thinking styles are also barriers to self-compassion. Neff (2003) described mindfulness as an important element of self-compassion rather than the 'over identification' of thoughts and feelings that participants frequently reported. In addition, most participants also referred to traits of perfectionism and how this impacted self-compassion:

> *"I'm not sure that they put a value judgement on it in the same way that I do being autistic, you know I need to be the best mum… I think that's been really hard to make it easier to be compassionate and kind to myself."* (Jessica)

It could be argued that the commonly reported traits of perfectionism are related to the pressure to conform to societal expectations to mitigate the risk of further rejection. Most participants reflected on the sense of purpose and value they felt from their current or previous employment. These comments echoed narratives around making contributions to society and feeling valued by others. Angela reflected on the detrimental impact seeking support from the benefits system had on her mental health.

Autism is misunderstood. Participants described an overwhelming sense of feeling misunderstood, underpinned by society's neurotypical definitions and expectations of autism. For some participants, these feelings prompted their aspirations to advocate for inclusion.

Participants reported wanting to improve other people's understanding of autism by facilitating autism training (Juliet, Natasha & Melissa) and participating in research. Participants expressed their frustration when reflecting on misconceptions of autism, including assumptions about intellectual and verbal abilities and suggestions that autism only occurs in males. Many participants suggested the media's portrayal of autism further perpetuates misunderstandings. Participants tended to be cautious in their responses when describing some of their experiences, not wanting to generalise to other autistic people, contrasting with how participants felt society often groups together their idiographic experiences.

> *"A lot of people still think of autism as nonverbal, rocking in a corner… they tend to be less aware that somebody who looks normal and is articulate and well educated can still have (pause), have a spectrum disorder"* (Karen).

Two participants (Juliet & Melissa) specifically referred to ABA and invalidating descriptions they have heard expressed about the autistic community:

> *"people who say they would abort their child if they were Autistic… people who are Autistic need to be more neurotypical and kind of backing the ABA therapy… I had this compassion for myself then I came across some of these comments and I just felt awful." (Juliet)*

This quote links to participants' reports of feeling rejected by not meeting society's expectations, with the ultimate rejection to be excluded from existence. Understandably, hearing these extreme views is reported to impact Juliet's self-compassion negatively. This illustrates the interlinked three flows of compassion (Gilbert, 2010) and how criticism from others can be internalized. Comparatively, most participants also referred to helpful resources from the autistic community (e.g., Temple Grandin) to challenge these misconceptions. Overall, participants felt inclusion could be improved and shared hopes for society to celebrate neurodiversity.

> *"Autistic people are often dismissed, ignored and misunderstood and we don't celebrate people who are autistic erm from history… it's almost like you are fighting to be seen and be understood but in the space of an oncoming express train of misunderstanding and misinterpretation… I know there are lots of us out there trying to be visible and give the authentic view…."* (Debby)

The "*express train*" metaphor illustrates the intensity and frequency of the misconceptions autistic people experience and efforts to challenge. Debby's pronoun use contrasts during the extract, with "*we*" not celebrating autistic people, suggesting society generally, contrasted with "*lots of us*" describing autistic people attempting to challenge misconceptions. This description may reflect the process of adjustment to her autistic identity and group membership.

Sue, Natasha and Juliet reflected on their previously limited understanding of autism, before questioning if they may meet the diagnostic criteria, echoing common misconceptions and the stark contrast to the reality of their experience and current understanding.

> *"…little boys that were playing on their own in a corner… they never want hugs err like mutism and erm massive meltdowns, that were just the picture of autism I had… it's hard to explain it's such a massive spectrum."* (Sue)

Professionals' limited understandings of autistic women were expressed as a barrier to assessment. Some participants reported requesting specialist assessments to ensure professionals understood gender differences.

> *"I wanted the Female Clinical Specialist Unit… someone who was really skilled and could break apart that masking that I'd built up for years… … I know with women who are autistic a lot of the time they are not believed, and I think that can almost be as damaging as being diagnosed or not diagnosed"* (Jessica)

Social challenges. All participants reported social challenges, including experiences of victimisation, "*gaslighting*" (Melissa & Karen) and interpersonal difficulties. Participants described the enormous effort required for social interactions and the necessity of self-care activities such as "*downtime*" (Jessica) and *"not doing"* (Tara) to "*recharge*" (Sue, Karen) their depleted energy resources. Many participants described the challenges of social expectations and expressed confusion around social rules:

> *"it felt like erm, other people had been given an instruction manual on how to navigate the world and I hadn't been given that."* (Stacey)

Despite the immense energy required for socialising, many participants described efforts to seek approval from others. Discussions illustrated how social interactions are internalised and influence participant's experiences of self-compassion. This quote demonstrates the interaction between the three flows of compassion (Gilbert, 2010). Debby described how receiving compassion from others cultivates her self-compassion:

> *"… it's easier to be kind to myself and forgiving when I've had a more positive interactions."*

Participants varied in their evaluations of social challenges they had experienced prior to receiving their autism diagnosis. Some suggested their diagnosis facilitated a shift from self-blame to anger towards people that had been unkind to them:

> *"I just felt bad about myself at the time… now I feel good about myself and cross with them."* (Karen).

Whereas Tara described feeling "*more forgiving*" of others, when reflecting on past social difficulties. She reported that receiving her autism diagnosis had prompted her to repair a relationship over 30 years after an argument. This suggested an increase in her compassion towards others post-diagnosis.

Mental health impact. Considering the sense of rejection from society and social challenges, unsurprisingly, most participants discussed experiencing mental health issues.

> *"…depression and anxiety from feeling so different and that I didn't understand the rest of the world."* (Karen)

Karen's description indicates elements of self-blame for not understanding the world and emphasises the sense of isolation. Participants also described feeling misunderstood by professionals and being misdiagnosed. Some participants reflected on the timing of their autism diagnosis and if they had been diagnosed earlier in life, their mental health might be improved:

> *"they diagnosed the social anxiety whereas I think it's just a reaction to you know the stress of masking… apparently that's quite common with autism that you get a lot of false diagnoses before you get the one that actually is you."* (Angela)

This description challenges the medical model approach and illustrates the power dynamic between professionals imposing diagnostic labels, which contrasted with Angela's understanding. Participants' reports also highlighted the psychological impact of rejection and the unintended consequences of coping strategies such as masking.

> *"you end up feeling like you, you've got either a deficiency or you're broken in some way, shape or form."* (Sue)

Pre-diagnosis, participants internalised the negative reactions from others, adding to their negative self-perception. This way of self-relating is linked to the 'self-kindness versus self judgement' element of Neff's (2003) definition and presents participants' self-criticism as a barrier to their self-compassion.

Unmasking: the process of self-acceptance

This super-ordinate theme considers how participants' autism diagnosis facilitated greater self-understanding and provided a new "*lens*" (Debby & Jessica) to their difficult past experiences. All participants expressed a range of emotions about receiving their diagnosis, including feelings of validation and grief. Most participants suggested that their increased self-understanding had developed their self-acceptance, whilst also recognising the process of "*unlearning*" (Melissa) and "*unmasking*" (Sue) would take time due to receiving the diagnosis later in life.

Autonomy and self-compassion. Participants described their autism diagnosis to explain some of their difficulties, particularly when reflecting on challenges in the past. This new understanding transformed previous negative feelings of "*failure*" (Stacey), "*blame*" (Natasha, Debby) and provided a new, "*less critical*" (Karen) view of themselves.

Many participants described a critical internal dialogue pre-diagnosis, searching for answers and often blaming themselves for difficulties. For most participants, the diagnosis facilitated greater self-understanding and self-compassion:

> *"… 'why am I like this', this little voice told me and now it's like I understand what I'm going through and I can sort of de-escalate it quicker… it's like I'm accepting of who I am whereas before I wasn't at all."* (Juliet)

Participants referred to their sense of autonomy, suggesting that their diagnosis provided "*permission*" (Jessica) to explain and "*a backing*" (Natasha) to assert their needs; "*it's just letting myself be me a bit more."* (Stacey). Most participants reported setting boundaries for self-care post-diagnosis, particularly with social activities and needing "*downtime*" (Jessica). Generally, learning to maintain boundaries was described as helpful, however; some participants expressed a concern that asserting their needs could limit their experiences:

> *"I probably have been a bit kinder with myself, but again it's striking that balance between being kind enough to yourself and not overindulging yourself."* (Stacey).

Most participants reflected on the process of adjusting to the new experience of self-kindness post-diagnosis. Stacey's quote also presents a common negative perception of self-compassion, fearing self-compassion is a weakness or self-indulgent (Gilbert & Mascaro, 2017). This quote also alludes to participants' commonly reported striving traits. It is unsurprising that self-compassion may feel threatening when people have had limited experiences of compassion previously.

Increased self-understanding from the diagnosis prompted participants to research autism and recommended soothing items, e.g. weighted blankets. Other commonly reported self-care strategies included spending time in nature, sensory activities (touch and music), and having time alone, "*being on my own, being wrapped up.*" (Stacey)

Increased self-understanding allowed most participants to begin to reveal their authentic selves.

> *"… it's given me my identity back because that had just totally vanished from the amount of masking I were doing..."* (Sue)

This process suggests the diagnosis facilitated participant's experiences of self-compassion, accepting their reality with kindness, rather than commonly report self-criticism pre-diagnosis.

Validation and grief. All the participants had requested their autism assessments and initially, the diagnosis provided "*relief*" (Melissa, Juliet, Sue & Karen) confirming their suspicions.

> *"it felt vindicating, it felt affirming, it felt really good, that, that I wasn't sort of erm mad or bad just, just different… it makes me feel a bit special I think (laugh), quite valuable and I think I see the skills that I have more than feeling a bit of a freak"* (Karen).

This quote illustrates how the diagnosis facilitated Karen to reframe her differences as "*skills*", compared to feeling a "*freak*". This description supports the suggestion the diagnosis facilitated participants' self-compassion.

Over time the initial relief and "*euphoria*" (Debby) towards receiving the diagnosis was accompanied by conflicting feelings, highlighting the "*long process to unravel all the damage there's been done from being undiagnosed"* (Melissa) and uncertainty for the future.

> *"you know when you try on a new suit and you're just getting comfortable in it and you're still not quite comfortable, you're not sure if it suits you or if it fits."* (Jessica)

Jessica's metaphor of "*a new suit*" illustrates the process of adjustment, the initial discomfort and alludes to the formality of the diagnosis. Most participants described "*a grieving process"* (Debby) and sadness towards their late diagnosis. In comparison, Natasha wondered if she would be as successful in her employment if she had received her diagnosis earlier:

> *"…would I have pushed myself to get to where I wanna be or where I am now had I had that [diagnosis]".*

Arguably this links the participants' striving traits with the experience of living with undiagnosed autism. Alternatively, this view may be more beneficial for Natasha's self-preservation as ultimately, it is impossible to know how an earlier diagnosis may have impacted her life. Some participants described questioning themselves, reflecting on the permanence of the diagnosis, their initial expectations, and occasional feelings of frustration:

> *"I do sometimes question why I am autistic, sort of why me."* (Tara)

Impact on relationships

This super-ordinate theme explores the impact on participant's relationships post-diagnosis, exploring reflections on diagnosis disclosure and shared experiences of autism.

Diagnosis disclosure. Participants described unhelpful stereotypes and previously invalidating responses as barriers to their autism diagnosis disclosure. Participants reflected on the process of adjustment to disclosing their diagnosis:

> *"I'm starting to accept myself so I feel comfortable saying it [diagnosis] now."* (Juliet)

Most participants described feeling hesitant about sharing their diagnosis with their employer and colleagues unless they require reasonable adjustments in the workplace. Sue was looking for work at the time of the interview and shared her dilemma about disclosing her diagnosis and suggested she was suspicious about future employer's inclusivity.

> *"…I'm not just going to be totally out and open with absolutely everyone straight away and go "I'm Autistic" because they will think stereotypical things… and then you're on the defensive straight away… do I tell people I've got autism in the application process, well I know legally in Disability Law you're not meant to erm discriminate but how are they gonna prove that at the end of the day."*

Participants reported supportive responses post-diagnosis disclosure from close friends and family but shared concerns about the impact of disclosure in professional settings.

> *"I've told my family, all my family know and they've been amazing about it, erm and I've told some really close friends and they've all been great about it but professionally I've been really guarded because I don't want anyone to judge me on that…"* (Jessica)

Connection and understanding. Participants suggested their shared experiences with other autistic people facilitate understanding and connection.

> *"I do make an effort to see my friend I made through that autism group, it's nice to talk about our experiences… what we're finding out about ourselves and to be with someone that you're not worried about being judged."* (Sue)

Sue, Natasha and Angela shared that since their diagnosis they suspected that one of their parents was undiagnosed autistic. Their suspicions helped make sense of challenges in their relationships, arguably cultivating compassion for their parents. In addition, Louise, Natasha, Karen, Debby and Jessica reported that their children or siblings also had confirmed or suspected autism. Two participants reflected on their enhanced ability to understand their client's needs in their employment working with autistic adults and children with additional needs.

> *"… to me it just feels normal…it feels natural and I can help them, I don't know what they are thinking but I can sense what they are wanting to do and feeling… if I hadn't got autism I probably wouldn't have been able to help them to that extent…"* (Louise)

In contrast, Debby shared that she continues to feel disconnected from peers post-diagnosis:

> *"…this new life even though theoretically I'm better informed to find that tribe but I don't always feel a part of it…*" (Debby).

This quote indicates that connection did not necessarily increase for all participants post-diagnosis.

Discussion

This study aimed to investigate autistic women's experiences of receiving their diagnosis in adulthood and whether receiving their diagnosis has influenced their reflection on, perception of and actions in relation to self-compassion. Three super-ordinate themes emerged: *'Disconnect between me and society'*; '*Unmasking: the process of self-understanding'* and *'Impact on relationships'*.

The first super-ordinate theme, '*Disconnect between me and society',* reflects the various social challenges experienced and participants' felt difference. This finding is consistent with previous research (e.g., Kanfiser et al., 2017) and the impact of these experiences on low mood (e.g., Jordan et al., 2021). Similarly, research suggests some autistic people view "difference" as an experience of not belonging (e.g., Griffith et al., 2012; Ruiz Calzada et al., 2012). The current study provides insight into the impact of these experiences on autistic women's self-compassion. Applying Neff's (2003) 'isolation over common humanity' element of self-compassion to the data suggests autistic people's felt difference is a barrier to developing self-compassion.

Mental health impact was discussed across the interviews. Previous research suggests mental health issues are common, with a 53% lifetime rate of mood disorders in autistic adults (Hofvander et al., 2009). Mental health issues are associated with lower levels of self-compassion (Macbeth & Gumley, 2012). The common co-occurrence of mental health issues is likely to be a barrier to autistic people's self-compassion. Experiences of mental health misdiagnosis were reported; this is consistent with previous research (Bargiela et al., 2016; Eaton, 2018) and is suggested to be underpinned by professionals' limited understanding of autism (Au-Yeung et al., 2019). This finding highlights the need for further training to reduce misdiagnosis and improve autism awareness.

Social stigma was discussed, including unhelpful stereotypes and misconceptions of autism. This finding is consistent with previous research where stereotypes consistently presented autistic individuals as "weird" (Treweek et al., 2019) and autistic traits were rated negatively by non-autistic people (Wood & Freeth, 2016). Recent qualitative research suggests the dominant social constructions of autism prioritise a deficit medical model and significantly impact autistic women's well-being (Seers & Hogg, 2021). Participants reported wanting to challenge negative narratives of autism; this is consistent with the Neurodiversity Movement (Silberman, 2017). Autistic self-advocates often challenge the medical model of autism and celebrate autism as inseparable from identity (Baker, 2011; Jaarsma & Welin, 2012; Jordan, 2010). Promoting the voice of the autistic community helps better understand their experience and attempts to counteract the 'double empathy problem' (Milton, 2012), which underpins misconceptions of autism. Several participants reported victimisation experiences, which is also consistent with previous literature (Treweek et al., 2019; Weiss & Fardella, 2018). Research suggested the social challenges associated with autism could increase the risk of mental health issues, including bullying (Bejerot & Mörtberg, 2009; Zablotsky et al., 2014) and non-acceptance from others (Cage et al., 2018; Sasson et al., 2017). Mead's (1934) view of the self is relational and symbolic, suggesting that our sense of self is developed in relation to others. Pre-diagnosis participants compared themselves to non-autistic others, feeling different and isolated. Arguably, later diagnosis equates to more years of comparisons and potentially more criticism from others which is internalised as self-criticism. This relates to Neff's (2003) description of 'self-judgement' as a barrier to 'self-kindness' and highlights the importance of earlier identification.

Participants described societal expectations, feeling different and unhelpful thinking styles as barriers to self-compassion. Research suggests people with low self-compassion are more likely to ruminate and tend to experience extreme emotional responses (Leary et al., 2007; Neff et al., 2007). Research also suggests emotional intensity and rumination positively correlate with autistic traits in autistic and non-autistic people (Brunyé et al., 2012; Joshi et al., 2018; Zhao et al., 2020). Perfectionism also has links with autism (Fung, 2009; Greenaway & Howlin, 2010). Galvin et al. (2021) suggested unhelpful thinking styles and social communication difficulties associated with autism lead to 'over-identification over mindfulness' and create critical self-perceptions, 'self-judgement over self-kindness'. This description suggests autistic people are more likely to have reduced self-compassion, compared to non-autistic people.

The second super-ordinate theme, *'Unmasking: the process of self-understanding',* considers how participants' autism diagnosis facilitated greater self-understanding, developing self-acceptance and self-compassion. Similarly, Hickey et al. (2018) suggested autism diagnosis promoted self-acceptance. In this study, participants resisted negative narratives of autism, embraced their strengths, and developed adaptive coping strategies post-diagnosis, as also reported by Seers and Hogg (2021). Participants stated that their diagnosis provided an explanation of their difficulties, consistent with previous research (e.g., Jordan et al., 2021). Most participants described their diagnosis to provide permission to assert their needs and reflected on various self-care activities, including boundaries for social interactions. Participants' descriptions align with Neff's (2003) definition of self-compassion, generating self-kindness and understanding towards their difficulties. However, some participants suggested that their diagnosis encouraged more self-analysis, which was not always reported as constructive.

All participants expressed a range of emotions about receiving their diagnosis, including feelings of validation and grief, illustrating how receiving the diagnosis is a very individual experience. This mixture of emotions is consistent with previous research exploring autistic women's experiences of their diagnosis in adulthood (e.g., Bargiela et al., 2016; Leedham et al., 2020). In terms of self-understanding, ASC terminology was briefly discussed. One participant expressed a preference for "high functioning Asperger's", whereas most participants preferred "autism" or "autistic" and suggested reductionistic "functioning labels" were invalidating. A UK online survey revealed autistic adults and family members favored identity-first terms, e.g., 'autistic' or 'autistic person' (Kenny et al., 2016).

The third super-ordinate theme, '*Impact on relationships',* illustrates the social changes post-diagnosis, including dilemmas around diagnosis disclosure and connection with autistic others. The potential genetic element of autism was discussed, with many participants reporting family members to have confirmed or suspected autism and described a mutual understanding of each other's needs. Recent qualitative research described feelings of closeness and intense connection between autistic mothers and their children with diagnosed or suspected autism (Dugdale et al., 2021). Several participants also reported working with autistic people and having a greater understanding due to their shared diagnosis. This finding supports previous research highlighting the mutual understanding and empathy between autistic people (Komeda, 2015).

Misconceptions of autism were reported as a barrier to diagnosis disclosure, particularly with employers. Previous research suggests barriers to autistic people gaining employment included limited understanding of autism, communication difficulties and stigma (Black et al., 2020). Comparatively, participants described supportive responses from close friends and family; consistent with previous research (Leedham et al., 2020; MacLeod et al, 2018).

Methodological Critique and Directions for Future Research

The IPA methodology gives a voice to participants' experience of receiving their autism diagnosis and experiences of self-compassion. Most participants reported receiving their diagnosis aged 35-39 years old. Research suggested that females are diagnosed with autism later in life than males, (Begeer et al., 2013; Siklos & Kerns, 2007), in adult diagnostic services the gender ratio is lower than in child services, with approximately 2 males to 1 female, in adult services (Rutherford, et al., 2016). Research also suggests having a child diagnosed with autism can prompt some parents to seek their own diagnosis (e.g., Powell & Acker, 2016), this was reported by some participants in this study. This suggests participants received their diagnosis at a similar age to other autistic women diagnosed in adulthood. Participants varied in their time since diagnosis, from two months to 24 years. Time post-diagnosis may have influenced their feelings towards their diagnosis, experiences of self-compassion and may limit the transferability of the results. However, transferability is not a goal of IPA research.

Several participants referred to the terms compassion and self-compassion when sharing their reflections. This was raised as a concern in supervision and the influence of social desirability bias on the findings was discussed. Researchers discussed the potential bias from the information sheet with Neff's (2003) definition of self-compassion. Participants' responses were considered with the information provided, noting similarities and differences, to identify participants' personal meanings of self-compassion.

All the participants identified as white British and their experiences may differ from autistic women from other ethnic backgrounds. Simmonds (2021) suggests "black autistics wear a triple mask". Consistent with previous research, participants in this study reported 'masking' to manage social situations (Cook et al., 2018) and the impact these compensatory behaviours have on mental health (Bargiela et al., 2016; Cage et al., 2017). It is hypothesized "a triple mask" presents further barriers to self-compassion. A report by the National Autistic Society (Slade, 2014) stated that ethnic minority communities face additional challenges to obtaining autism diagnoses and support. Kandeh et al. (2018) also highlighted the importance of culturally aware autism education. Kelly et al. (2019) reported ethnic minority children had lower levels of autism diagnosis in the UK. Comparatively Keen et al. (2010) reported higher rates of autism in Black ethnic groups, with non-significant differences for autism diagnosis in South Asian groups. Future research may wish to explore autistic women's experiences of self-compassion from other ethnic backgrounds.

Research suggests socio-economic inequalities exist for the diagnosis of autism in the UK; Kelly et al. (2019) reported that children of mothers with higher education had twice the rate of autism diagnosis, compared to children of mothers with lower-level education status. Similarly, Adak and Halder's (2017) systematic review stated higher prevalence rates of autism are reported in developed countries and prevalence was also positively associated with parental socio-economic status (SES). Information about participants' SES was not collected, limiting the exploration of the influence of SES on their experiences of diagnosis and self-compassion.

The interviews were conducted during the COVID-19 pandemic and restrictions prevented face-to-face interviews. The interview method may have impacted the data, potentially excluding participants less confident in using remote options. Most participants celebrated the reduced pressures of socializing in the national lockdowns; this is consistent with Pais and Knapp (2020) findings.

One of the interviews was inaudible for transcribing due to technical issues and subsequently excluded from the analysis. Excluding the interview reduces the data available and potentially limits alternative viewpoints and experiences. However, a variety of responses were obtained from the eleven audible interviews and this sample size is within the range of participants commonly found in IPA studies.

Clinical Implications

This study highlights several clinical implications and provides an insight into autistic women’s experiences of self-compassion. Most participants reported that their diagnosis facilitated self-compassion, compared to high levels of self-criticism pre-diagnosis. This finding has important clinical implications given the relationship between reduced self-compassion and mental health symptoms (MacBeth & Gumley, 2012). This research highlights the importance of early identification and recommends that clinical psychologists consider potential indicators of undiagnosed autism in formulations with women accessing mental health services. This study suggests the potential benefit of self-compassion interventions to improve autistic women’s well-being. Clinical psychologists often receive training in Compassion Focused Therapy (Gilbert, 2009) and have the relevant skills to explore the effectiveness of self-compassion interventions and potential adaptations for autism.

Participants commonly reported limited understanding from others, misconceptions of autism and experiences of misdiagnosis. These experiences highlight the need for further training for professionals in primary care, mental health services, schools, and other agencies to support all individuals and reduce the unmet needs of autistic women. Training should be provided by autistic individuals where possible. Similarly, Fletcher-Watson et al. (2019) also recommends participatory autism research to provide relevant outcomes for the community. Clinical psychologists can promote patient and public involvement in autism research, staff training and consultations for service developments.

This study suggests late diagnosis equates to more years of social challenges, adding to feelings of isolation and detrimental impact on mental health. In comparison, receiving the diagnosis was reported to generate self-kindness and self-understanding, aligning with Neff’s (2003) definition of self-compassion. Participants described the process of adjusting to the diagnosis and learning new ways of self-relating as ongoing. These reports highlight the importance of early identification and post-diagnostic support. These findings have specific implications for clinical psychologists to influence autism pathways in services. These findings could also extend to the experiences of late-diagnosed autistic men and non-binary autistic individuals, reiterating the importance of early identification.

Conclusions

Previous research suggests neurotypical women have lower levels of self-compassion than men (Yarnell et al., 2015). This study suggests self-compassion could be even more reduced in autistic women, particularly undiagnosed. Unhelpful thinking styles, social rejection and misconceptions of autism were commonly reported as barriers to self-compassion. Participants' felt difference aligns with Neff's (2003) 'isolation over common humanity' highlighting the barrier to self-compassion. This emphasises the importance of early identification to reduce the risks associated with low self-compassion and mental health symptoms (MacBeth & Gumley, 2012). Training for professionals is essential to improve autism awareness and should be delivered using a participatory approach. Most participants reported that their diagnosis facilitated self-understanding and developed self-compassion. For some, diagnosis also developed compassion towards others, providing a greater understanding of other autistic people's needs. This included some participants choosing to work with autistic people, while others considered whether family members might also meet diagnostic criteria, explaining previous interpersonal challenges. Participants also reported increased autonomy post-diagnosis and confidence to assert their needs. The findings relate to Neff's (2003) elements of self-compassion and suggest the potential benefit of self-compassion interventions to improve autistic women's well-being.

References

Abbott, M., Bernard, P., & Forge, J. (2012). Communicating a diagnosis of Autism Spectrum Disorder-a qualitative study of parents' experiences. *Clinical Child Psychology and Psychiatry*, *18*, 370-382. https://doi.org/10.1177/1359104512455813

American Psychiatric Association. (2013). *Diagnostic and Statistical Manual of Mental Disorders 5 (DSM-5).* Washington, DC: American Psychiatric Association.

Attwood, T. (2007). The pattern of abilities and development of girls with Asperger's syndrome. In T. Attwood, & T. Grandin (Eds.), *Asperger's and girls* (pp. 1-6). Texas, USA: Future Horizons.

Au-Yeung, S. K., Bradley, L., Robertson, A. E., Shaw, R., Baron-Cohen, S., & Cassidy, S. (2019). Experience of mental health diagnosis and perceived misdiagnosis in autistic, possibly autistic and non-autistic adults. *Autism*, *23*, 1508-1518. https://doi.org/10.1177/1362361318818167

Baker, D. L. (2011). *The Politics of Neurodiversity: Why Public Policy Matters*. Boulder, CO: Lynne Rienner Publishers.

Bargiela, S., Steward, R., & Mandy, W. (2016). The experiences of late-diagnosed women with autism spectrum conditions: An investigation of the female autism phenotype. *Journal of Autism and Developmental Disorders, 46,* 3281-3294. https://doi.org/10.1007/s10803-016-2872-8.

Barnard, L., & Curry, J. (2011). Self-Compassion: Conceptualizations, Correlates, & Interventions. *Review of General Psychology*, *15*, 289-303. https://doi.org/10.1037/a0025754

Begeer, S., Mandell, D., Wijnker-Holmes, B., Venderbosch, S., Rem, D., Stekelenburg, F., & Koot, H. M. (2013). Sex differences in the timing of identification among children and adults with autism spectrum disorders. *Journal of Autism and Developmental Disorders*, *43*, 1151-1156. https://doi.org/10.1007/s10803-012-1656-z

Bejerot, S., & Mörtberg, E. (2009). Do autistic traits play a role in the bullying of obsessive-compulsive disorder and social phobia sufferers? *Psychopathology*, *42*, 170-176. https://doi.org/10.1159/000207459

Biggerstaff, D., & Thompson, A. (2008). Interpretative phenomenological analysis (IPA): A qualitative methodology of choice in healthcare research. *Qualitative Research in Psychology*, *5*, 214-224. https://doi.org/10.1080/14780880802314304

Black, M. H., Mahdi, S., Milbourn, B., Scott, M., Gerber, A., Esposito, C., Falkmer, M., Lerner, M. D., Halladay, A., Strom, E., D'Angelo, A., Falkmer, T., Bolte, S., & Girdler, S. (2020). Multi-informant international perspectives on the facilitators and barriers to employment for autistic adults. *Autism Research*, *13*, 1195-1214. https://doi.org/10.1002/aur.2288

Brunyé, T. T., Ditman, T., Giles, G. E., Mahoney, C. R., Kessler, K., & Taylor, H. A. (2012). Gender and autistic personality traits predict perspective-taking ability in typical adults. *Personality and Individual Differences*, *52*, 84-88. https://doi.org/10.1016/j.paid.2011.09.004

Cage, E., Di Monaco, J., & Newell, V. (2017). Experiences of autism acceptance and mental health in autistic adults. *Journal of Autism and Developmental Disorders*, *48*, 473-484. https://doi.org/10.1007/s10803-017-3342-7

Cook, A., Ogden, J., & Winstone, N. (2018). Friendship motivations, challenges and the role of masking for girls with autism in contrasting school settings. *European Journal of Special Needs Education*, *33*, 302-315. https://doi.org/10.1080/08856257.2017.1312797

Cooper, K., Smith, L., & Russell, A. (2017). Social identity, self-esteem, and mental health in autism. *European Journal of Social Psychology*, *47*, 844-854. https://doi.org/10.1002/ejsp.2297

DePape, A., & Lindsay, S. (2016). Lived experiences from the perspective of individuals with autism spectrum disorder. *Focus on Autism and Other Developmental Disabilities*, *31*, 60-71. https://doi.org/10.1177/1088357615587504

Dugdale, A. S., Thompson, A. R., Leedham, A., Beail, N., & Freeth, M. (2021). Intense connection and love: The experiences of autistic mothers. *Autism,*1-12. https://doi.org/10.1177/13623613211005987

Eaton, J. (2018). *A Guide to Mental Health Issues in Girls and Young Women on the Autism Spectrum. Diagnosis, Intervention and Family Support.* London, UK: Jessica Kingsley Publishers.

Fletcher-Watson, S., Adams, J., Brook, K., Charman, T., Crane, L., Cusack, J., Leekam, S., Milton, D., & Pellicano, E. (2019). Making the future together: Shaping autism research through meaningful participation. *Autism*, *23*, 943-953. https://doi.org/10.1177/1362361318786721

Fung, C. H. (2009). Asperger's and musical creativity: The case of Erik Satie. *Personality and Individual Differences*, *46*, 775-783. https://doi.org/10.1016/j.paid.2009.01.019

Fusar-Poli, L., Brondino, N., Politi, P., & Aguglia, E. (2020). Missed diagnoses and misdiagnoses of adults with autism spectrum disorder. *European Archives of Psychiatry and Clinical Neuroscience*, 1-12. https://doi.org/10.1007/s00406-020-01189-w

Galvin, J., Howes, A., McCarthy, B., & Richards, G. (2021). Self-compassion as a mediator of the association between autistic traits and depressive/anxious symptomatology. *Autism*, *25*, 502-515. https://doi.org/10.1177/1362361320966853

Gilbert, P. (2009). Introducing compassion-focused therapy. *Advances in Psychiatric Treatment*, *15,* 199-208. https://doi.org/10.1192/apt.bp.107.005264

Gilbert, P. (2010). *Compassion focused therapy: Distinctive features.* London, UK: Routledge.

Gilbert, P., & Mascaro, J. (2017). Compassion fears, blocks, and resistances: An evolutionary investigation. In E. Sappla, & J. Doty (Eds.). *Handbook of Compassion* (pp. 399–416). New York, NY: Oxford University Press.

Gould, J. (2017). Towards understanding the under-recognition of girls and women on the autism spectrum. *Autism, 21,* 703-705. https://doi.org/10.1177/1362361317706174

Greenaway, R., & Howlin, P. (2010). Dysfunctional attitudes and perfectionism and their relationship to anxious and depressive symptoms in boys with autism spectrum disorders. *Journal of Autism and Developmental Disorders*, *40*, 1179-1187. https://doi.org/ 10.1007/s10803-010-0977-z

Griffith, G., Totsika, V., Nash, S., & Hastings, R. (2012). 'I just don't fit anywhere': support experiences and future support needs of individuals with Asperger syndrome in middle adulthood. *Autism*, *16*, 532-546. https://doi.org/10.1177/1362361311405223

Hacking, I. (2009). Autistic autobiography. *Philosophical Transactions of the Royal Society B: Biological Sciences*, *364*, 1467-1473. https://doi.org/10.1098/rstb.2008.0329

Hedley, D., Uljarević, M., Foley, K. R., Richdale, A., & Trollor, J. (2018). Risk and protective factors underlying depression and suicidal ideation in autism spectrum disorder. *Depression and Anxiety*, *35*, 648-657. https://doi.org/10.1002/da.22759

Hickey, A., Crabtree, J., & Stott, J. (2018). 'Suddenly the first fifty years of my life made sense': Experiences of older people with autism. *Autism*, *22*, 357-367. https://doi.org/10.1177%2F1362361316680914

Hirvikoski, T., Mittendorfer-Rutz, E., Boman, M., Larsson, H., Lichtenstein, P., & Bölte, S. (2016). Premature mortality in autism spectrum disorder. *British Journal of Psychiatry*, *208*, 232-238. https://doi.org/10.1192/bjp.bp.114.160192

Hofvander, B., Delorme, R., Chaste, P., Nydén, A., Wentz, E., Ståhlberg, O., Herbrecht, E., Stopin, A., Anckarsater, H., Gillberg, C., Rastam, M., & Leboyer, M. (2009). Psychiatric and psychosocial problems in adults with normal-intelligence autism spectrum disorders. *BMC Psychiatry, 9,* 1-9. https://doi.org/10.1186/1471-244X-9-35

Howard, K., Katsos, N., & Gibson, J. (2019). Using interpretative phenomenological analysis in autism research. *Autism*, *23*, 1871-1876. https://doi.org/10.1177/1362361318823902

Howes, A., Richards, G., & Galvin, J. (2020). A preliminary investigation into the relationship between autistic traits and self-compassion. *Psychological Reports*. https://doi.org/10.1177/0033294120957244

Hull, L., Petrides, K.V., Allison, C., Smith, P., Baron-Cohen, S., Lai, M.-C., & Mandy, W. (2017).“Putting on my best normal”: Social camouflaging in adults with autism spectrum conditions. *Journal of Autism and Developmental Disorders, 47,* 2519-2534. https://doi.org/10.1007/s10803-017-3166-5

Humphrey, N., & Lewis, S. (2008). Make me normal' The views and experiences of pupils on the autistic spectrum in mainstream secondary schools. *Autism*, *12*, 23-46. https://doi.org/10.1177/1362361307085267

Jaarsma, P., & Welin, S. (2012). Autism as a natural human variation: Reflections on the claims of the neurodiversity movement. *Health Care Analysis, 20,* 20–30. https://doi.org/10.1007/s10728-011-0169-9

Jordan, A. L., Marczak, M., & Knibbs, J. (2021). ‘I felt like I was floating in space’: autistic adults’ experiences of low mood and depression. *Journal of Autism and Developmental Disorders*, *51*, 1683-1694. https://doi.org/10.1007/s10803-020-04638-6

Jordan, C. J. (2010). Evolution of autism support and understanding via the World Wide Web. *Intellectual and Developmental Disabilities*, *48*, 220-227. https://doi.org/10.1352/1934-9556-48.3.220

Joshi, G., Wozniak, J., Fitzgerald, M., Faraone, S., Fried, R., Galdo, M., Furtak, S. L., Conroy, K., Kilcullen, R. J., Belser, A., & Biederman, J. (2018). High risk for severe emotional dysregulation in psychiatrically referred youth with autism spectrum disorder: A controlled study. *Journal of Autism and Developmental Disorders*, *48*, 3101-3115. https://doi.org/10.1007/s10803-018-3542-9

Kandeh, M.S., Kandeh, M.K., Martin, N. and Krupa, J. (2018), "Autism in black, Asian and minority ethnic communities: a report on the first Autism Voice UK Symposium", *Advances in Autism, 6,* 165-175. https://doi.org/10.1108/AIA-12-2018-0051

Kanfiszer, L., Davies, F., & Collins, S. (2017). ‘I was just so different’: The experiences of women diagnosed with an autism spectrum disorder in adulthood in relation to gender and social relationships. *Autism*, *21*, 661-669. https://doi.org/10.1177%2F1362361316687987

Keen, D. V., Reid, F. D., & Arnone, D. (2010). Autism, ethnicity and maternal immigration. *The British Journal of Psychiatry*, *196*, 274-281. https://doi.org/10.1192/bjp.bp.109.065490

Kelly, B., Williams, S., Collins, S., Mushtaq, F., Mon-Williams, M., Wright, B., Mason, D., & Wright, J. (2019). The association between socioeconomic status and autism diagnosis in the United Kingdom for children aged 5–8 years of age: Findings from the Born in Bradford cohort. *Autism*, *23*, 131-140. https://doi.org/10.1177/1362361317733182

Kenny, L., Hattersley, C., Molins, B., Buckley, C., Povey, C., & Pellicano, E. (2016). Which terms should be used to describe autism? Perspectives from the UK autism community. *Autism*, *20*, 442-462. https://doi.org/10.1177/1362361315588200

Komeda, H. (2015). Similarity hypothesis: understanding of others with autism spectrum disorders by individuals with autism spectrum disorders. *Frontiers in Human Neuroscience*, *9*, 124. https://doi.org/10.3389/fnhum.2015.00124

Larkin, M., & Thompson, A.R. (2012). Interpretative phenomenological analysis in mental health and psychotherapy research. In D. Harper, A.R. Thompson (Eds.), *Qualitative Research Methods in Mental Health and Psychotherapy* (pp. 101-116). West Sussex, UK: John Wiley & Sons Ltd.

Leary, M., Tate, E., Adams, C., Batts Allen, A., & Hancock, J. (2007). Self-compassion and reactions to unpleasant self-relevant events: The implications of treating oneself kindly. *Journal Of Personality and Social Psychology*, *92*, 887-904. https://doi.org/10.1037/0022-3514.92.5.887

Leedham, A., Thompson, A., Smith, R., & Freeth, M. (2020). ‘I was exhausted trying to figure it out’: The experiences of females receiving an autism diagnosis in middle to late adulthood. *Autism, 24,* 135-146. https://doi.org/10.1177/1362361319853442

Lever, A., & Geurts, H. (2016). Psychiatric co-occurring symptoms and disorders in young, middle-aged, and older adults with autism spectrum disorder. *Journal of Autism and Developmental Disorders*, *46*, 1916-1930. https://doi.org/10.1007/s10803-016-2722-8

Lewis, L. F. (2017). A mixed methods study of barriers to formal diagnosis of autism spectrum disorder in adults. *Journal of Autism and Developmental Disorders, 47,* 2410-2424. https://doi.org/10.1007/s10803-017-3168-3

MacBeth, A., & Gumley, A. (2012). Exploring compassion: A meta-analysis of the association between self-compassion and psychopathology. *Clinical Psychology Review*, *32*, 545-552. https://doi.org/10.1016/j.cpr.2012.06.003

MacLeod, A. (2019). Interpretative phenomenological analysis (IPA) as a tool for participatory research within critical autism studies: A systematic review. *Research in Autism Spectrum Disorders*, *64*, 49-62. https://doi.org/10.1016/j.rasd.2019.04.005

Maddox, B., & White, S. (2015). Comorbid social anxiety disorder in adults with autism spectrum disorder. *Journal of Autism and Developmental Disorders*, *45*, 3949-3960. https://doi.org/10.1007/s10803-015-2531-5

Mandy, W., Chilvers, R., Chowdhury, U., Salter, G., Seigal, A., & Skuse, D. (2012). Sex differences in autism spectrum disorder: evidence from a large sample of children and adolescents. *Journal of Autism and Developmental Disorders*, *42*, 1304-1313. https://doi.org/10.1007/s10803-011-1356-0

Matson, J. L., & Williams, L. W. (2013). Differential diagnosis and comorbidity: distinguishing autism from other mental health issues. *Neuropsychiatry*, *3*, 233-243. https://doi.org/10.2217/npy.13.1

Mead, G. H. (1934). *Mind, self and society*. University of Chicago Press: Chicago.

Midence, K., & O’Neill, M. (1999). The experience of parents in the diagnosis of autism: A pilot study. *Autism*, *3*, 273-285. https://doi.org/10.1177%2F1362361399003003005

Milton, D. (2012). On the ontological status of autism: the ‘double empathy problem’. *Disability & Society*, *27*, 883-887. https://doi.org/10.1080/09687599.2012.710008

Neff, K. (2003). Self-Compassion: An alternative conceptualization of a healthy attitude toward oneself. *Self and Identity*, *2*, 85-101. https://doi.org/10.1080/15298860309032

Neff, K. D., & Vonk, R. (2009). Self-compassion versus global self-esteem: Two different ways of relating to oneself. *Journal of Personality*, *77*, 23-50. https://doi.org/10.1111/j.1467-6494.2008.00537.x

Neff, K., & Faso, D. (2014). Self-compassion and well-being in parents of children with autism. *Mindfulness*, *6*, 938-947. https://doi.org/10.1007/s12671-014-0359-2

Neff, K., & Germer, C. (2017). Self-compassion and psychological wellbeing. In E. Sappla, & J. Doty (Eds.). *Handbook of Compassion Science* (Chapter 7). Oxford University Press.

Neff, K., Kirkpatrick, K., & Rude, S. (2007). Self-compassion and adaptive psychological functioning. *Journal of Research in Personality*, *41*, 139-154. https://doi.org/10.1016/j.jrp.2006.03.004

Oliver, M. (1983). *Social Work with Disabled People*. Basingstoke: Macmillan.

Pais, S., & Knapp, M. (2020). *The impact of COVID-19 on autistic people, including children and young people, in the United Kingdom.* Policy Innovation and Evaluation Research Unit: London School of Economics and Political Science.

Pakenham, K., Sofronoff, K., & Samios, C. (2004). Finding meaning in parenting a child with Asperger syndrome: correlates of sense making and benefit finding. *Research in Developmental Disabilities*, *25*, 245-264. https://doi.org/10.1016/j.ridd.2003.06.003

Pavlopoulou, G., Wood, R. & Papadopoulos, C. (2020) *Impact of Covid-19 on the experiences of parents and family carers of autistic children and young people in the UK.* UCL Institute of Education: London, UK.

Pellicano, E., Dinsmore, A., & Charman, T. (2014). What should autism research focus upon? Community views and priorities from the United Kingdom. *Autism, 18,* 756-770. https://doi.org/10.1177/1362361314529627.

Pietkiewicz, I. & Smith, J. A. (2012). A practical guide to using Interpretative Phenomenological Analysis in qualitative research psychology. *Psychological Journal, 18,* 361-369. https://doi.org/10.14691/CPPJ.20.1.7

Portway, S., & Johnson, B. (2005). Do you know I have Asperger's syndrome? Risks of a non-obvious disability. *Health, Risk & Society*, *7*, 73-83. https://doi.org/10.1080/09500830500042086

Powell, T., & Acker, L. (2016). Adults' experience of an Asperger syndrome diagnosis: analysis of its emotional meaning and effect on participants' lives. *Focus on Autism and Other Developmental Disabilities*, *31*, 72-80. https://10.1177/1088357615588516

Punshon, C., Skirrow, P., & Murphy, G. (2009). The `not guilty verdict'. *Autism*, *13*, 265-283. https://doi.org/10.1177/1362361309103795

Ruiz Calzada, L. R., Pistrang, N., & Mandy, W. P. (2012). High-functioning autism and Asperger's disorder: Utility and meaning for families. *Journal of Autism and Developmental Disorders*, *42*, 230-243. https:// 10.1007/s10803-011-1238-5

Rutherford, M., McKenzie, K., Johnson, T., Catchpole, C., O'Hare, A., McClure, I., Forsyth, K., McCartney, D., & Murray, A. (2016). Gender ratio in a clinical population sample, age of diagnosis and duration of assessment in children and adults with autism spectrum disorder. *Autism*, *20*, 628-634. https://doi.org/10.1177/1362361315617879

Sasson, N. J., Faso, D. J., Nugent, J., Lovell, S., Kennedy, D. P., & Grossman, R. B. (2017). Neurotypical peers are less willing to interact with those with autism based on thin slice judgments. *Scientific Reports*, *7*, 1-10. http://doi.org/10.1038/srep40700

Scherff, A., Taylor, M., Eley, T. C., Happé, F., Charman, T., & Ronald, A. (2014). What causes internalising traits and autistic traits to co-occur in adolescence? A community-based twin study. *Journal of Abnormal Child Psychology*, *42*, 601-610. https://doi.org/10.1007/s10802-013-9796-y

Seers, K., & Hogg, R. C. (2021). You don't look autistic': A qualitative exploration of women's experiences of being the 'autistic other. *Autism, 25,* 1553-1564. https://doi.org/10.1177/1362361321993722

Shors, T. J., Millon, E. M., Chang, H. Y. M., Olson, R. L., & Alderman, B. L. (2017). Do sex differences in rumination explain sex differences in depression?. *Journal of Neuroscience Research*, *95*, 711-718. https://doi.org/10.1002/jnr.23976

Siklos, S., & Kerns, K. A. (2007). Assessing the diagnostic experiences of a small sample of parents of children with autism spectrum disorders. *Research in Developmental Disabilities*, *28*, 9-22. https://doi.org/10.1016/j.ridd.2005.09.003

Silberman, S. (2017). *NeuroTribes*. Atlantic Books.

Simmonds, M. (2021, March 29). *Autism and the Black Community* [video file]. Retrieved from https://autismresearchlab.group.shef.ac.uk/UpcomingSeminars.html.

Slade, G. (2014). *Diverse perspectives: The challenges for families affected by autism from black, Asian and Minority Ethnic communities.* London: The National Autistic Society.

Smith, J. (1996). Beyond the divide between cognition and discourse: Using interpretative phenomenological analysis in health psychology. *Psychology & Health*, *11*, 261-271. https://doi.org/10.1080/08870449608400256

Smith, J., Flowers, P., & Larkin, M. (2009) *Interpretative Phenomenological Analysis: Theory, Method and Research.* London, UK: SAGE Publications Ltd.

Stevenson, O., & Batts, A. (2016). Women's empowerment: Finding strength in self-compassion. *Women & Health, 57,* 295-310. https://doi.org/10.1080/03630242.2016.1164271

Strang, J., Kenworthy, L., Daniolos, P., Case, L., Wills, M., Martin, A., & Wallace, G. (2012). Depression and anxiety symptoms in children and adolescents with autism spectrum disorders without intellectual disability. *Research In Autism Spectrum Disorders*, *6*, 406-412. https://doi.org/10.1016/j.rasd.2011.06.015

Thompson, A. R., Larkin, M., Smith, J. A. (2011). Interpretative phenomenological analysis and clinical psychology training: results from a survey of the group of trainers in clinical psychology. *Clinical Psychology Forum, 222,* 15-19.

Treweek, C., Wood, C., Martin, J., & Freeth, M. (2018). Autistic people's perspectives on stereotypes: An interpretative phenomenological analysis. *Autism*, *23*, 759-769. https://doi.org/10.1177/1362361318778286

Ward, D., & Webster, A. (2018). Understanding the lived experiences of university students with autism spectrum disorder (ASD): A phenomenological study. *International Journal of Disability, Development and Education*, *65*, 373-392. https://doi.org/10.1080/1034912X.2017.1403573

Weiss, J. A., & Fardella, M. A. (2018). Victimization and perpetration experiences of adults with autism. *Frontiers in Psychiatry*, *9*, 203. https://doi.org/10.3389/fpsyt.2018.00203

Willig, C. (2008). *Introducing Qualitative Research in Psychology*. Open University Press. https://doi.org/10.4135/9780857029034

Wong, C., Mak, W., & Liao, K. (2016). Self-Compassion: a potential buffer against affiliate stigma experienced by parents of children with autism spectrum disorders. *Mindfulness*, *7*, 1385-1395. https://doi.org/10.1007/s12671-016-0580-2

Wood, C., & Freeth, M. (2016). Students' stereotypes of autism. *Journal of Educational Issues*, *2*, 131-140. http://dx.doi.org/10.5296/jei.v2i2.9975

Yarnell, L. M., Neff, K. D., Davidson, O. A., & Mullarkey, M. (2018). Gender differences in self-compassion: examining the role of gender role orientation. *Mindfulness, 10,* 1136-1152. https://doi.org/10.1007/s12671-018-1066-1

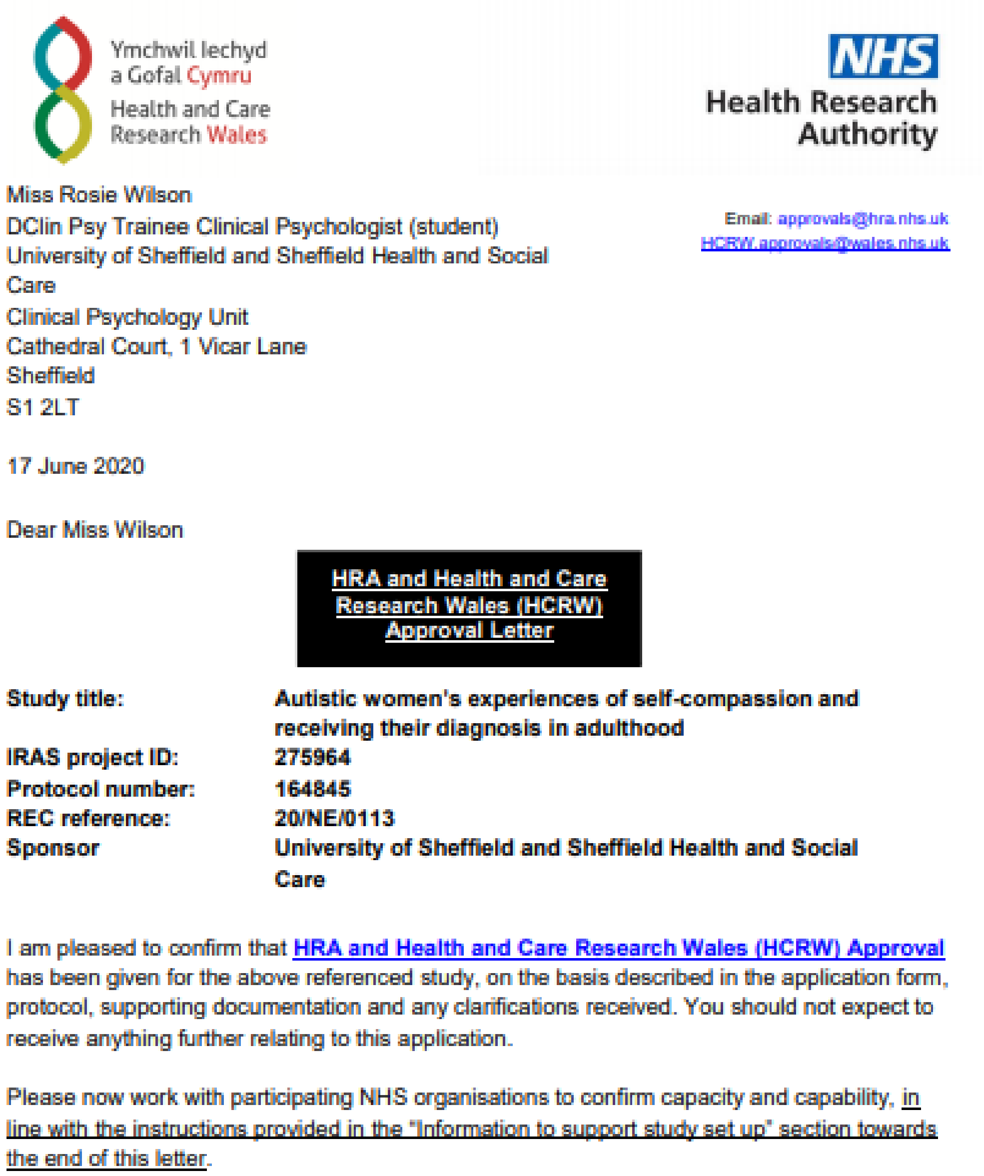
Yarnell, L., Stafford, R., Neff, K., Reilly, E., Knox, M., & Mullarkey, M. (2015). Meta-analysis of gender differences in self-compassion. *Self And Identity*, *14*, 499-520. https://doi.org/10.1080/15298868.2015.1029966

Zablotsky, B., Bradshaw, C. P., Anderson, C. M., & Law, P. (2014). Risk factors for bullying among children with autism spectrum disorders. *Autism*, *18*, 419-427. https://doi.org/10.1177/1362361313477920

Zhao, X., Li, X., Song, Y., Li, C., & Shi, W. (2020). Autistic traits and emotional experiences in Chinese college students: Mediating role of emotional regulation and sex differences. *Research in Autism Spectrum Disorders*, *77*, 101607. https://doi.org/10.1016/j.rasd.2020.101607

Appendices

Appendix A: Ethical Approval Letters



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Miss Rosie Wilson
DClin Psy Trainee Clinical Psychologist (student)
University of Sheffield and Sheffield Health and Social Care
Clinical Psychology Unit
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17 June 2020

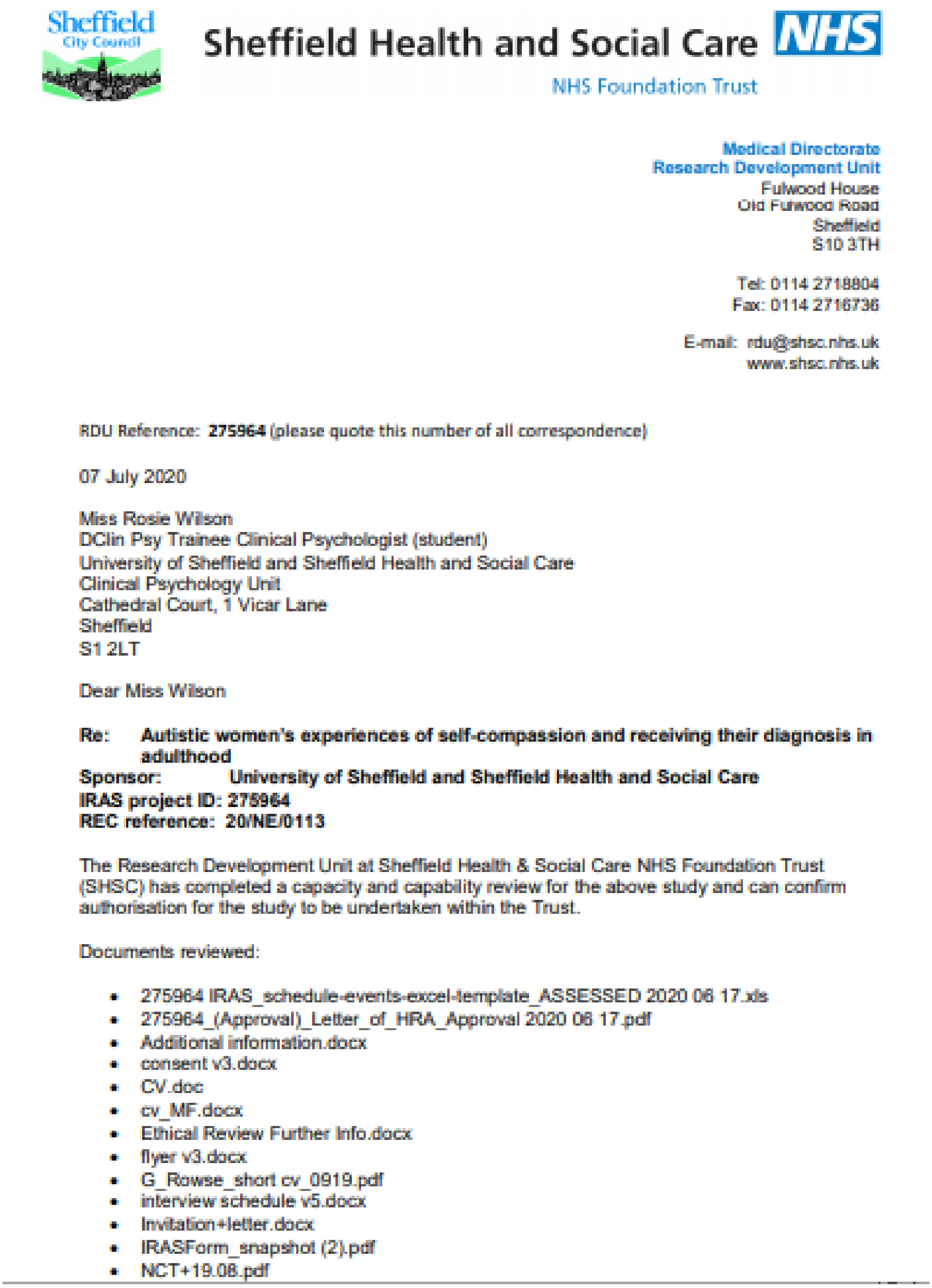
Dear Miss Wilson

HRA and Health and Care Research Wales (HCRW) Approval Letter

Study title:	**Autistic women's experiences of self-compassion and receiving their diagnosis in adulthood**
IRAS project ID:	**275964**
Protocol number:	**164845**
REC reference:	**20/NE/0113**
Sponsor	**University of Sheffield and Sheffield Health and Social Care**

I am pleased to confirm that **HRA and Health and Care Research Wales (HCRW) Approval** has been given for the above referenced study, on the basis described in the application form, protocol, supporting documentation and any clarifications received. You should not expect to receive anything further relating to this application.

Please now work with participating NHS organisations to confirm capacity and capability, in line with the instructions provided in the "Information to support study set up" section towards the end of this letter.



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07 July 2020

Miss Rosie Wilson
DClin Psy Trainee Clinical Psychologist (student)
University of Sheffield and Sheffield Health and Social Care
Clinical Psychology Unit
Cathedral Court, 1 Vicar Lane
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S1 2LT

Dear Miss Wilson

Re: Autistic women's experiences of self-compassion and receiving their diagnosis in adulthood
Sponsor: University of Sheffield and Sheffield Health and Social Care
IRAS project ID: 275964
REC reference: 20/NE/0113

The Research Development Unit at Sheffield Health & Social Care NHS Foundation Trust (SHSC) has completed a capacity and capability review for the above study and can confirm authorisation for the study to be undertaken within the Trust.

Documents reviewed:

- 275964 IRAS_schedule-events-excel-template_ASSESSED 2020 06 17.xls
- 275964_(Approval)_Letter_of_HRA_Approval 2020 06 17.pdf
- Additional information.docx
- consent v3.docx
- CV.doc
- cv_MF.docx
- Ethical Review Further Info.docx
- flyer v3.docx
- G_Rowse_short cv_0919.pdf
- interview schedule v5.docx
- Invitation+letter.docx
- IRASForm_snapshot (2).pdf
- NCT+19.08.pdf

Appendix B: Participant Information Sheet

Department of Psychology.
Clinical Psychology Unit.

Doctor of Clinical Psychology (DClin Psy) Programme
Clinical supervision training and NHS research training & consultancy.

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Research Project: Autistic women's experiences of self-compassion and receiving their diagnosis in adulthood

Information Sheet

This research is being conducted by Rosie Wilson, a Trainee Clinical Psychologist at the University of Sheffield.

Rosie is interested in investigating Autistic women's experiences of receiving their diagnosis in adulthood and whether receiving the diagnosis has influenced experiences of self-compassion. She will be interviewing autistic individuals one at a time, and you have said that you would like to take part. This information sheet includes more details about the project.

Rosie will be supervised during this project by two supervisors. They are:

- Dr Megan Freeth, Lecturer in Cognitive Psychology, Sheffield Autism Research Lab (ShARL), University of Sheffield
- Dr Georgina Rowse, Clinical Psychologist, Clinical Psychology Unit, University of Sheffield

Rosie will also be supported by two co-investigators. They are:

- Dr Andrew Thompson, Professor of Clinical Psychology/Programme Director, University of Cardiff/Cardiff & Vale NHS Board
- Dr Richard Smith, Senior Clinical Psychologist, Sheffield Adult Autism and Neurodevelopmental Service (SAANS)

What is the project’s purpose?

The aim of this project is to explore autistic women’s experiences of receiving their diagnosis in adulthood and whether receiving their diagnosis has influenced their perception of self-compassion.

What is Self-compassion?

Self-compassion involves being kind and caring to ourselves. This involves acting in a caring and comforting way towards ourselves during difficult times, rather than criticizing or judging ourselves.

In a research paper published in 2003, Kristin Neff proposed that there are three elements of self-compassion:

- self-kindness versus self-judgment
- common humanity versus isolation
- mindfulness versus overidentification

The image above is based on Neff (2003).

Self-compassion is based on three principles:

1. **Self-kindness** and non-judgement of self, or being as understanding with yourself as you are with others.
2. **Mindfulness** or seeing your thoughts and emotions as they are without pushing them away or over-identifying with them.
3. **Common Humanity** or recognising that the human experience is full of ups and downs and that everyone struggles at times.

Rosie attended a monthly discussion group at Sheffield Adult Autism and Neurodevelopmental Service (SAANS) to talk about this research study and self-compassion. Some autistic adults described self-compassion as being “more forgiving” and “less critical” of themselves.

Why have I been chosen to take part?

Rosie would like to interview between 10-14 women identified formally as autistic for this research project to discuss their experiences of receiving their diagnosis in adulthood and experiences of self-compassion. The information sheet was given to you as you have received a diagnosis on the autism spectrum in adulthood. You have indicated that you would like to take part in the research.

Do I have to take part?

No. You do not have to take part in this research study. Choosing not to take part will not affect any of the support you receive. Your participation in this study is entirely on a voluntary basis and you are free to withdraw from the study at any time, without giving any reason. You can only withdraw your interview data up to 48 hours after the interview session as after this time the data will be anonymised. You have the right to not answer any questions during the interview. If you do decide to take part in the study, you will be asked to sign a consent form.

What do I have to do?

We would like to talk to you about your experiences of self-compassion and your experiences of receiving a diagnosis on the autism spectrum. Questions will be asked in a one-to-one interview with the researcher (Rosie).

Due to the current COVID-19 restrictions all interviews will be conducted remotely by telephone or Google Meet.

If the COVID-19 restrictions are reduced it may be possible to conduct face to face interviews at the University of Sheffield Clinical Psychology Department (Cathedral Court, Floor F, 1 Vicar Lane, Sheffield S1 2LT) or, the Sheffield Adult Autism and Neurodevelopmental Service (SAANS) team base (SAANS, Michael Carlisle Centre 75 Osborne Road, Sheffield S11 9BF).

1. After you have returned the consent form Rosie will arrange a time to telephone or video call (using Google Meet) to complete the interview.
2. If you have decided to conduct the interview using Google Meet, Rosie will email you a link to join the interview. If you have decided to conduct the interview via telephone,

Rosie will call you at the arranged time. Rosie will ask that you consent to the interview and check that you understand the purpose of the research interview.

3. You will be able to talk about your experiences of self-compassion and your experience of receiving a diagnosis on the autism spectrum. Rosie will ask you about yourself, including your name and diagnosis. She will then ask you questions about your experiences self-compassion and receiving your diagnosis. For example: What effect has receiving the diagnosis had on how you feel about yourself?
4. Rosie would like to digitally audio record the interview using an encrypted smart tablet, so she can listen back to it. The interview will take between 30-60 minutes. The audio from the interview will be transcribed by Rosie or an employed transcriber.

What are the possible benefits of taking part?

We are completing this research to find out about autistic women's experiences of self-compassion and their experience of receiving an autism diagnosis in adulthood. There have been lots of studies exploring the relationship between self-compassion and mental health in different populations, but there is no current research with autistic individuals. This study will develop understandings of autistic women's experiences of self-compassion and how their experience relates to receiving their diagnosis.

Whilst there are no immediate benefits for those people participating in this project, it is hoped that this work will build up a picture of self-compassion in the autistic community. Findings from the study will be shared with professionals who work with autistic people. It is hoped that this work will have a positive impact by helping professionals to understand your experiences and learn what things can be helpful in meeting the needs of autistic people.

What are the possible disadvantages and risks of taking part?

We will be asking you about your personal experiences of self-compassion and receiving your autism diagnosis as part of the interview. This may generate distress for some participants, if this happens please tell Rosie if you would like to take a break or stop the interview at any time.

You can ask a friend or family member to support you during the interview, but they will not be able to answer the interview questions. Informal time will be provided after the interviews to reflect on experience of participation. Information about support services e.g. Samaritans and their GP, will also be provided after interviews if you wish to access emotional support.

Confidentiality policy will be discussed before all interviews, this means that if Rosie has any concerns about your well-being, she may need to talk to someone about this (e.g. contacting your GP). For interviews conducted remotely via Google Meet and telephone, you will be asked where you are during the interview. This will provide an address so that if it was assessed that there was an imminent risk Rosie could contact the police to perform a welfare check.

Participating in this research should not incur any increased risk than would be reasonably expected to be experienced by the same person in their day-to-day life.

What will happen to my information?

The electronic consent forms and personal information (e.g. contact details) will be stored on the research project password protected, secure account on the University of Sheffield data repository. Your personal details such as name, phone number, address and email address etc, will not be revealed to anyone other than Rosie unless you explicitly give consent for this to happen. As discussed above, the exception to sharing information would be if confidentiality needed to be broken to ensure my safety and that of other people (as per the confidentiality policy).

Any paper documents e.g. paper interview transcripts will be stored in a locked box file at Rosie’s home. When the University of Sheffield buildings re open, all paper documents will be stored in a locked in a cabinet at the University of Sheffield. Only Rosie and the appointed person at the University responsible for this cabinet will have access to this information.

All audio recordings will be kept private and confidential. Only the research team will have access to the data. Information from the audio recorder will be used for analysis only. The smart tablet used for the audio recordings is encrypted, meaning only a person with a password can access this. This will be stored in a locked box file at Rosie's home. Recordings from the interview will be stored on a password protected, encrypted USB memory stick and the research project password protected, secure account on the University of Sheffield data repository. Only Rosie, her supervisors and a member of the research admin team have access to the recordings from the interviews in the university data repository.

All electronic data including audio recordings and your contact details will be stored until publication of the study, which we aim to complete within 12 months from the time of the interview but will be no longer than 6 years. There will be paper versions of the anonymised interview transcripts. These will be stored for a maximum of 6 years in a locked cabinet at the University of Sheffield. They will be securely disposed of after this time.

What happens if the research study stops earlier than expected?

This would only happen due to unforeseen circumstances e.g. if a planned interview is cancelled due to the research stopping. If the research stopped earlier than planned, Rosie would contact you to explain this.

What if something goes wrong?

If you are concerned about anything about the project, please contact Rosie and she will do her best to address this. If you feel your concerns have not been answered, you may contact:

Dr Georgina Rowse, Clinical Psychology Unit, University of Sheffield, Cathedral Court Floor F, 1 Vicar Lane, Sheffield, S1 2LT.

If you have a complaint and you feel it has not been dealt with to your satisfaction, you can contact the Head of Department, Glenn Waller via email on G.Waller@sheffield.ac.uk or telephone on 0114 222 6568.

Will people know I have taken part in this project?

All the information that we collect about you during the research will be kept strictly confidential. You will not be able to be identified in any reports or publications, pseudonyms will be used. As explained earlier on this information sheet, if Rosie has any concerns about your wellbeing, she may need to talk to somebody about this. When you meet Rosie for the interview, she can explain this further and you can ask any questions.

Will I receive any reimbursement of expenses for taking part in this research?

Due to current COVID-19 restrictions interviews need to be completed remotely via Google Meet or telephone. If the COVID-19 restrictions reduce there may be opportunity to complete face to face interviews at the University of Sheffield or the Sheffield Adult Autism and Neurodevelopmental Service. If you are asked to attend a face to face interview there will be reimbursement of relevant travel expenses incurred by participating in this research (subject to providing receipts of travel).

What will happen to the results of the project?

A report will be written but no real names will be used. All the answers in the report will be anonymous. You will be offered a copy of the report when it is completed. Rosie plans to publish the findings from the research in the Journal of Autism and Developmental Disorders, or a similar journal. She will also share the findings with individuals at SAANS and findings will be shared on the Sheffield Autism Research Lab (ShARL) webpage which you can access if you wish.

Who has ethically reviewed the project?

The project has been reviewed by the University of Sheffield research governance and Sheffield Health and Social Care Trust research governance.

Research funding

This research is funded by the Research Department of Clinical Psychology Unit, Sheffield University. If you have any questions, you can ask Rosie these at your interview. If you have any before this time, she can be contacted on: rwilson4@sheffield.ac.uk

Additional Information about your data

New data protection legislation came into effect across the EU, including the UK on 25 May 2018; this means that we (the study sponsor, the University of Sheffield) need to provide you with some further information relating to how your personal information will be used and managed within this research project.

The University of Sheffield will act as the Data Controller for this study. This means that the University is responsible for looking after your information and using it properly. In order to collect and use your personal information as part of this research project, we must have a basis in law to do so. The basis that we are using is that the research is ‘a task in the public interest’. As we will be collecting some data that is defined in the legislation as more sensitive (e.g. information about your health, we also need to let you know that we are applying an additional condition in law: that the use of your data is ‘necessary for scientific or historical research purposes’.

Further information, including details about how and why the University processes your personal information, how we keep your information secure, and your legal rights (including how to complain if you feel that your personal information has not been handled correctly), can be found in the University’s Privacy Notice https://www.sheffield.ac.uk/govern/data-protection/privacy/general.

How will we use information about you?

We will need to use information from you for this research project.

This information will include your name & contact details. People will use this information to do the research or to check your records to make sure that the research is being done properly. People who do not need to know who you are will not be able to see your name or contact details. Your data will have a code number instead.

We will keep all information about you safe and secure. Once we have finished the study, we will keep some of the data so we can check the results. We will write our reports in a way that no-one can work out that you took part in the study.

What are your choices about how your information is used?

You can stop being part of the study at any time, without giving a reason, but we will keep information about you that we already have.

We need to manage your records in specific ways for the research to be reliable. This means that we won't be able to let you see or change the data we hold about you.

Where can you find out more about how your information is used?

You can find out more about how we use your information

- at www.hra.nhs.uk/information-about-patients/
- our leaflet available from **www.hra.nhs.uk/patientdataandresearch**
- by asking one of the research team
- by sending an email to the University of Sheffield Data protection officer (dataprotection@sheffield.ac.uk)
- by ringing 0114 222 117

Who to contact for more information about the research?

- Amrit Sinha, research support officer: a.sinha@sheffield.ac.uk

- Rosie Wilson, chief investigator: rwilson4@sheffield.ac.uk

Thank you for taking part in this research

Appendix C: Consent Form

The University Of Sheffield.

Department of Psychology.
Clinical Psychology Unit.

Doctor of Clinical Psychology (DClin Psy) Programme
Clinical supervision training and NHS research training & consultancy.

Clinical Psychology Unit
University of Sheffield
Cathedral Court
Floor F
1 Vicar Lane,
Sheffield,
S1 2LT

Telephone: 0114 222 6550
Fax: 0114 222 6610
Email: rwilson4@sheffield.ac.uk

Research Project: Autistic women's experiences of self-compassion and receiving their diagnosis in adulthood.

Researcher: Rosie Wilson

Participant identification number: ……………………..

Please read the information below and write your initials in the boxes if you agree to the statements.

1. I confirm that I have read and understand the information sheet dated *[insert interview date]* for the above study. ☐

2. The information sheet and the researcher explained the research project. Any questions I had about this information have been answered. ☐

3. I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason and with no negative consequences. ☐

4. If I do not want to answer any question, I understand that I can decline to answer ☐

5. I understand that nothing will affect any of the support I receive. ☐

6. I understand that I can contact the researcher, Rosie Wilson on 0114 222 6550 or rwilson4@sheffield.ac.uk if I wish to withdraw. ☐

7. I understand that my participation and the information I provide during my interview will be kept strictly confidential. ☐

8. I understand my personal details such as name, phone number, address and email address etc, will not be revealed to anyone other than the lead researcher unless I explicitly give consent for this to happen. With the exception that confidentiality may be broken to ensure my safety or that of other people. ☐

9. If, during my interview, I were to tell the researcher that I or someone else was at risk of harm, I understand that confidentiality may be broken to ensure my safety and that of other people (as outlined in the participant information sheet). ☐

10. I give permission for members of the research team to have access to my anonymised interview data. I understand and agree that my words may be quoted in the research report. My name will not be linked with the research materials, and I will not be identified or identifiable in the report or reports that result from the research. ☐

11. I agree to take part in the above research project. ☐

Name of Participant Date Signature

Name of Researcher Date Signature

Rosie Wilson

Appendix D: Study Flyer

Department of Psychology.
Clinical Psychology Unit.

Doctor of Clinical Psychology (DClin Psy) Programme
Clinical supervision training and NHS research training & consultancy.

Clinical Psychology Unit
University of Sheffield
Cathedral Court
Floor F,
1 Vicar Lane,
Sheffield,
S1 2LT

Telephone: 0114 222 6550
Fax: 0114 222 6610
Email: rwilson4@sheffield.ac.uk

You are invited to take part in the following research project:

Autistic women's experiences of self-compassion and receiving their diagnosis in adulthood.

Information Sheet

This research is being conducted by Rosie Wilson, a Trainee Clinical Psychologist at the University of Sheffield.

Rosie is interested in investigating Autistic women's experiences of receiving their diagnosis in adulthood and whether receiving the diagnosis has influenced experiences of self-compassion. She will be interviewing individuals one at a time, and you are being invited to take part.

Rosie will be supervised during this project by four supervisors. They are:

- Dr Megan Freeth, Lecturer in Cognitive Psychology, Sheffield Autism Research Lab (ShARL), University of Sheffield
- Dr Georgina Rowse, Clinical Psychologist, Clinical Psychology Unit, University of Sheffield

- Dr Andrew Thompson, Professor of Clinical Psychology/Programme Director, University of Cardiff/Cardiff & Vale NHS Board
- Dr Richard Smith, Senior Clinical Psychologist, Sheffield Adult Autism and Neurodevelopmental Service (SAANS)

Why have I been chosen?

You have been invited to take part because you have received a diagnosis on the autism spectrum in adulthood.

What is the project's purpose?

The purpose of this research is to better understand autistic women experiences of self-compassion. It also aims to explore autistic women's experiences of receiving their diagnosis in adulthood.

What is Self-compassion?

Self-compassion involves being kind and caring to ourselves. This involves acting in a caring and comforting way towards ourselves during difficult times, rather than criticizing or judging ourselves.

In a research paper published in 2003, Kristin Neff proposed that there are three elements of self-compassion:

- Self-kindness versus self-judgment
- Common humanity versus isolation
- Mindfulness versus overidentification

The image above is based on Neff (2003).

Self-compassion is based on three principles:

1. **Self-kindness** and non-judgement of self, or being as understanding with yourself as you are with others.
2. **Mindfulness** or seeing your thoughts and emotions as they are without pushing them away or over-identifying with them.
3. **Common Humanity** or recognising that the human experience is full of ups and downs and that everyone struggles at times.

Rosie attended a monthly discussion group at Sheffield Adult Autism Neurodevelopmental Service (SAANS) to talk about this research study and self-compassion. Some autistic adults described self-compassion as being "more forgiving" and "less critical" of themselves.

To be included in the project you need to meet the following criteria:

- To be able to consent to participate
- To be cisgender female (female at birth and raised as female).

- To speak English fluently
- To have received an autism spectrum disorder diagnosis, or a related diagnosis on the autism spectrum (it is ok to have received other diagnoses as well)
- To have been aged 18 years old or above when you received your diagnosis

How do I take part?

If you are interested in the study, please go to the webpage below and this will tell you more information about the project, including a longer version of this information sheet.

http://autismresearchlab.group.shef.ac.uk/Take_Part.html

To register, please follow the steps below:

1. Click on the link titled **Female Compassion ASD Study** and enter the password **Female2020**
2. This will take you to an online form where you can register your interest in the study and provide your contact details.
3. Rosie will then contact you by telephone or email so that you can arrange an interview time together.
4. Rosie will send you a letter to confirm the date and time of the interview. She will also send you a paper copy of the information sheet from the webpage and a consent form. You can also request a copy of the interview questions if you would like to read them before the interview. You will be asked to attend an interview at the Clinical Psychology department at Sheffield University or the Sheffield Adult Autism and Neurodevelopmental Service, to talk about your experiences of self-compassion and receiving your diagnosis. Alternatively, you can choose to complete your interview online using Skype. If you have any questions or any difficulty accessing the webpage, please contact Rosie on: rwilson4@sheffield.ac.uk

This study is voluntary. If you decide you do not want to take part, please ignore this information sheet. This will not affect any of the support you receive.

Appendix E: Reflective Diary Extract

Reflections after interview:

P mentioned the family experiences of autism – sister's diagnosis. P also reflected on how her understanding of other people she works with whom have autism/ ID, and how she wonders if being autistic helps her understanding of their needs. 30s when started wondering about her own diagnosis – I reflected how this is a similar age to me now. Similar challenges of school and socializing discussed. I wondered if receiving her diagnosis had made her more critical of herself in some ways/ more frustrated for not seeking a diagnosis earlier. I was mindful to not interpret during the interview and tried to get P to explain more what she meant. Interesting to think about the interlinking presentations of autism, OCD and anxiety. I feel pleased that she has been able to access support for ocd and anxiety, without these being viewed by professionals as "part of her autism" typically seen by over diagnostic shadowing. I felt that the idea of perfectionism and over analyzing situations has come up in other interviews. Over thinking. Interesting the p's reflections on empathy and how she feels autistic people over empathize rather than traditional views that autistic individuals do not feel empathy at all. I wondered about her thoughts of reading the materials on self-compassion as part of the PIS and if this linked in with her experiences of self-care exercises in current therapy. Short time since diagnosis, she recognizes she is still processing this diagnosis and I wondered how opting into this research fit with that. Some references to having to wait for support/ services related to autism. I noted that she said she feels much more able to help others than herself, evident from her employment, this also reminded me of a comment from another p that they felt the diagnosis had developed their compassion towards others – how to manage their differences, rather than their own acceptance.

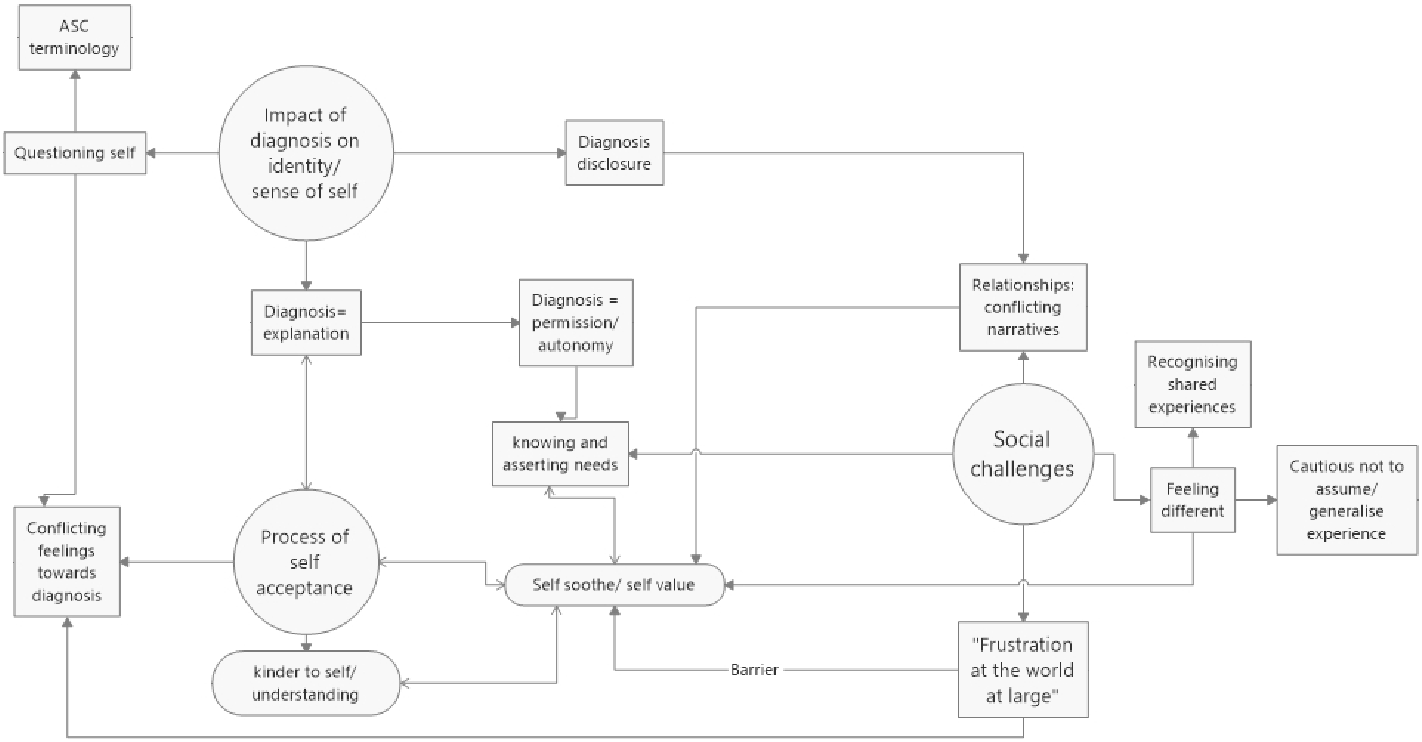
Reflections during analysis:

Autism diagnosis prompted other diagnoses relating to mental health – uncertainties. P suggested she did not feel like she anticipated after receiving diagnosis. Link own experiences of autism and how now is her work. Wondered about other ps choosing to work with other autistic people “feels normal to me”.

Others can relax more – kinder to self. Learning self-compassion skills now.

“quite happy” – late diagnosis then wonder what life might have been like if received earlier. Balanced – some positives include working with disabled children – might not have done. Wonders if had more support what could have been different? less mental health issues?

Appendix F: Example of Participant Conceptual Map



Appendix G: Audit Forms

Audit form (GR)

Data collection

1. Is there evidence that raw data was collected and is appropriate for the research aims?

   Yes (As evidenced by anonymised transcripts/photo-elicitation/data etc)

2. Has relevant demographic and background information been collected to contextualise the sample (e.g. gender, age, interview location/time)?

   Yes

3. Are there reflections/notes/summaries on the data collection process?

   Yes

Research/analysis process

4. Has the researcher engaged appropriately in supervision as part of the research process?

   Yes

5. Has the data been sufficiently coded? (e.g. is all the relevant data coded?)

   Yes

6. Has the data been systematically coded?

   Yes

7. Is it clear that the researcher has engaged in a process of refining and redefining the themes and subthemes and are these processes justified? (This may be evidenced by looking at different versions of the NVivo documents and notes, and changes to coding/themes should be justified).

Yes

Cross-checks

8. Crosschecking randomly selected excerpts from the interviews and photo-elicitation items against the corresponding coding and themes recorded on NVivo.

   Are these consistent?

   Yes

9. Vice-versa crosschecking randomly selected themes and subthemes from NVivo against the corresponding data.

   Are these consistent?

   Yes

Study write-up/results

10. Are quotes sufficient to provide evidence of the themes and subthemes?

    Yes

11. Does the results/write-up sufficiently address the aims of the study?

    Yes

    Signature of researcher

    Signature of auditor

    Georgina Rowse

Audit Form (AT)

Data collection

1. Is there evidence that raw data was collected and is appropriate for the research aims?

   Yes (As evidenced by anonymised transcripts/photo-elicitation/data ect)

2. Has relevant demographic and background information been collected to contextualise the sample (e.g. gender, age, interview location/time)?

   Yes

3. Are there reflections/notes/summaries on the data collection process?

   Yes

Research/analysis process

4. Has the researcher engaged appropriately in supervision as part of the research process?

   Yes

5. Has the data been sufficiently coded? (e.g. is all the relevant data coded?)

   Yes

6. Has the data been systematically coded?

   Yes

7. Is it clear that the researcher has engaged in a process of refining and redefining the themes and subthemes and are these processes justified? (This may be evidenced by looking at different versions of the NVivo documents and notes, and changes to coding/themes should be justified).

   Yes

Cross-checks

8. Crosschecking randomly selected excerpts from the interviews and photo-elicitation items against the corresponding coding and themes recorded on NVivo.

   Are these consistent?

   Yes

9. Vice-versa crosschecking randomly selected themes and subthemes from NVivo against the corresponding data.

   Are these consistent?

   Yes

Study write-up/results

10. Are quotes sufficient to provide evidence of the themes and subthemes?

    Yes

11. Does the results/write-up sufficiently address the aims of the study?

    Yes/

Signature of researcher – Rosie Wilson

Signature of auditor

Audit form (M.F)

Data collection

1. Is there evidence that raw data was collected and is appropriate for the research aims?

   Yes (As evidenced by anonymised transcripts/photo-elicitation/data ect)

2. Has relevant demographic and background information been collected to contextualise the sample (e.g. gender, age, interview location/time)?

   Yes

3. Are there reflections/notes/summaries on the data collection process?

   Yes

Research/analysis process

4. Has the researcher engaged appropriately in supervision as part of the research process?

   Yes

5. Has the data been sufficiently coded? (e.g. is all the relevant data coded?)

   Yes

6. Has the data been systematically coded?

   Yes

7. Is it clear that the researcher has engaged in a process of refining and redefining the themes and subthemes and are these processes justified? (This may be evidenced by looking at different versions of the NVivo documents and notes, and changes to coding/themes should be justified).

Yes

Cross-checks

8. Crosschecking randomly selected excerpts from the interviews and photo-elicitation items against the corresponding coding and themes recorded on NVivo.

   Are these consistent?

   Yes

9. Vice-versa crosschecking randomly selected themes and subthemes from NVivo against the corresponding data.

   Are these consistent?

   Yes

Study write-up/results

10. Are quotes sufficient to provide evidence of the themes and subthemes?

    Yes

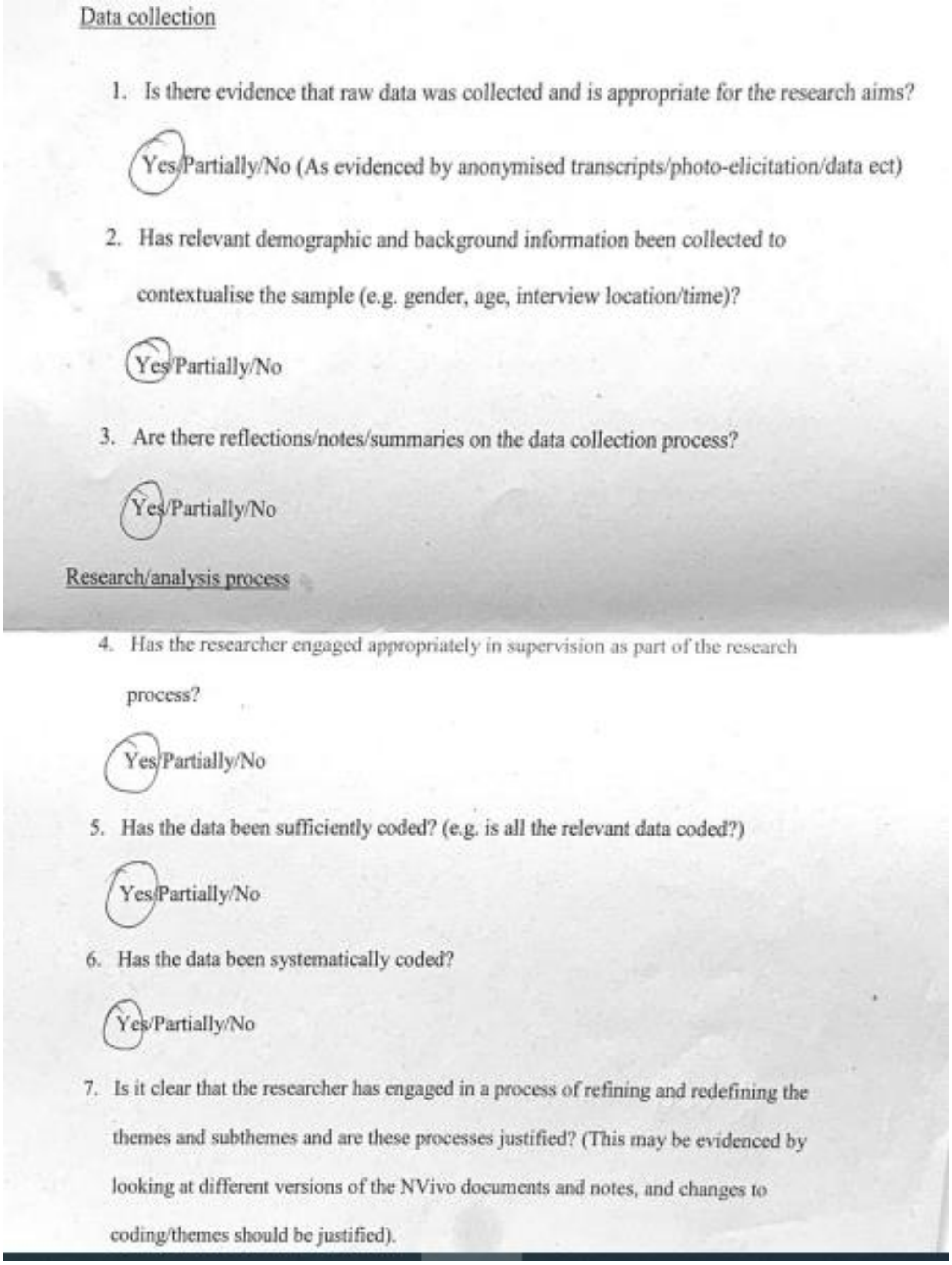
11. Does the results/write-up sufficiently address the aims of the study?

    Yes

Signature of researcher

Signature of auditor Megan

Audit form (P.S.)



Data collection

1. Is there evidence that raw data was collected and is appropriate for the research aims?

   [✓ Yes]/Partially/No (As evidenced by anonymised transcripts/photo-elicitation/data ect)

2. Has relevant demographic and background information been collected to contextualise the sample (e.g. gender, age, interview location/time)?

   [✓ Yes]/Partially/No

3. Are there reflections/notes/summaries on the data collection process?

   [✓ Yes]/Partially/No

Research/analysis process

4. Has the researcher engaged appropriately in supervision as part of the research process?

   [✓ Yes]/Partially/No

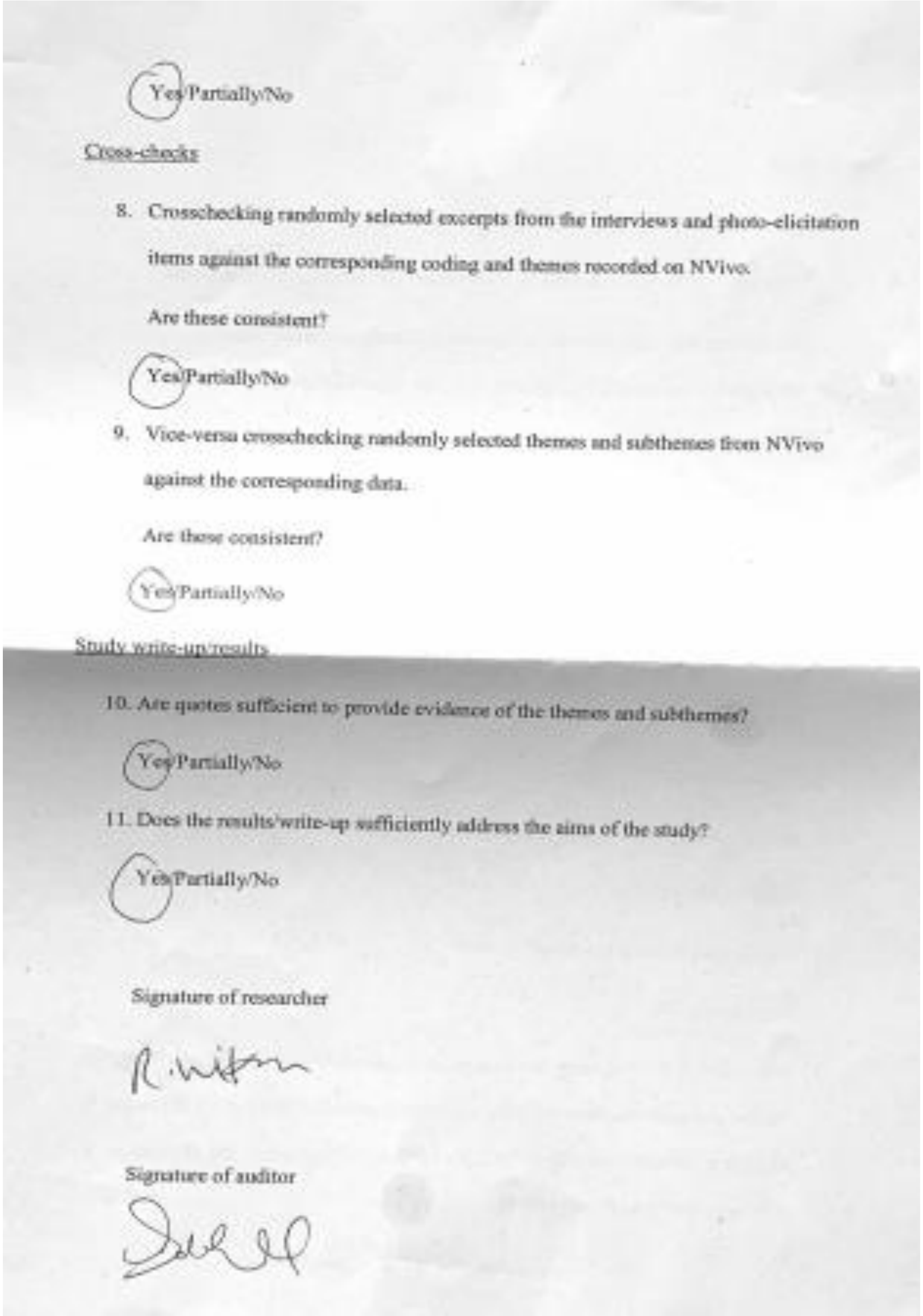
5. Has the data been sufficiently coded? (e.g. is all the relevant data coded?)

   [✓ Yes]/Partially/No

6. Has the data been systematically coded?

   [✓ Yes]/Partially/No

7. Is it clear that the researcher has engaged in a process of refining and redefining the themes and subthemes and are these processes justified? (This may be evidenced by looking at different versions of the NVivo documents and notes, and changes to coding/themes should be justified).



[✓ Yes]/Partially/No

Cross-checks

8. Crosschecking randomly selected excerpts from the interviews and photo-elicitation items against the corresponding coding and themes recorded on NVivo.

   Are these consistent?

   [✓ Yes]/Partially/No

9. Vice-versa crosschecking randomly selected themes and subthemes from NVivo against the corresponding data.

   Are these consistent?

   [✓ Yes]/Partially/No

Study write-up/results

10. Are quotes sufficient to provide evidence of the themes and subthemes?

    [✓ Yes]/Partially/No

11. Does the results/write-up sufficiently address the aims of the study?

    [✓ Yes]/Partially/No

Signature of researcher

Signature of auditor

Appendix H: Additional Supporting Quotes

Superordinate theme	Sub-theme	Additional Quotes
Disconnect between the autistic self and experience of societal expectations	The burden of conformity	*"being Autistic means that you ruminate about what other people say because you don't know what it means."* (Jessica) *"I think very, very deeply on things… I've always been very painfully aware of that and it's caused a lot of distress over the years of not feeling connected to people."* (Juliet) *"it feels like a disorder in how society regards me, yeah so it's a disconnect between me and society rather than something that's wrong with me."* (Angela)
	Autism is misunderstood	*"when you see headlines of someone that has committed a crime or something and they will use autistic in the headline as a way of explaining that behaviour where actually it has nothing to do with that."* (Debby) *"She [psychologist] did a lot of damage like 'you are not autistic, they are all boys and you can't, they can't talk'."* *(*Melissa)

Superordinate theme	Sub-theme	Additional Quotes

	Social challenges	*"I remember being at school and feeling very different from my peers and behaving very different from people and I felt like everyone else had the clues to what was going on and I was always playing catch up…I felt like everyone else had this key to unlock what you do in a group."* (Jessica) *"it's harder to be kind to myself after a difficult interaction… I've been misunderstood or dismissed or ignored or erm avoided… I can give myself a hard time, it's difficult to forgive myself… it's easier to be kind to myself and forgiving when I've had a more positive interactions."* (Debby) *"gaslighting… you know a lot of our problems are often caused by other people… people lie to us and mess with our head it can be much harder for Autistic people to be able to process it and react to it."* (Melissa)
	Mental health impact	*"…depression and anxiety from feeling so different and that I didn't understand the rest if the world."* (Karen) *Yes I have been very, very, very depressed in the past and I am very anxious… but I think those two they are more*

		of a reaction to how society has treated me.” (Angela) *“perhaps if I’d been diagnosed earlier with my autism I wouldn’t have had such anxiety and OCD.” (Louise)*
Unmasking: the process of self-understanding	Autonomy and self-compassion	*“It’s helped me to understand why certain things are difficult and why I don’t get any better at them… so I’m no longer just failure in that way. I have a reason for it and that’s been really really helpful.” (Stacey)* *“I understand myself more whereas beforehand I was almost like clutching at straws in the dark wondering why, like I say; why haven’t I got loads of friends and like going out, why am I not interested in really making small talk with people and you know things what other people tend to enjoy doing… its just letting myself be me a bit more.”* (Stacey) *“…since diagnosis it’s given me permission to say, you know I can’t be expected to do all of this, I do need support, I do need help and its okay you know it’s really okay that I need that because my brain can’t cope with that level of input.”* (Jessica)

		“it’s definitely helped me just to feel more comfortable in my skin and to, and to know what my limits are but also not to become a hermit and never go out because I know there’s times I’ve got to do things or its just finding that fine line, that ultimate fine line and living life best you can without being too over stressed or overwhelmed.” (Sue)
	Validation and grief	*“I was becoming more self-critical in another way and almost erm questioning whether having the diagnosis was the right thing to do… it’s not this ‘oh I’ve got a diagnosis, now I’m on this trajectory to somewhere else’, it’s really quite erm bumpy.” (Debby)*
		“I think the overriding sense was one of being pleased that this is actually the case, because that, its such a good explanation for everything, but also then being a bit scared because what does that actually mean” (Stacey).
Impact on relationships	Diagnosis disclosure dilemmas	*“I just wish I was more confident to say to people “I’m autistic”, you know just to, just throw it out there but I think that statement feels so loaded because of what I do, because of my profession, so I think (PAUSE), and I guess because I don’t know*

		what people would think if they found out and whether they would judge me on that… I know with women who are autistic a lot of the time they are not believed, and I think that can almost be as damaging as being diagnosed or not diagnosed you know so it's, it's almost like for me I get it, it makes sense to me but then to share that with other people and to then be questioned on it that makes me quite vulnerable" (Jessica) *"what has been less good was my brother and sister don't understand, you know my brother will say 'oh you mean like Rain Man', 'kind of I guess'"* (Angela) *"I felt like I wanted to tell people about it, and just have the new normal start now, kind of thing, but then also didn't want to do that in a place of just rushing to do that and get it out the way"* (Stacey)
	Connection and understanding	*"its only since I've had the diagnosis that I can see that quite probably erm he was autistic himself" (Angela)* *"yeah I like rules and other autistic people do" (Stacey)* *"I remember telling the children erm really happily… because I was able to say 'look I do get it'" (Debby)*