



**Empathy and personal distress: A thematic analysis of the lived experience  
of autistic adults.**

Lisa Ellen Powney

Supervised by

Dr Andrea Flood

Dr Helen Brooks

Melissa Chapple

25<sup>th</sup> January 2021

Submitted in partial fulfilment of the degree of Doctorate in Clinical Psychology at the

Division of Clinical Psychology, School of Psychology,

Liverpool University

## **Acknowledgements**

I wanted to start by saying a huge thank you to the people who participated in this study and those who inspired it too. Your time, wisdom and words are greatly appreciated and will always stay with me.

A huge thank you to Andrea, Helen and Melissa who have been through every step of this 'never ending story' with me. You have been amazing supervisors and guides. You have all taught me so much and you have supported me through so much, thank you doesn't even begin to cover it.

Thank you to my personal tutor James, your support kept my head above water every time I felt like there was no air to breathe.

Thank you to my big, wonderful family, who probably thought the day of completion would never come. I am lucky to have you all in my life and your support and belief in me has helped keep me going. Thank you to Spider and Tiger, you have been my warm, furry, safe space away from the stresses and you have given me much needed unconditional love throughout.

Finally thank you to all my friends who have listened patiently, but especially to a very special few, I would not have got through any of this without you. The support, tolerance, cheerleading, reading, listening and containment have kept me afloat.

## Table of Contents

<i>Thesis overview</i> .....	1
<i>Abstract</i> .....	5
<i>Introduction</i> .....	6
<i>Methods</i> .....	8
<i>Eligibility Criteria</i> .....	10
<i>Review strategy and study selection</i> .....	10
<i>Screening</i> .....	11
<i>Included</i> .....	11
<i>Eligibility</i> .....	11
<i>Identification</i> .....	11
<i>Quality assessment and critical appraisal</i> .....	12
<i>Results</i> .....	14
<i>Study characteristics</i> .....	14
<i>Theme 1: My Autistic Self</i> .....	19
1.1 <i>Diagnostic impact</i> .....	19
1.2 <i>A lens to make sense of one’s self</i> .....	20
1.3 <i>Externalising difficulties</i> .....	20
<i>Theme 2: The View of Others</i> .....	21
2.1 <i>Stereotypes</i> .....	21
2.2 <i>Stigma</i> .....	22
2.3 <i>Connection to the autistic community</i> .....	22
<i>Theme 3: Fitting In</i> .....	23
3.1 <i>Difference</i> .....	23
3.2 <i>Sensory experiences</i> .....	24
3.3 <i>Camouflaging, mimicking and masking</i> .....	25
3.4 <i>Relationships and learning from experience</i> .....	26
<i>Theme 4: The Systems Around Us</i> .....	27
4.1 <i>Lack of knowledge</i> .....	27
4.2 <i>Employment</i> .....	28
4.3 <i>Lack of services and barriers to support</i> .....	28
<i>Discussion</i> .....	29
<i>Strengths and limitations</i> .....	33

<i>Conclusion and implications of the review</i> .....	34
<i>References</i> .....	36
<i>Empathy and personal distress: A thematic analysis of the lived experience of autistic adults.</i> .....	44
<i>Abstract</i> .....	44
<i>Introduction</i> .....	45
<i>Asperger Syndrome and Autism</i> .....	45
<i>Current Context and Terminology</i> .....	45
<i>What is empathy?</i> .....	46
<i>Empathy and Autism</i> .....	46
<i>Deficit or difference?</i> .....	48
<i>Current study</i> .....	49
<i>Methodology</i> .....	51
<i>Research team and reflexivity</i> .....	51
<i>Ethical considerations</i> .....	52
<i>Expert by experience consultation</i> .....	53
<i>Study design</i> .....	53
<i>Participants</i> .....	54
<i>Interview settings</i> .....	56
<i>Data collection</i> .....	56
<i>Data analysis</i> .....	57
<i>Results</i> .....	58
<i>Theme 1: Empathetic Identity</i> .....	59
1.1 <i>Autistic conceptualisation of empathy</i> .....	59
1.2 <i>Empathetic identity and the development of empathy</i> .....	60
<i>Theme 2: Similarity, difference and influencing factors</i> .....	61
2.1 <i>Communication styles</i> .....	62
2.2 <i>Autistic and non-autistic empathy</i> .....	63
2.3 <i>Shared experiences and interests “touch points”</i> .....	64
2.4 <i>Balancing demands and resources</i> .....	65
<i>Theme 3: Connectivity and other consequences</i> .....	67
3.1 <i>Connectivity with others</i> .....	67
3.2 <i>The difficulties of empathetic connection</i> .....	68
3.3 <i>The salience and impact of negative stereotyping of empathy in autism</i> .....	68
<i>Discussion</i> .....	70

<i>Clinical implications</i> .....	73
<i>Strengths and limitations</i> .....	74
<i>Conclusion</i> .....	76
<i>References</i> .....	77
<i>List of tables</i> .....	88
<i>List of figures</i> .....	88
<i>Appendices</i> .....	89
.....	93

# Word Count

## 22,140

Word Count

Statistics:

Pages	93
Words	22,140
Characters (no spaces)	117,372
Characters (with spaces)	139,240
Paragraphs	566
Lines	2,360

Include footnotes and endnotes

Close

the United Kingdom. In the past qualitative studies have often  
of autistic people in order to gather data (DePage & Lindsay,  
arch in the UK reported focus on biology, cognition and risk  
tively little research focuses on the day to day experience of

living with autism; which could help inform and identify effective  
(Polliciano et al., 2014).

This review aims to focus on the voice of autistic people  
capture what this research tells us about their lived experience of autism. Fourteen papers  
were identified systematically, they were quality assessed and reviewed using thematic  
synthesis. The synthesis revealed four superordinate themes; My autistic self, The view of  
others, Fitting in, and The systems around us. Findings from the review can help to represent  
the voices of autistic people in the empirical literature. This can inform commissioners about  
the lived experience of autistic people in the UK in order to help inform decisions regarding  
clinical pathways and service provision.

Chapter two is an empirical paper that takes an exploratory approach to capture  
qualitative data incorporating semi-structured interviews with autistic adults. The study aims  
to capture the autistic people's lived experience and understanding of autism and any  
potential links to distress. Eleven autistic adults participated in the study. The qualitative data  
was analysed using Braun and Clarke's (2006) thematic analysis which identified three  
overarching themes. The first theme described the participants understanding of empathy,  
how they identified as empathetic, to what extent they felt able to empathise with others and  
how their empathy is developed. The second theme described what facilitates or hinders their  
empathy. The third theme described how empathy affects them. The results of the study are  
discussed in relation to the existing empirical literature and strengths and limitations are  
explored. Future directions of research are recommended and possible implications are

Chapter 1: Systematic review  
experience of autism in the UK: a systematic review and  
analysis of the qualitative evidence of autistic adults.

Lisa Ellen Powsey.

Prepared for submission to Autism (Appendix B)

## **Thesis overview**

This thesis explores the lived experience of people with autism. Autistic people make up approximately 1.04% percent of the population and yet their voices are under-represented in the empirical literature. Much of autism research focuses on the potential causes of autism whilst autistic people's phenomenological experience is largely absent. There has been a longstanding link between a 'lack of empathy' and autism, and this has led to assumptions being made about autistic people, their moral natures, their relational capabilities, and their values.

Regarding terminology, a study by Kenny et al., (2016) indicated that despite discrepancies between preferred descriptors, both within and outside of the autistic community, the descriptor 'autistic people' was the most widely accepted by a small majority within the community. This thesis will be directed by this research and will use the term 'autistic people' unless directly quoting source materials.

Milton (2014) speaks of a mistrust that has developed between autistic people and researchers and reflects on the importance of participatory research and the inclusion of autistic scholars if non-autistic social scientists continue to try and capture the phenomenological lived experience of autistic people. The empirical paper involved the meaningful and essential collaboration with an autistic scholar who impacted each stage of the development, implementation and analysis of the data.

Chapter one is a systematic literature review which aims to explore the daily lived experience of autistic adults in the United Kingdom. In the past, qualitative studies have often relied on families and friends of autistic people in order to gather data (DePape & Lindsay, 2016). A review of autism research in the UK reported a focus on biology, cognition and risk factors for autism and comparatively little focus on the day-to-day experience of living with

autism, which could help inform and identify effective services for autistic people (Pellicano et al., 2014).

This review aims to focus on the voice of autistic people themselves in order to capture what research tells us about their lived experience of autism. Fourteen papers were identified systematically, quality assessed and reviewed using thematic synthesis. The synthesis revealed four superordinate themes: My autistic self, The view of others, Fitting in, and, The systems around us. Findings from the review can help to represent the voices of autistic people in the empirical literature. This can inform commissioners about the lived experience of autistic people in the UK to help inform decisions regarding clinical pathways and service provision.

Chapter two is an empirical paper that takes an exploratory approach to capture qualitative data incorporating semi-structured interviews with autistic adults. The study aims to capture the autistic people's lived experience and understanding of autism and any potential links to distress. Eleven autistic adults participated in the study. The qualitative data were analysed using Braun and Clarke's (2006) thematic analysis which identified three overarching themes. The first theme described the participant's understanding of empathy, how they identified as empathetic, to what extent they felt able to empathise with others and how their empathy is developed. The second theme described what facilitates or hinders their empathy. The third theme described how empathy affects them. The results of the study are discussed in relation to the existing empirical literature and strengths and limitations are explored. Future directions of research are recommended, and possible implications are discussed.

In the appendices is further information for the examiner to supplement the thesis. The systematic review and empirical paper have been written for publication in the journal Autism.



## References

- Braun, V. & Clarke, V. (2006) Using thematic analysis in psychology. *Qualitative Research in Psychology*, 3(2): 77-101.
- Brugha, T., Cooper, S. A., McManus, S., Purdon, S., Smith, J., Scott, F. J., ... & Tyrer, F. (2012). *Estimating the Prevalence of Autism Spectrum Conditions in Adults: Extending the 2007 Adult Psychiatric Morbidity Survey*. Retrieved from:  
<http://digital.nhs.uk/catalogue/PUB05061>.
- 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(1), 60–71. DOI: 10.1177/1088357615587504
- 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: The International Journal of Research and Practice*, 20(4), 442–462. DOI: 10.1177/1362361315588200
- MacKay, T., Knapp, M., Boyle, J., Iemmi, V., Connolly, M., & Rehill, A. (2018). *The microsegmentation of the autism spectrum: Economic and research implications for Scotland*. The Scottish Government.
- Milton, D. E. M. (2014). Autistic Expertise: A Critical Reflection on the Production of Knowledge in Autism Studies. *Autism: The International Journal of Research and Practice*, 18(7), 794–802. DOI: 10.1177/1362361314525281
- Pellicano, E., Dinsmore, A., & Charman, T. (2014). What Should Autism Research Focus Upon? Community Views and Priorities from the United Kingdom. *Autism: The International Journal of Research and Practice*, 18(7), 756–770.  
<https://doi.org/10.1177%2F1362361314529627>

## **Chapter 1: Systematic review**

### **Understanding the lived experience of autism in the UK: a systematic review and thematic synthesis of the qualitative evidence of autistic adults.**

Lisa Ellen Powney

Prepared for submission to Autism (Appendix 8)

# **Understanding the lived experience of autism in the UK: a systematic review and thematic synthesis of the qualitative evidence of autistic adults.**

## **Abstract**

The lived experience of autistic people in the United Kingdom (UK) is an under researched area. Many studies rely on the reports of families and professionals to gather qualitative data. This study aimed to review and synthesise qualitative studies that captured the daily lived experience and voice of autistic adults in the UK using thematic synthesis.

Fourteen papers met our inclusion criteria and were reviewed and synthesised. The synthesis revealed four superordinate themes; My autistic self, The view of others, Fitting in, and The systems around us

Findings from the review can help to represent the voices of autistic people in the empirical literature. This can inform commissioners about the lived experience of autistic people in the UK in order to help inform decisions regarding clinical pathways and service provision.

**Key Words:** Autism, adults, United Kingdom, thematic synthesis, qualitative

## **Introduction**

Autism Spectrum Condition is a neurodevelopmental condition with a heterogeneous presentation. The International Classification of Disease and Related Health Problems (ICD) states that autism is typically characterised by persistent difficulties in the development and maintenance of reciprocal social relationships and social communication, and by a range of restricted, repetitive, inflexible patterns of behaviour and interests (Research Autism, 2018). There are around 700,000 people (Baird et al., 2006; Brugha et al., 2012), approximately 1.04% of the population (MacKay et al., 2018), diagnosed with Autism in the UK. The term ‘spectrum’ reflects the range of symptoms and the uniqueness of an individual’s presentation, rather than the severity of symptoms (The National Autistic Society [NAS], 2016). A study by Kenny et al., (2016) indicated that despite discrepancies between preferred descriptors, both within and outside of the autistic community, the descriptor ‘autistic people’ was the most widely accepted by a small majority within the community. This paper will be directed by this research and will use the term ‘autistic people’ unless directly quoting source materials.

Research examining autism has traditionally been dominated by a deficit model lens (Nicolaidis et al., 2018). This is changing however, as the neurodiversity perspective gains momentum and looks at the intersection between how a ‘non-autistic’ society and autistic people interact, and how this exacerbates many of the challenges autistic people experience (Robertson, 2010). This is leading to an increase in qualitative research, to capture the voice of autistic people, which traditionally has been largely underrepresented. DePape and Lindsay (2016) conducted a meta-synthesis of 33 qualitative studies from across several countries and identified themes around perception of self, suggesting that whilst adult’s autistic identity was accepted and important, awareness of difference to others could lead to

difficulties. They also describe strengths and challenges in family and social relationships, experiences at school, and factors relating to employment.

Much autism research has been viewed through the lens of a deficit model, locating autism as a constellation of symptoms within the individual, an inherently medicalised approach assuming constructs like autism have biological truths (O'Reilly, & Lester, 2017). There are other more critical ways of viewing autism despite the dominance of the deficit/medical model, for example, a contextualised understanding of autism as a cultural phenomenon. A critical approach to autism would encourage understanding the experience and identity of autism as being shaped by culture, language and social discourses, and that this understanding can be shaped and reconstructed as our discourses are changed (Begon and Billington, 2019). This approach does not stand in opposition of the medical model, instead it can be conceptualised as encouraging critical consideration of autism. Such critical approaches to understanding autism can have real clinical significance when considering diagnosis, intervention, and service provision. Our understanding of autism and therefore the full remit of autism services are not based on objective scientific process but constructs that are shaped by social, cultural discourses (Georgaca, 2012). It is these discourses that need more focus in research to understand their influence and impact.

There is a longstanding lack of inclusion of autistic people in decision-making consultations and research (Pellicano et al., 2014). Milton (2014) speaks of a mistrust that has developed between autistic people and researchers and reflects on the importance of participatory research and the inclusion of autistic scholars if non-autistic social scientists continue to try and capture the phenomenological lived experience of autistic people. Research that has meaningful participatory research and represents the voices of autistic people and their lived experience is essential to address their historical lack of inclusion (Fletcher-Watson et al., 2019).

Traditionally however, qualitative research in autism focuses on parents', siblings', or health care providers' accounts of autism with less attention paid to autistic people themselves (DePape & Lindsay, 2016). A review on autism research in the UK reported focus on biology, cognition, risk factors for autism and comparatively little research focuses on the day-to-day experience of living with autism, which could help inform and identify effective services for autistic people (Pellicano et al., 2014).

This review aims to examine and synthesise qualitative research about the lived experience of autistic adults in the UK. Emphasis will be on the view of autistic people themselves, rather than the report of those around them. Historically the voice of autistic people has been underrepresented in the empirical literature. This review will differ from the DePape and Lindsay (2016) review as it focuses on autistic adults in the UK. The review will focus on qualitative research to explore the question of 'what is the lived experience of autistic adults in the UK?', which historically has been underrepresented in the empirical literature.

Qualitative studies offer the opportunity to capture the voices of autistic adults, as well as the intersections of the individual, societal attitudes and social environments that could not otherwise be measured (O'Day & Killeen, 2002). A synthesis of the qualitative research of the lived experience of autistic adults will help to keep the voice and perspectives of autistic people present in the empirical literature. This will also allow for clinicians, commissioners and stakeholders to be informed by the narratives of autistic adults to help guide their practice and decision making where this will impact autistic people in the UK.

## **Methods**

This paper systematically reviewed available literature to explore the lived experience of autistic adults in the UK. The Cochrane Library and PROSPERO were searched to identify

existing or anticipated similar reviews and piloting searches were undertaken in December 2019. The experience and skills of the searcher are highly important to the effectiveness of a systematic review (McKibbin et al., 1990; Rethlefsen et al., 2015) and therefore, the primary author sought discussion with the supervisory team at all stages of the selection process.

The search strategy was developed using the Sample, Phenomenon of Interest, Design, Evaluation, Research type tool (SPIDER; Cooke et al., 2012). Table 1 outlines the search terms identified for the review following the pilot searches using the SPIDER framework. The terms were organised using the Boolean operator ‘OR’ and across components using ‘AND’.

Table 1. SPIDER tool for the identification of search terms

Domain	Search terms
S Sample	“adult” or “adults” or “adulthood”
Pi Phenomenon of interest	Asperger* or Autism Spectrum* or “Autism” or “High Functioning Autism” or Autis*
D Design	“Qualitative” or “Phenomenology” or “Interviews“ or “focus group” or “thematic analysis” or “interpretative phenomenological analysis”
E Evaluation	“Opinions” or “stories” or “lived experience” or “personal narratives” or “experience”

The review was undertaken in February 2020 utilising the following databases: PubMed, Web of Science and APA PsychInfo. Bramer (2017) recommends that a small set of well-chosen databases will yield a good quality number of papers. Egger et al., (2003) suggest careful consideration be given to the time factors involved with the searching of

unpublished literature, versus the robustness this would add to the review. There was no unpublished literature identified to be included in the review.

### *Eligibility Criteria*

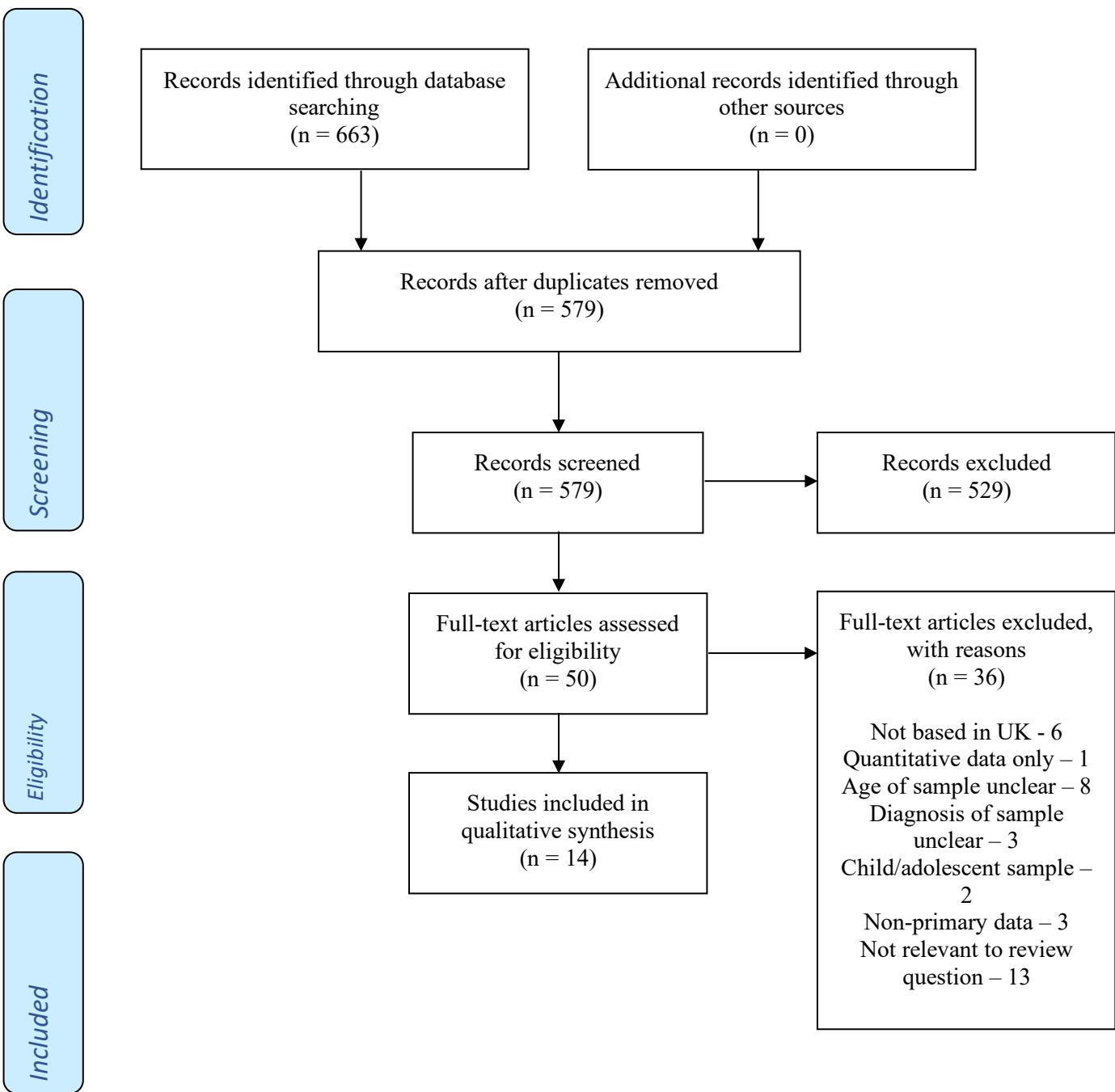
This review sought to identify studies that used primary data exploring the lived experience of autistic people over the age of 18 in the UK. Following careful review, papers were included if ; a) they were undertaken in the UK b) were from the general population sample; c) at least 75% of the study population were over the age of 18; d) at least 75% of the population had a diagnosis of Autism Spectrum Condition or equivalent (papers were excluded if this was not clearly identifiable); e) the paper was published in a peer review journal; e) the paper contained primary qualitative data; f) the focus of the paper should be on that which is inherent in the daily lived experience of autism for a majority of the autistic population. No date limitations were set for the searches. Studies were excluded if one or more of the inclusion criteria were not met, or where the qualitative data were not extractable. Systematic reviews were not included.

### *Review strategy and study selection*

This review followed methods and results reporting of Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA; Moher et al., 2009) guidelines (Figure 1). A total of 579 studies were identified from initial searches once duplicates (84) were removed. Titles and abstracts were reviewed leading to 50 full-text articles being assessed for eligibility. Following application of the eligibility criteria, 14 papers remained for inclusion in the synthesis. The first author [EP] reviewed all papers to determine eligibility. An independent reviewer undertook the same process on a sample of 10% of the papers (both title and abstracts and full text), leading to full agreement on the inclusion and exclusion of the sample papers.



Figure 1. PRISMA flowchart of study selection process



### *Quality assessment and critical appraisal*

Included studies were quality assessed by first author EP using the Critical Appraisal Skills Programme (CASP, 2010). The checklist consists of 10 items that span the research process and reflect on elements important in qualitative research, for example, aims, design, methodology and reflexivity (Table 2). The overall quality of the papers was good using the CASP criteria (for example see Appendix 1). The critical appraisal indicated that most studies fail to explore the potential relationship between the researcher and the participants. One study met decidedly fewer criteria than the others, and one study has a very small amount of extractable qualitative data, but overall, the quality of the included papers was good. The use of quality appraisal supports the contextualisation of the synthesis. All papers were kept for inclusion of the study following critical appraisal, as is common practice (Soilemezi & Linceviciute, 2018). This was considered amongst the team as the synthesis was developed. It is common to still include lower quality studies as though they may not have reported adequately, they may still add important and authentic accounts of people's experiences (McKenna-Plumely et al., 2020). Appendix 1 illustrates the CASP criteria met for each paper so that these can be considered throughout the review.

**Table 2. CASP quality assessment of included studies**

Reference	CASP										Total
	1	2	3	4	5	6	7	8	9	10	
Bargeila et al., 2016	1	1	1	1	1	.5	1	.5	1	1	9
Camm-Crosbie et al., 2019	1	1	1	1	.5	0	0	1	.5	0	6
Forster & Pearson, 2019	1	1	1	1	1	1	1	1	1	.5	9.5
Griffith et al,2011	1	1	1	1	1	.5	1	1	1	1	9.5
Hickey et al., 2018	1	1	1	1	1	.5	1	1	1	1	9.5
Kapp et al., 2019	1	1	1	1	1	.5	1	1	1	1	9.5
Kock et al., 2019	1	1	1	1	1	.5	1	1	1	1	9.5
Leedham et al., 2020	1	1	1	1	1	0	1	.5	1	1	8.5
Powell & Acker, 2016	1	1	1	1	1	0	1	1	1	1	9
Robertson & Simmons, 2015	1	1	1	1	1	.5	1	1	1	1	9.5
Rodgers et al., 2019	1	1	1	1	1	.5	1	1	1	1	9.5
Russell et al,2019	1	1	1	1	1	0	.5	1	1	1	8.5
Stagg, & Belcher, 2019	1	1	1	1	1	.5	1	1	1	1	9.5
Treweek et al, 2019	1	1	1	1	1	.5	1	1	1	1	9.5

One point was awarded for meeting the criteria, .5 for partial fulfilment, and 0 for failure to meet the criteria.

CASP criteria: 1 Clear aims; 2 Appropriate method; 3 Appropriate design; 4 Appropriate recruitment; 5 Appropriate data collection; 6 Relationship between researcher and participants; 7 Ethical issues considered; 8 Data analysis rigorous; 9 Clear stated findings; 10 Research valuable.

## Results

The key characteristics of the included papers are described in Table 3.

### *Study characteristics*

The 14 studies described the experiences of 441 participants from the UK, with a reported age range of 18 to 67 years old. In the papers where gender was recorded, 191 participants identified as female, 151 male, 1 non-binary; 98 were not specified. All participants were described as autistic adults. Various data collection methods were used; interviews, focus groups, on-line data and survey. Analysis methods were largely split between interpretative phenomenological analysis, thematic analysis, framework analysis and a general inductive qualitative approach. The focus of the studies are as follows; The female autism phenotype and its impact upon the under-recognition of ASC in girls and women (Bargiela et al., 2016). Autistic people's experiences of treatment and support for mental health difficulties (Camm-Crosbie et al., 2019). Perceptions of friendship and the concept of mate crime in autistic adults (Forster & Pearson, 2019). The experiences of individuals in middle adulthood with Asperger syndrome (Griffith et al., 2011). The experience of growing older with autism (Hickey et al., 2018). Stimming from the perspective of autistic adults (Kapp et al., 2019). The experience of intimate relationships of women who have been diagnosed with Autism in adulthood (Kock et al., 2019). The lived experiences of female adults diagnosed with an autism spectrum condition in middle to late adulthood (Leedham et al., 2020). The impact of attending an Asperger syndrome diagnosis clinic (Powell & Acker, 2016). The sensory experiences of adults with autism spectrum disorder (Robertson & Simmons, 2015). The nature of the worries autistic adults have about their futures (Rodgers et al., 2019). What abilities attributed to their autism do adults find helpful (Russell et al., 2019). Living with autism without knowing, receiving a diagnosis in later life (Stagg &

Belcher, 2019). How autistic people think they are perceived by others, and what they think autism stereotypes are (Treweek et al., 2019).

### *Data synthesis*

The data was synthesised in three stages following the thematic synthesis guidelines of Thomas and Harden (2008). The results sections of the papers were inductively coded line by line to capture the meaning and context, staying as close to the original data as possible. Only qualitative data were coded where the study used a mixed methods design and, where the samples included non-autistic people, only the data relating to autistic people were coded. The data coded were direct quotes of the autistic adult participants or summaries of quotes from the authors but interpretations by the authors were not included, in order to stay as close to the words of the participants as possible. This was discussed at length within the research team and we decided not to include author interpretations to stay close to the primary data of the original studies. In stage two, descriptive themes were developed by clustering similar codes from across the 14 studies. Each stage of the process was discussed with the full research team in order to circumnavigate possible biases of the primary researcher. The third and most controversial stage, 'going beyond the data' (Thomas & Harden, 2008), is where additional concepts and understandings are generated to answer the review question. All authors met to discuss these emerging themes on three occasions. During these discussions excerpts of the raw data, codes and superordinate themes were examined together with the results of the quality assessment which were also considered during this process. Once the final superordinate themes and subthemes were reviewed the frequency of contributions of each study to the themes was discussed. Four over-arching themes were identified; My autistic self, The view of others, Fitting in, and The systems around us (See Appendix 2 for example illustrative quotes).

Table 3. Study characteristics

<i>Reference</i>	<i>Focus of Study</i>	<i>Participants and recruitment</i>	<i>Formal diagnosis present?</i>	<i>Method of data collection</i>	<i>Method of Analysis</i>	<i>Primary Findings</i>
<i>Bargiela et al., (2016)</i>	The female autism phenotype and its impact upon the under-recognition of ASC in girls and women.	N=14 Recruited via existing contacts of the research team and through social media adverts	Yes – all participants had clinical diagnosis	Semi-structured interviews	Framework analysis	Primary themes: You're not autistic. Pretending to be normal. Passive to assertive. Forging an identity as a woman with ASD.
<i>Camm-Crosbie et al., (2019)</i>	Autistic people's experiences of treatment and support for mental health difficulties.	N=200 Recruited through the Cambridge Autism Research Database, charities, support groups, educational institutions, and social media	Not specified	On-line survey	Thematic Analysis	Overarching Theme: Tailored support is beneficial and desirable. Three themes: People like me don't get support. Lack of Understanding and knowledge. Well-being.
<i>Forster &amp; Pearson, (2019)</i>	Perceptions of friendship and the concept of mate crime in autistic adults.	N=5 Opportunity sampling via personal networks and online platforms	Yes – confirmed through self-report	Semi-structured interviews	Interpretative phenomenological analysis	Superordinate themes: Perceptions and 'learning the formula'. Socialising . . . 'It's more complicated than that'. 'Taking advantage of you'.
<i>Griffith et al., (2011)</i>	The experiences of individuals in middle adulthood with Asperger syndrome .	N=11 Recruited via adverts on two autism charity websites	Yes - 9 participants diagnosed with Asperger Syndrome. 2 participants were seeking a diagnosis	Semi-structured interviews	Interpretative phenomenological analysis	Master Themes: 'Some days I struggle' – living with Asperger Syndrome. 'They don't expect you to have problem with things' – employment. 'I just fall through the gaps between' – experiences with mainstream support. 'Raising awareness' – future steps towards supporting people with Asperger Syndrome.

<i>Hickey et al., (2018)</i>	The experience of growing older with autism.	N=13 Recruited from an NHS diagnosis service and via autism support and social groups in London.	Yes - 5 participants with formal diagnosis. 8 confirmed through self-report	Semi-structured interviews	Thematic analysis	Overarching themes: Difference. Life review. Longing for connection.
<i>Kapp et al., (2019)</i>	Stimming from the perspective of autistic adults.	N=31 Recruitment took place across residential homes, a training centre for autistic adults and existing networks.	Yes – all participants	Individual interviews and focus groups	Thematic analysis	Themes identified: Stimming as a self-regulatory mechanism. (de)stigmatisation of stimming.
<i>Kock et al., (2019)</i>	The experience of intimate relationships of women who have been diagnosed with Autism in adulthood.	N=8 Purposive sampling from two specialist diagnostic services in London.	Yes – all participants	Semi-structured interviews	Interpretative phenomenological analysis	Themes identified: Response to receiving the diagnosis of ASD. Factors influencing the decision to date. Experience of relationships as a person with ASD. Sex and sexual experiences.
<i>Leedham et al. (2020)</i>	The lived experiences of female adults diagnosed with an autism spectrum condition in middle to late adulthood.	N=11 Recruitment via a local NHS diagnostic service.	Yes – all participants		Interpretative phenomenological analysis	Themes identified: A hidden condition. The process of acceptance. Post diagnostic impact of others. A new identity on the autism spectrum.
<i>Powell &amp; Acker (2016)</i>	The impact of attending an Asperger syndrome diagnosis clinic	N=74 Recruited through attending a diagnostic service.	Yes - 54 participants with formal diagnosis. 20 participants were from a sub-clinical group.	Survey data from open ended questions	Thematic Content Analysis	Themes (in regard to emotional reaction to assessment): Relief. Positive/negative/mixed feelings. No clear feelings. Diagnostic disappointment.
<i>Robertson &amp;</i>	The sensory experiences of adults	N=6	Yes – all participants	Focus group	A general inductive	Themes identified: Particular aspects of stimuli.

<i>Simmons, (2015)</i>	with autism spectrum disorder	Recruited through a gatekeeper at a local company who employs people with a diagnosis of ASC.			qualitative approach	Control over stimuli. The impact of emotions and mental states, physical responses to stimuli.
<i>Rodgers et al., (2019)</i>	The nature of the worries autistic adults have about their futures.	N=23 Recruited through autism charities and support groups.	Yes – all participants	Focus groups	Thematic analysis	Themes identified: Uncertainty about the future. Support. Diagnosis. Living circumstances. Relationships. Health.
<i>Russell et al., (2019)</i>	What abilities attributed to their autism do adults find helpful.	N=24 Maximum variation sampling. Residential homes and National Autistic Society skills training centres.	Yes – all participants	Semi-structured interviews using a topic guide	Thematic analysis	Themes identified: Experience of difference. False dichotomies. Moderating influences.
<i>Stagg &amp; Belcher, (2019)</i>	Living with autism without knowing, receiving a diagnosis in later life.	N=9 Recruitment was through online ASC forums and messages on a blog run by the second author.	Yes – all participants	Free-associative interviews.	Thematic analysis	Superordinate themes: Early signs of ASC. Awareness of being different. Receiving a diagnosis. The usefulness of a diagnosis. Support and coping.
<i>Treweek et al., (2019)</i>	How autistic people think they are perceived by others, and what they think autism stereotypes are.	N=12 In person from social groups	Yes - 11 participants with formal diagnosis. 1 confirmed through self-report	Semi-structured interviews	Interpretative phenomenological analysis	Themes identified: The primary stereotype is that autistic people are 'weird'. Autistic stereotypes have negative effects and co Autistic people are heterogenous.



## Theme 1: My Autistic Self

This theme describes what it meant to participants to be diagnosed as autistic, the timing of receiving their diagnosis and how this affected their sense of identity. Autism for some, became a lens to re-examine past difficulties with renewed understanding and context. This process appeared to lead to difficulties becoming externalised from an internal locus to that of autism.

### *1.1 Diagnostic impact*

Participants in many of the included studies described ways in which diagnosis impacted them in their everyday lives (Griffith et al., 2011; Powell & Acker, 2015; Bargiela et al., 2016; Hickey et al., 2017; Rodgers et al., 2018; Forster & Pearson, 2019; Kock et al., 2019; Leedham et al., 2019; Russell et al., 2019; Stagg & Belcher, 2019). The timing of diagnosis was described as difficult. Some articulated that if diagnosed younger, support and understanding may have been accessible earlier, potentially circumnavigating some of the difficulties experienced; ". . . *If I had known and people had helped me out earlier on then life would have been a whole lot easier*" (Bargiela et al., 2016). There were mixed responses to receiving a diagnosis of autism; "*I was happy . . . I feel validated . . . Liberated*", to, "*I feel shocked . . . daunted . . . confused*", and, "*very depressing to realise that I will never change or get better*" (Powell & Acker, 2015). While it seemed many participants in included papers described a "*eureka moment*" (Stagg & Belcher, 2019) other papers captured negative impacts of diagnosis, narratives around worrying about when and if to share their diagnosis, or being "*stuck like this forever*" (Leedham et al., 2019).

A number of included studies described being diagnosed with autism leading to a new sense of identity (Powell & Acker, 2015; Bargiela et al., 2016; Hickey et al., 2017; Kock et al., 2019; Leedham et al., 2019; Russell et al., 2019; Stagg & Belcher, 2019). Participants

also described a new confidence and permission to embrace who they are “*a newfound confidence to live shaped by their values . . . ‘letting go’ of an old life, pre-diagnosis, one where they no longer needed to assimilate to meet the social norm*” (Leedham et al., 2019).

Autistic identity seemed to be liberating, giving permission to be authentic, positively impacting their daily lives. Autistic identity could facilitate legitimising and communicating needs more confidently, “*I’m more comfortable with who I want to be and who I am . . .*” (Kock et al., 2019).

### *1.2 A lens to make sense of one’s self*

Following diagnosis many spoke of a fresh perspective, a new ‘autism’ lens to view, make sense of, and understand one’s self, not just presently but retrospectively (Powell & Acker, 2015; Hickey et al., 2017; Leedham et al., 2019). This appeared important for many, allowing reflection on experiences previously accompanied by confusion and difficulty, with new ways of formulating them; “*It’s good ... at least 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. Sorry, it’s making me really emotional*” (Leedham et al., 2019); “*almost every day I’d think of some incident way back; Ah yes, that happened because I was Asperger*” (Hickey et al., 2017).

### *1.3 Externalising difficulties*

The diagnosis was described as a new way of viewing difficulties and as playing a role in externalising the difficulties, from an internal negative identity, to being externalised to autism; “*I was starting to get comfortable with the idea that I don’t fit in, but I didn’t think of Asperger’s I just thought I was naughty by nature*”, (Stagg & Belcher, 2019); “*feel better about myself because . . . I know it’s not my fault*”(Powell & Acker, 2015). This externalisation of difficulties appeared to reduce shame and self-criticism and facilitate self-

compassionate acceptance, allowing difficulties to be named and worked on for those who want to (Powell & Acker, 2015; Kock et al., 2019; Stagg & Belcher, 2019).

## **Theme 2: The View of Others**

A prominent theme amongst included studies was the salience and importance attributed to the views of others. The ‘view of others’ was described as impacting autistic people’s emotional wellbeing and as having the potential to limit opportunities for autistic people living in the UK. Across the studies were reported descriptions of the impact, of both anticipated and actual experience, of negative stereotypes and stigma.

### *2.1 Stereotypes*

A dominant feature in the everyday experience of living with autism was the impact of negative stereotypes; this was pervasive throughout the included studies. Participants reported that expectations of autistic people, what they need and how they may experience the world, can be significantly shaped by stereotypes. This can lead to limiting opportunities for autistic people by making assumptions based on stereotypes rather than being informed by lived experience (Bargiela et al., 2016; Treweek et al., 2018; Forster & Pearson, 2019; Kock et al., 2019; Leedham et al., 2019). This was described very astutely by one participant, *“I think most stereotypes are negative, because the very nature of a stereotype is to create a perimeter within which you should or ought to operate, and people are just not like that, and the minute you step outside the boundary of a stereotype, so if someone says ‘oh, you’re like this, therefore you’re not allowed to do that’, the idea that you’re creating a boundary around that person, beyond which they shouldn’t or ought not to cross, so it’s saying, well, if you can do that, that means you’re not disabled”* (Treweek et al., 2018).

The influence stereotypes can have on autism being recognised in individuals; or of autistic people failing to identify as autistic due to negative stereotypes, was also described (Bargiela et al., 2016). This was reported to have led to misdiagnosis, invisible difficulties, being misunderstood, and delay of accurate diagnosis (Griffith et al., 2011; Bargiela et al., 2016; Camm-Crosbie et al., 2019; Rodgers et al., 2018; Leedham et al., 2019; Stagg & Belcher, 2019).

Many papers reported the anticipation fear of negative judgements by others (Rodgers et al., 2018; Treweek et al., 2018; Kapp et al., 2019; Kock et al., 2019; Russell et al., 2019). Fears of negative perceptions appeared to be heightened in social interactions with others: *"I'll often get worried are they bored of what I am saying? Are they tired of me blathering on?"* (Forster & Pearson, 2019). This appeared to create a sense of social vulnerability; *"I would be a bit embarrassed at being duped and upset with myself"* (Forster & Pearson, 2019).

## 2.2 Stigma

The presence and impact of stigma was a dominant theme across included studies (Rodgers et al., 2018; Treweek et al., 2018; Kapp et al., 2019; Kock et al., 2019; Russell et al., 2019). Stereotypes clearly had a role in the stigma the participants described; *"I think Autism still has this really big stigma so that if I tell someone I'm autistic - they just like think of someone who can't communicate"* (Kock et al., 2019). Stigma was also described in terms of how accepted or rejected by society the participants felt; *". . . Likely that they will be rejected by society because we don't fit in"* (Camm-Crosbie et al., 2019).

## 2.3 Connection to the autistic community

Feeling different and the perception of others was not a concern when spending time with other autistic people. In fact, the autistic community was a place participants described

feeling belonging, accepted and understood (Hickey et al., 2017; Camm-Crosbie et al., 2019; Forster & Pearson, 2019; Leedham et al., 2019; Russell et al., 2019); *"I've never fitted in that jigsaw puzzle ... [now]I fit somewhere, I belong somewhere with other people somewhere who are like me Yes, it's good"*, (Leedham et al., 2019). *"You're accepted. You don't have to sort of hide anything"*. *"The people, some of them are on my wave-length"*, (Hickey et al., 2017).

### **Theme 3: Fitting In**

This theme describes how participants spoke of an awareness of being different to many of those around them. Participants spoke of strategies employed to help them to reduce or hide this visible difference in order to fit in and/or establish relationships. They also spoke of how expectations of them could deepen their awareness of perceived differences to non-autistic people. There was a narrative that this pressure to conform and awareness of difference can lessen with age for some, and that with life experience skills can be developed to create more ease in fitting in.

#### *3.1 Difference*

Many described an awareness of being different to their non-autistic peers and how this impacted them (Griffith et al., 2011; Bargiela et al., 2016; Hickey et al., 2017; Camm-Crosbie et al., 2019; Forster & Pearson, 2019; Kapp et al., 2019; Kock et al., 2019; Russell et al., 2019; Stagg & Belcher, 2019). From one study, an autistic person reported *"I'd try and get students not to display (stimming) if they didn't want to be seen as different . . ."* (Kapp et al., 2019). This awareness of 'being different' for many began in childhood, though it was often not well understood pre-diagnosis; *"The very first time I thought I was different . . ."*

*When they didn't put me up to the junior school from the primary school. And I thought, 'Oh why are they doing that? What's wrong with me?'*, (Hickey et al., 2017).

### 3.2 Sensory experiences

Many participants in the included studies commented on their difference in sensory experiences and how this impacted their day-to-day functioning. This was described as overwhelming and challenging, but also, at times, as a positive 'extra' level to an experience (Griffith et al., 2011; Robertson & Simmons, 2015; Hickey et al., 2017; Forster & Pearson, 2019; Kapp et al., 2019; Kock et al., 2019; Leedham et al., 2019; Russell et al., 2019).

Sensory atypicalities were described as challenging and impacting socialising, capacity to work, and generally navigating the world; *"sensory overload problems: noise, strong lights and smells could become so overwhelming it was difficult to focus on anything"*. . . *Social situations that prompted such comments included a crowded street, a busy restaurant, and a highly interactive workplace*" (Russell et al., 2019). Descriptions suggested that sensory demands could reduce capacity for other demands, for example, work or social interactions.

Though sensory experiences could be challenging there were also enjoyable elements, *"being able to experience things more intensely, such as art or nature, even though sensory sensitivities can be awful at times"*, (Russell et al., 2019). Comfort being derived from sensory experience was also described; *"I would just keep repeating ... the same 10 seconds of a song ... it is something to comfort me . . . just have that looping constantly and that would bring great comfort"*, (Robertson & Simmons, 2015).

Stimming, self-stimulating behaviours i.e., hand flapping, vocalisations, or even whole-body movements, were described as a sensory response that was both conscious and unconscious. Many described stimming as a way of regulating their excessive sensory

experience, as a form of coping or self-soothing. *As one participant (Luke) explained that the regulatory aspect of stimming worked through attending to a single point of focus over which one had control, to self-regulate by blocking or reducing excessive input. . . .* (Kapp et al., 2019).

### 3.3 Camouflaging, mimicking and masking

Participants in included studies expressed a desire and an expectation from others for people to fit in with non-autistic people (Griffith et al., 2011; Bargiela et al., 2016; Hickey et al., 2017; Forster & Pearson, 2019; Kock et al., 2019; Leedham et al., 2019). Camouflaging their autistic traits in order to appear similar to non-autistic people was described as a strategy to reduce visible differences. This was particularly strongly represented by female participants reflecting on their school years where many described masking, mimicking and developing personas to fit in (Bargiela et al., 2016; Leedham et al., 2019); *"when you emulate things long enough, they become a habit . . . you actually outwardly become exactly like everybody else. But you aren't. You never - you never forget. You're never not autistic"*, (Hickey et al., 2017).

These strategies were described widely across the papers and described as exhausting and effortful (Bargiela et al., 2016; Griffith et al., 2011; Forster & Pearson., 2019). *"I can wear this mask that I used to wear when I used to have to deal with people . . . And it's exhausting, but I just wear this mask where I'm jovial, cheerful person"*, (Griffith et al., 2011). *"I feel like I have taught myself just through loads of very strict, conscious practise over the years . . . It's like playing a role"*, (Forster & Pearson, 2019).

Attempts to fit in through masking, camouflaging and/or mimicking as a way of hiding difficulties was widely described in included studies (Griffith et al., 2011; Robertson & Simmons, 2015; Bargiela et al., 2016; Hickey et al., 2017; Camm-Crosbie et al., 2019;

Forster & Pearson, 2019; Kock et al., 2019; Leedham et al., 2019). A consequence of hiding autistic traits however, combined with a lack of knowledge from those around them, can be a lack of needed support or adjustments; *"I was unbearable with my mother but at school I was perfect" . . . "the reward for trying hard to be normal was to be ignored . . ."* (Bargiela et al., 2016).

### *3.4 Relationships and learning from experience*

Relationships were widely discussed by participants in included studies and often seen as a key feature of fitting in, a part of everyday life (Griffith et al., 2011; Robertson & Simmons, 2015; Bargiela et al., 2016; Powell & Acker, 2015; Hickey et al., 2017; Rodgers et al., 2018; Camm-Crosbie et al., 2019; Forster & Pearson, 2019; Kock et al., 2019; Leedham et al., 2019; Russell et al., 2019). Relationships were described as intimidating but desired; and perceived as a societal expectation to fit in (Leedham, et al., 2019). Participants also described positive impacts of sharing their autism, for example improved communication in relationships; *"he knows exactly what to do . . . he can tell if I am uncomfortable and he'll take me out of that situation"* (Kock et al., 2019). Some however, described autism rendering them vulnerable to exploitation or negative relational interactions leading to a sense of difference, vulnerability and not fitting in (Bargiela et al., 2016; Rodgers et al., 2018; Forster & Pearson, 2019; Kock et al., 2019; Leedham et al., 2019)

Though some behavioural features of autism were felt to become less socially acceptable with age, for example, stimming (Kapp et al., 2019) there was a sense that with increased age and experiences that life generally can become more positive. Social stressors reducing with age and learning through experience were described (Bargiela et al., 2016; Forster & Pearson, 2019; Hickey et al., 2017; Kapp et al., 2019). *"When you're young you've got to make friends, you've got to find a partner, find a job, take exams and all this sort of*



*thing. But when you're older you don't have those pressures maybe", (Hickey et al., 2017). This included feeling vulnerable but learning from this; Young women who had reported difficult interpersonal experiences were able to later reflect on and describe how they had been manipulated. As a result, many described having learnt to read others' intentions better and used this knowledge to leave situations where they felt uncomfortable . . . (Bargiela et al., 2016).*

#### **Theme 4: The Systems Around Us**

Across the included studies participants described uncertainty about how well autism was understood and accommodated in the systems around them. There were descriptions of the advantages of autistic traits (Russel et al., 2019), but there were clearly described concerns around professional knowledge of autism in educational, employment and support services, alongside gaps in service provision in the UK and the impact of this.

##### *4.1 Lack of knowledge*

There were feelings of concern and frustration described in the included studies relating to the lack of knowledge of professionals in the systems surrounding autistic people, and the impact this can have. Concerns were expressed around the facilitation of reasonable adjustments when autism may not be recognised (Griffith et al., 2011; Bargiela et al., 2016; Camm-Crosbie et al., 2019; Rodgers et al., 2018; Kapp et al., 2019; Stagg & Belcher, 2019).

There was also a description of some people being left in a liminal space between the autistic and non-autistic communities and therefore not fitting within either services and left reliant upon family and friends for support (Rodgers et al., 2018). There also appeared to be a worry about being a burden in this context, *"I am too high functioning for most ASD*

*programming . . . but not NT enough to function well in conventional environments”,*  
(Camm-Crosbie et al., 2019).

#### 4.2 Employment

Participants described positives and negatives to how their autism affects their ability to navigate the workplace demands and environment (Griffith et al., 2011; Powell & Acker, 2015; Robertson & Simmons, 2015; Russell et al., 2019). One participant clearly described the cumulative effect of demands from working; *“I have this stress going into the workplace, then I had the stress in the workplace . . . I'll stress going home and then it'll take me a couple of hours to wind down and go through the same thing the next day”*, (Griffith et al., 2011).

Some felt social difficulties that were poorly understood by employers and colleagues impacted their career progression; *“I'm very intelligent, I'm very capable, very dedicated . . . if you can't interact socially, you're not going to progress, so you sort of stay in a corner as a virtual nobody”*; (Griffith et al., 2011). Conversely, there were also descriptions of autistic traits having strengths in the workplace: *“using lunchtimes to focus on sorting out stuff for the children when others were just gossiping”* (Russell et al., 2019).

#### 4.3 Lack of services and barriers to support

Though some participants spoke of their autism opening up support opportunities, many described ‘falling between the gaps’ or of a ‘lack of specialised services’ (Griffith et al., 2011; Camm-Crosbie et al., 2019; Rodgers et al., 2018); *“I think actually a lot of the time it does fall on your personal support, your parents, your partner, it always falls on them, overwhelmingly falls on them because there's huge gaps in service provision and that can cause huge problems in and of itself”*, (Rodgers et al., 2018). Participants spoke of a

widespread ‘lack of understanding’ about autism which impacted the support available; *“the biggest difficulty in getting the support I need is the lack of understanding of autism. Even after decades of research, many institutions still don’t have the first clue in dealing with such a condition . . . The support I have received I feel isn’t suitable enough”*, (Camm-Crosbie et al., 2019).

The combination of sometimes invisible disabilities, lack of knowledge amongst professionals, exacerbated by widely held stereotypes, appears to instil a sense of vulnerability in many of the autistic participants. This was discussed in the context of high prevalence rates of mental health difficulties (Griffith et al., 2011; Robertson & Simmons, 2015; Bargiela et al., 2016; Powell & Acker, 2015; Rodgers et al., 2018; Camm-Crosbie et al., 2019; Kapp et al., 2019; Leedham et al., 2019; Russell et al., 2019; Stagg & Belcher, 2019). *“ . . . the biggest difficulty in getting the support I need is the lack of understanding of autism. . . . many institutions still don’t have the first clue in dealing with such a condition, and hence I have found only select places deal with autism specifically”*, (Camm-Crosbie et al., 2019).

Given the concerns around lack of support provision and autism awareness when looking ahead, there was a concern about where future support will come from; *“The support being there [is a worry]. Will the support still be there for us? . . . and the support actually understanding and what happens when I’m older and I need more support?”* (Rodgers et al., 2018). It seemed in different ways many participants were asking who understands enough about autism to be able to support me?

## **Discussion**

This review aimed to explore the lived experience of autistic adults in the United Kingdom using thematic synthesis of qualitative research (Thomas & Harden, 2008). The quality assessment of the included studies using the CASP was held in mind when weighting

the studies in the analysis. The quality assessment indicated that most studies failed to overtly explore the potential relationship between the researcher and the participants. One study met decidedly fewer criteria than the others, and one study has a very small amount of extractable qualitative data, but overall, the quality of the included papers was good. The synthesis revealed four superordinate themes: My autistic self, The view of others, Fitting in, and The systems around us.

Many participants in the included studies described that their diagnosis of autism helped them to make sense of their previous and often difficult experiences, and to move them from a position of self-blame to externalising the difficulties to their autism. This process of formulating their experiences through the new lens of autism appeared to have a range of potential benefits from reducing self-blame for difficulties, improving self-compassion

Though some participants spoke of their autism as opening avenues of support from professionals, there was a clear narrative that many felt there were not enough opportunities for support with difficulties associated with their autism or comorbid mental health and emotional wellbeing difficulties. Murphy et al., (2016) argues an urgent need for increased awareness of autism, its comorbid health difficulties and development of evidence-based health care after reviewing pathways and service provision for autistic people. This appears to align with the voices of the participants, some of whom described support and service opportunities having opened. Yet for many there was a lack of services with knowledge of autism and its intersections with mental health. This was described as leading to a sense of liminality for some of ‘not being autistic enough’ for some services, and not ‘neurotypical’ enough for others.

Given that evidence suggests that autistic people have significantly increased prevalence of mental health problems, including mood and anxiety disorders (Lugnegård et

al., 2011) this is of grave importance in considering policy and service development for this largely marginalised population of people. The findings from this review around the lack of understanding from others, and its impact appear to echo the survey results of Beardon and Edmonds (2007) who concluded that that professionals generally had very little understanding of autism in the UK. They found that 83% of autistic respondents found great challenge in the lack of acceptance and understanding from those they interacted with daily. This could suggest that increasing the awareness and understanding of autism both in the general population and amongst professionals could be beneficial to the quality of life of autistic adults in the UK. The impact of living in a society not accommodating and aware of autism is argued by the neurodiversity movement to contribute to and exacerbate the daily challenges of autistic people (Robertson, 2010). Examples of the disadvantages for autistic people are that they are less likely to have a well-paying job, have fewer social connections outside their family, higher rates of marital difficulty and higher prevalence rates of mental health difficulties than non-autistic people (Howlin et al., 2004, 2013; Howlin & Moss, 2012).

Some participants however named a perceived sense of inadequacy and shame, and a fear around being labelled as lacking or disabled with fears that autism would not change or get better. This was offset somewhat by the narrative that with age and experience difficulties can lessen and more confidence in being an authentic version of oneself can emerge. This was also described in the context of connecting with the autistic community for many of the cohort; as finding a place where although difference still exists, there was a strong sense of acceptance and belonging. A reduction of shame seemed to facilitate self-compassionate acceptance or allowed difficulties to be named and worked on for those who want to. In the company of non-autistic people, exhausting coping strategies such as masking and camouflaging were frequently described. This is consistent with the findings of Milton &

Sims (2016) who discuss that some autistic people, although difficult, find it easier to conform via these strategies, though some find themselves unable to.

For the majority interviewed in these studies a diagnosis appeared to be a relief, an explanation and vehicle for communicating their needs to make their lives, relationships, and employment better where possible. The impact of being diagnosed as autistic seemed, for many, to facilitate a reduction in self-criticism and provided an opportunity for people to legitimise their needs and/or develop coping strategies for difficulties no longer viewed as personal failures. A more critical approach to autism advises consideration cultural formulations of autism by engaging with the social discourses in society, and how this would then offer further externalisation opportunities and could potentially further mitigate the experiences of shame and inadequacy described in the review. This could be an interesting direction for further research. Rather than locating deficits in an individual under the medicalised model it could lead to formulating more systemically and this would naturally feed into a cultural shift in how we approach clinical training, formulation, and intervention. Perhaps also leading to wider, much needed, systemic change in how we raise awareness of, and formulate, autism in other contexts, for example, education and employment.

The implications of this being that diagnosis can be a very affirming and important process. Yet, gaining a diagnosis and/or post-diagnostic support to process this in the UK can be very challenging. Beardon and Edmonds (2007) conducted a survey with 237 autistic adults in the UK and reported that 64% found a diagnosis difficult to receive and that 86% of respondents received too little or no post-diagnostic support.

Similarly, in a survey of over 1000 parents in the UK, diagnosis from first point of contact with a professional typically took 3.5 years and for nearly 40% of parents no post-diagnostic support was offered (Crane et al., 2016). It is important to hold in mind that autism pathways and service provisions will vary regionally across the UK. There is much regional

post-diagnostic support provision variation as they are usually provided by third sector organisations (Crane et al., 2018). This review offers potential insight into how autistic people could benefit from more timely diagnosis, though some spoke of feeling daunted by receiving a diagnosis of autism, many clear benefits articulated.

### *Strengths and limitations*

A particular strength of this review was the general good quality of the included papers as assessed by the CASP. Meaningful participation has been cited as highly important to the future of research in autism given the underrepresentation of the autistic voice in empirical research (Milton & Moon, 2012; Milton, 2014). Two studies clearly identified autistic people as part of their research team and three studies included participation at the interview schedule development level and one triangulated their results with autistic people giving more rigour to their research findings. For the most part meaningful participation was not identifiable rather than necessarily absent.

A potential limitation was that the data extraction was performed by the primary author and this can risk bias. The risk of bias from data extraction was somewhat circumnavigated by extracts being presented to the research team and discussed at length. In reflecting upon the nature of the research question it was felt that while the focus was left intentionally broad, this was a possible limitation of the study, a more specific focus could have yielded thicker richer data for analysis. The data provided by the included studies did yield rich and interesting descriptions about the everyday lives of autistic people, but perhaps future reviews could focus more on what could be unique to the UK i.e., service provisions, differences due to regional differences and devolved nations. This could have more specific implications for service development. An element that could have been considered in this

review is if there were any regional differences within the included studies and how that could have affected the themes.

Participants of qualitative research also tend to be self-selecting and therefore may be homogenous as a group, this could also include higher intellectual and communication abilities given the nature of the research. This could limit the generalisability of the review to the wider autistic population that will include those with communication and intellectual difficulties.

### *Conclusion and implications of the review*

This review synthesised the findings from 14 qualitative papers and found that there were rich descriptions of the positive impact of being diagnosed as autistic. This included engagement with autistic identity, a sense of belonging with the autistic community, and the externalisation of difficulties from self to autism. These seemed to develop a greater sense of self compassion and wellbeing. Despite these positive descriptions there were also those who felt their diagnosis should have come earlier, who described being diagnosed and left unsupported. Invisible differences in sensory experiences and ways of relating impacted the wellbeing of autistic people negatively. This is unsurprising given the diversity within regional service provision, commissioning, and variation of often third sector-based support. This review highlights the felt difference of autistic people in their everyday lived experience exacerbated by a systemic lack of awareness and knowledge within the society that surrounds them in the UK. This leads to the question of how much difficulty is created by the social discourses around autism, or the lack of awareness and accommodation for autistic members of society? If clinicians and those who impact diagnosis, policy, service provision and intervention were encouraged to think critically about autism and to explore further the phenomenological lived experience of autistic people in the UK then perhaps approaches



could be both individual and systemic in nature. It is clear from this review that more meaningful participatory research is needed to explore the lived experience of autistic people to better maximise their strengths and to inform and develop pathways and service provision.

## References

- Baird, G, Simonoff E., Pickles A, Chandler S., Lucas T., et al. (2006) Prevalence of disorders of the autism spectrum in a population cohort of children in South Thames: The Special Needs and Autism Project (SNAP). *Lancet* 368: 210–215. DOI: 10.1016/S0140-6736(06)69041-7
- 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(10), 3281-3294.
- Beardon, L., & Edmonds, G. (2007). *The ASPECT consultancy report: A national report on the needs of adults with Asperger Syndrome*. Sheffield, UK: Sheffield Hallam University, The Autism Centre. Retrieved from:  
[https://www.sheffield.ac.uk/polopoly\\_fs/1.34791!/file/ASPECT\\_Consultancy\\_report.pdf](https://www.sheffield.ac.uk/polopoly_fs/1.34791!/file/ASPECT_Consultancy_report.pdf)
- Begon, R., & Billington, T. (2019). Between category and experience: constructing autism, constructing critical practice. *Educational Psychology in Practice*, 35(2), 184–196.  
<https://doi-org.liverpool.idm.oclc.org/10.1080/02667363.2019.1571481>
- Bramer, W. M., Rethlefsen, M. L., Kleijnen, J., & Franco, O. H. (2017). Optimal database combinations for literature searches in systematic reviews: a prospective exploratory study. *Systematic Reviews*, 6(1), 245. <https://doi.org/10.1186/s13643-017-0644-y>
- Brugha, T., Cooper, S. A., McManus, S., Purdon, S., Smith, J., Scott, F. J., ... & Tyrer, F. (2012). *Estimating the Prevalence of Autism Spectrum Conditions in Adults: Extending the 2007 Adult Psychiatric Morbidity Survey*. Retrieved from:  
<http://digital.nhs.uk/catalogue/PUB05061>.
- 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(6), 1431-1441.

- Cooke, A., Smith, D., & Booth, A. (2012) Beyond PICO: The SPIDER tool for qualitative evidence synthesis. *Qualitative Health Research*. 22(10): 1435-1443.  
Doi:10.1177/1049732312452938.
- 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(11), 3761–3772. DOI: 10.1007/s10803-018-3639-1
- Crane, L., Chester, J. W., Goddard, L., Henry, L. A., & Hill, E. (2016). Experiences of autism diagnosis: A survey of over 1000 parents in the United Kingdom. *Autism: The International Journal of Research and Practice*, 20(2), 153–162. DOI: 10.1177/1362361315573636
- Critical Appraisal Skills Programme International. (2010). *Critical appraisal skills programme*. Retrieved from <http://www.casp-uk.net/#!/casp-tools-checklists/c18f8>
- 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(1), 60–71. DOI: 10.1177/1088357615587504
- Egger, M., Juni, P., Bartlett, C., Holenstein, F., & Sterne, J. (2003). How important are comprehensive literature searches and the assessment of trial quality in systematic reviews? Empirical study. *Health Technology Assessment*, 7(1), 1-76. DOI 10.3310/hta7010
- Fletcher-Watson, S., Adams, J., Brook, K., Charman, T., Crane, L., Cusack, J., Leekam, S., Milton, D., Parr, JR., & Pellicano, E. (2019). Making the future together: Shaping autism research through meaningful participation. *Autism*, 23(4), 943-953. DOI: 10.1177/1362361318786721
- Forster, S., & Pearson, A. (2020). “Bullies tend to be obvious”: autistic adult’s perceptions of friendship and the concept of ‘mate crime’. *Disability & Society*, 35(7), 1103-1123.  
<https://doi.org/10.1080/09687599.2019.1680347>

- Georgaca, E. (2012). Discourse analytic research on mental distress: A critical overview. *Journal of Mental Health, 23*(2), 55-61 doi: [10.3109/09638237.2012.734648](https://doi.org/10.3109/09638237.2012.734648)
- 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*(5), 532-546.
- Hickey, A., Crabtree, J., & Stott, J. (2017). 'Suddenly the first fifty years of my life made sense': Experiences of older people with autism. *Autism, 22*(3), 357-367. <https://doi-org.liverpool.idm.oclc.org/10.1177/1362361316680914>
- Howlin, P., Goode, S., Hutton, J., & Rutter, M. (2004). Adult outcome for children with autism. *Journal of Child Psychology and Psychiatry, 45*(2), 212-229. DOI: 10.1111/jcpp.13180
- Howlin, P., Moss, P., Savage, S., & Rutter, M. (2013). Social outcomes in mid-to later adulthood among individuals diagnosed with autism and average nonverbal IQ as children. *Journal of the American Academy of Child & Adolescent Psychiatry, 52*(6), 572-581. doi: 10.1016/j.jaac.2013.02.017
- Kapp, S. K., Steward, R., Crane, L., Elliott, D., Elphick, C., Pellicano, E., & Russell, G. (2019). 'People should be allowed to do what they like': Autistic adults' views and experiences of stimming. *Autism, 23*(7), 1782-1792. <https://doi-org.liverpool.idm.oclc.org/10.1177/1362361319829628>
- 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: The International Journal of Research and Practice, 20*(4), 442-462. DOI: 10.1177/1362361315588200
- 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*(1), pp. 38-49. <https://doi.org/10.1108/AIA-09-2018-0035>

- 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(1), 135-146. <https://doi.org/10.1177/1362361319853442>
- Lugnegård, T., Hallerbäck, M. U., & Gillberg, C. (2011). Psychiatric comorbidity in young adults with a clinical diagnosis of Asperger syndrome. *Research in Developmental Disabilities*, 32(5), 1910–1917. DOI: 10.1016/j.ridd.2011.03.025,
- MacKay, T., Knapp, M., Boyle, J., Iemmi, V., Connolly, M., & Rehill, A. (2018). *The microsegmentation of the autism spectrum: Economic and research implications for Scotland*. The Scottish Government.
- McKenna-Plumley, P, E., Groarke, J, M., Turner, R, N., & Yang, . (2020). Experiences of loneliness: a study protocol for a systematic review and thematic synthesis of qualitative literature. *Systematic Reviews*, 9(1), 1–8. <https://doi-org.liverpool.idm.oclc.org/10.1186/s13643-020-01544-x>
- McKibbin KA, Haynes RB, Dilks CJW, Ramsden MF, Ryan NC, Baker L, Flemming T, Fitzgerald D. (1990) How good are clinical MEDLINE searches? A comparative study of clinical end-user and librarian searches. *Computers Biomedical Research*. DOI: 10.1016/0010-4809(90)90042-B
- Milton, D., & Moon, L. (2012). The normalisation agenda and the psycho-emotional disablement of autistic people. *Autonomy, the Critical Journal of Interdisciplinary Autism Studies*, 1(1). <https://orcid.org/0000-0003-3825-6194>
- Milton, D. E. M. (2014). Autistic Expertise: A critical reflection on the production of knowledge in autism studies. *Autism: The International Journal of Research and Practice*, 18(7), 794–802. DOI: 10.1177/1362361314525281

- Milton, D., & Sims, T. (2016). How is a sense of well-being and belonging constructed in the accounts of autistic adults? *Disability and Society*, 31(4), 520–534. DOI: 10.1080/09687599.2016.1186529
- Moher, D., Liberati, A., Tetzlaff, J., Altman, D. G. (2009). Preferred Reporting Items for Systematic Reviews and Meta-Analyses: The PRISMA Statement. *Public Library of Science Med*, 6(7): e1000097. doi:10.1371/journal.pmed1000097
- Murphy, C. M., Wilson, C. E., Robertson, D. M., Ecker, C., Daly, E. M., Hammond, N., Galanopoulos, A., Dud, I., Murphy, D. G., & McAlonan, G. M. (2016). Autism spectrum disorder in adults: diagnosis, management, and health services development. *Neuropsychiatric Disease and Treatment*, 12, 1669–1686.  
<https://doi.org/10.2147/NDT.S65455>
- Nicolaidis, C., Milton, D., Sasson, N. J., Sheppard, E., & Yergeau, M. (2018). An expert discussion on autism and empathy. *Autism in Adulthood*, 1(1), 4-11.  
<https://doi.org/10.1089/aut.2018.29000.cjn>
- O’Day, B., & Killeen, M. (2002). Research on the lives of persons with disabilities: the emerging importance of qualitative research methodologies. *Journal of Disability Policy Studies*, 1(9). DOI: 10.1177/10442073020130010201
- O’Reilly, M., & Lester, J. N. (2017). Social constructionism, autism spectrum disorder, and the discursive approaches. In M. O’Reilly, J. N. Lester, & T. Muskett (Eds.), *A practical guide to social interaction research in autism spectrum disorders*. (pp. 61–86). Palgrave Macmillan/Springer Nature.
- Pellicano, E., Dinsmore, A., & Charman, T. (2014). What should autism research focus upon? Community views and priorities from the United Kingdom. *Autism: The International Journal of Research and Practice*, 18(7), 756–770.  
<https://doi.org/10.1177%2F1362361314529627>

- 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*(1), 72-80. <https://doi.org/10.1177%2F1088357615588516>
- Research Autism (2018) with ICD-11 *Autism diagnostic description*. Retrieved from: <https://researchautism.org/resources/>
- Rethlefsen, M. L., Farrell, A. M., Osterhaus Trzasko, L. C., & Brigham, T. J. (2015). Librarian co-authors correlated with higher quality reported search strategies in general internal medicine systematic reviews. *Journal of Clinical Epidemiology, 68*(6), 617–626. <https://doi.org/10.1016/j.jclinepi.2014.11.025>
- Robertson, A. E., Stanfield, A. C., Watt, J., Barry, F., Day, M., Cormack, M., & Melville, C. (2018). The experience and impact of anxiety in autistic adults: A thematic analysis. *Research in Autism Spectrum Disorders, 46*, 8–18. <https://doi-org.liverpool.idm.oclc.org/10.1016/j.rasd.2017.11.006>
- Robertson, S. M. (2010). Neurodiversity, quality of life, and autistic adults: shifting research and professional focuses onto real-life challenges. *Disability Studies Quarterly, 30*(1), 27.
- Robertson, A. E., & Simmons, D. R. (2015). The sensory experiences of adults with autism spectrum disorder: A qualitative analysis. *Perception, 44*(5), 569-586. <https://doi.org/10.1068%2Fp7833>
- 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*(7), 1817-1836.
- Russell, G., Kapp, S. K., Elliott, D., Elphick, C., Gwernan-Jones, R., & Owens, C. (2019). Mapping the autistic advantage from the accounts of adults diagnosed with autism: A qualitative study. *Autism in Adulthood, 1*(2), 124-133. <https://doi.org/10.1089/aut.2018.0035>

- Soilemezi, D., Linceviciute, S. (2018) Synthesizing qualitative research: reflections and lessons learnt by two new reviewers. *International Journal of Qualitative Methods*. 2018;17(1): 1609406918768014.
- Stagg, S. D., & Belcher, H. (2019). Living with autism without knowing: receiving a diagnosis in later life. *Health Psychology and Behavioral Medicine*, 7(1), 348-361.  
<https://doi.org/10.1080/21642850.2019.1684920>
- The National Autistic Society [NAS], 2016. *What is autism?* Retrieved from:  
<https://www.autism.org.uk/advice-and-guidance/what-is-autism>
- Thomas, J., & Harden, A. (2008) Methods for the thematic synthesis of qualitative research in systematic reviews. *BMC Medical Research Methodology*. 8(1): 45. Doi10.1186/1471-2288-8-45.
- Treweek, C., Wood, C., Martin, J., & Freeth, M. (2019). Autistic people's perspectives on stereotypes: An interpretative phenomenological analysis. *Autism*, 23(3), 759-769.  
<https://doi.org/10.1177%2F1362361318778286>



## **Chapter 2: Empirical paper**

Empathy and personal distress: A thematic analysis of the lived experience  
of autistic adults.

Lisa Ellen Powney

Prepared for submission to Autism (Appendix 10)

# **Empathy and personal distress: A thematic analysis of the lived experience of autistic adults.**

## **Abstract**

‘A lack of empathy’ has historically been seen as a defining feature of autism, despite research to the contrary. Much existing research aims to measure empathy in autistic people and contrasts results with non-autistic people, locating ‘the deficit of empathy’ in the autistic person. This research took an exploratory step into capturing autistic people’s lived experience and understanding of empathy. Eleven autistic adults participated in semi-structured interviews exploring their lived experience and understanding of empathy, and potential links to personal distress. Thematic analysis identified three over-arching themes capturing the participants’ understanding and experience of empathy, factors that facilitated or hindered their empathy, and the impact of empathy on their everyday lives. This study highlighted how key facets of empathy are also shared by autistic people. However, the communication of empathy, particularly with non-autistic people, entails bidirectional differences that can, and do lead to distress. This study demonstrates the need for a richer understanding of empathy from the perspective of autistic people and challenges the assumptions held by some research that measures empathy in autistic people using non-autistic constructs.

**Keywords** Autism. Empathy. Lived experience. Thematic Analysis.

## **Introduction**

### *Asperger Syndrome and Autism*

Asperger Syndrome is a neurodevelopmental condition considered to be a form of Autism Spectrum Condition (ASC). The term ‘spectrum’ reflects the range of symptoms and the uniqueness of an individual’s presentation, rather than a linear representation of symptom severity (The National Autistic Society [NAS], 2016). Historically, Asperger Syndrome was distinguished from Autism by no delay of speech onset and other cognitive/adaptive skills (Wing, 1996; World Health Organisation, 1994). Hans Asperger’s paper in 1944 characterised Asperger Syndrome by the presence of restricted behaviours and interests, and impaired social interactions (Dell’Osso et al., 2016). Other diagnostic characteristics can include repetitive behaviours, special interests, and hyper/hypo sensory difficulties (Jackson, 2002). In the United Kingdom (UK) there are approximately 700,000 people (Brugha et al., 2012), around 1.04% (MacKay, et al., 2018) of the population, diagnosed with Autism.

### *Current Context and Terminology*

In the UK, Asperger Syndrome is no longer typically used as a diagnostic category (Landau, 2010). Whilst the Diagnostic and Statistical Manual of Mental Disorders, 5<sup>th</sup> Edition (DSM-5) no longer includes Asperger Syndrome as a discrete diagnostic category, clinicians using the International Statistical Classification of Diseases and Related Health Problems (ICD-10), may continue to use this term (Lake, Perry & Lunskey, 2014). People with Asperger Syndrome appear divided on whether it should remain a diagnostic category (Kite et al., 2013). Though many argue that Asperger’s forms an integral part of their identity and feel a sense of belonging to the “Asperger’s community”, (Chambers et al., 2020).

The terms ‘autism spectrum’ and ‘autistic people’ are used in this paper except when the source material uses a different term. These terms were identified to be the most acceptable term

to a small majority according to research by Kenny, et al., (2016) with autistic people, their families and professionals. The authors of this paper have opted to use Autism Spectrum Condition rather than ‘disorder’, again in support of less stigmatising language (Baron-Cohen, 2000; Kenny et al., 2016), moving towards a model of difference rather than deficit.

### *What is empathy?*

There is no agreed definition of empathy (Fletcher-Watson & Bird, 2020). One of the difficulties of studying empathy in any context is its broad and multifaceted nature that may complicate its measurement (Nicolaidis et al., 2018). Despite these difficulties, empathy is often viewed positively, as the ‘social glue’ that holds society together; motivating action to help rather than harm others (Baron-Cohen & Wheelwright, 2004). Empathy is suggested to be beneficial in social relationships, workplaces, and in contrast, a lack of empathy can be understood to have negative consequences (Nicolaidis et al., 2018).

Research has largely focused on cognitive and emotional empathy as two separate but related constructs (Rogers et al., 2007). Cognitive empathy is the process of understanding the perspective of another and hypothesised as related to theory of mind (Baron-Cohen & Wheelwright, 2004; Mead, 1934; Piaget, 1932). Affective empathy is hypothesised as the emotional response of an observer to another’s emotional state (Baron-Cohen & Wheelwright, 2004; Hoffman, 1984; Mehrabian & Epstein, 1972). Baron-Cohen et al., (2003) describes empathising as the ‘drive to identify emotions and thoughts in others and respond appropriately’.

### *Empathy and Autism*

There has been a longstanding focus on the role of empathy in autism. From the initial use of the diagnostic label Asperger Syndrome, ‘a lack of empathy’ was described as a distinguishing

behavioural feature (Lawson et al., 2004). Research suggests autistic people score lower than neuro-typical people on measures of empathy (Baron-Cohen & Wheelwright, 2004; Kok et al., 2016). Research exploring cognitive and affective empathy in autistic people has demonstrated that they may score lower on measures of cognitive empathy than non-autistic people but are more similar to non-autistic people on measures of emotional empathy (Rogers et al., 2007). Smith (2009) reported that many caregivers and autistic people believe heightened emotional empathy is in fact a feature of autism.

The Imbalance Theory (Smith, 2009) suggests a different understanding of empathy in autism. The principal tenet of this theory is that autistic people experience a deficit of cognitive empathy but a surfeit of emotional empathy. This model is argued by Smith (2006) to predict the key behavioural characteristics of autism which differs from the historical view of autism as lacking empathy, by the prediction of high emotional empathy. The theory suggests possible avoidance of empathetic connections due to susceptibility to empathetic overarousal (Smith, 2009). Bastiaansen et al. (2008) similarly suggest that people with autism do not engage in the social world, not because it does not interest them, but because it overwhelms them. Despite research suggesting that a more complex mechanism may underpin the perceived lack of empathy, the notion of a deficit continues to be largely associated with autistic people (Asperger Foundation, n.d.; Aarons & Gittens, 1999; Lawson & Prior, 2001).

A primary criticism of research into the relationship/understanding of empathy and autism has been that these measures may not measure empathy and that they may overlap with other emotional difficulties, undermining their validity (Baron-Cohen & Wheelwright, 2004; Fletcher-Watson & Bird, 2020). Standard measures of empathy may not incorporate the process of empathy or the more nuanced aspects that may influence autistic people, for example sensory processing. There is evidence to suggest that sensory 'atypicalities' could impact the development of a range of social and cognitive abilities (Mayer, 2016). Sensory

‘atypicalities’, for example becoming overwhelmed by information from more than one sensory modality, affect an estimated 60 – 90% of autistic people (Crane et al., 2009).

Despite this high incidence rate, sensory atypicality does not appear to have been explored in the context of empathy and autism.

The association of ‘a lack of empathy’ and autism has been regarded as dehumanising and perpetuating of stereotypes (Nicolaidis et al., 2018), that increases stigma (Gregoire, 2016) and has resulted in autism being described as an empathy disorder (American Psychiatric Association, 1980; Baron-Cohen & Wheelwright, 2004; Gillberg, 1992). In response, a growing number of autistic people are challenging the assumption that they lack empathy (seventhvoice, n.d; Asperger/Autism Network, n.d.). Personal accounts suggest some autistic people identify as empathetic and that some may “over-empathise” leading to distress (seventhvoice, n.d; Asperger/Autism Network, n.d.), which may reflect the theory of Smith (2009). This speaks to the need for empirical exploration of the lived experience of empathy capturing the voices of autistic people.

### *Deficit or difference?*

There is a shift in the exploration of autism and empathy, that moves from the historically dominating deficit model (Nicolaidis et al., 2018) to a model of difference. As stated, this paper aims to employ language that supports this conceptual shift. Most notably, Milton’s (2012) ‘double empathy problem’ highlights the mutual difficulty of autistic and non-autistic people attempting to empathise and understand each other when they have different outlooks and different personal conceptual understandings of the world.

Importantly, Milton (2012) stresses that this is a difference that exists for both people, it is bidirectional, not a problem located in the autistic person, hence it being termed the ‘double

empathy' problem. This is further supported by Sasson et al., (2017) who claim that social interaction difficulties are relational, bidirectional, and not located solely in autistic people. It is important to consider that autism has different ways of being conceptualised or 'held in mind' when reviewing research and when considering its potential implications. One of the most dominant positions is the diagnostic medical model which often holds autism as a construct with clear visible boundaries and clinical criteria. This aligns with structuralist ideas in psychology which propose that knowledge about autism has a definitive and discoverable structure, essentially that 'something on the surface belies something down below' (Combs & Freedman, 2012). This approach would also claim to find universal and stable characteristics of autism that can be grouped together, extolling the value of expert knowledge in knowing/discovering these classification/structures. Often this conceptualisation seeks to categorise, to find physiological differences between autistic and non-autistic people and to distinguish a single clear demonstrable truth that is autism (Beagon & Billington, 2019). This leads into viewing autism through a lens of deficit and illness, and as a difficulty located within individuals reflecting the "culturally dominant metaphor of autism as a disease", (Broderick & Ne'eman, 2008). Similarly, there is a school of thought described as critical autism, whereby autism is considered a social construct, a cultural phenomenon consisting of multiple truths (Beagon & Billington, 2019). This does not stand in opposition to the medical model, instead it can be conceptualised as encouraging critical consideration of autism. That autism cannot be seen as a singular truth but instead multiple truths may well reflect the heterogeneity often described within the autistic population.

### *Current study*

In reviewing the empirical literature, there appears to be a paucity of research reflecting the lived experience of empathy in autistic people. In fact, a review of autism

research in the UK and a survey of autistic people suggested that insight into the day-to-day experiences of autistic people would be valuable, as so little is understood about their lived experience (Pellicano et al., 2014). Much existing research of empathy and autism uses pre-existing measures rather than exploring the phenomenological experience, leaving the voice of autistic people largely absent. Milton (2014) describes the mistrust that has developed between autistic people and researchers. Fletcher-Watson et al., (2019) herald the importance of meaningful participatory research. This led the research team to reflect on our intent for a quantitative study using pre-designed measures and moved us to a position of exploration, of wanting to capture the lived experience of autistic people.

Research suggests that empathy is a considerable determinant of psychological wellbeing (Khanjani et al., 2015), potentially due to its role in prosocial behaviours (Sahar, 2018). Yet not much is known about this relationship between empathy and its relation to wellbeing in the autistic population, despite the key feature of social differences. It would be important to understand potential contributors to personal distress, which have been positively correlated with depression, self-criticism, and negative self-concept (Kim & Han, 2018). Mental health difficulties are more prevalent in the autistic population (Lugnegard et al., 2011; Mattila et al., 2010). With a reported higher prevalence rate, it is also essential to explore and understand everyday experiences that can potentially negatively impact the wellbeing and quality of life of autistic people. Understanding the experience of empathy for autistic adults and potential links to distress could therefore inform clinical knowledge and interventions.

In summary, the aims of this study are to address the lack of voice given to autistic people in the empirical literature by employing a qualitative approach to capture their lived experience and understanding of empathy. We also aim to explore the impact that empathy has on autistic adults and any reported links with emotional distress. Exploring empathy from



an autistic perspective could also offer additional insight into studies that use measures of empathy from a pre-existing neurotypical perspective.

## **Methodology**

This research incorporated semi-structured interviews to gather qualitative data allowing for an iterative process (Blee & Taylor, 2001). The 11 interviews were recorded, transcribed verbatim, and analysed using thematic analysis (TA) as described by Braun and Clarke (2006). The research embraced a contextualist stance, characterised by critical realism (Willig, 1999). This places the method between essentialism and constructivism, drawing upon how the participants make meaning of their experience whilst acknowledging the role of the wider social context in developing those meanings (Braun & Clarke, 2006). The methods were informed by COREQ (Consolidated Criteria for Reporting Qualitative studies), which was developed to promote explicit and comprehensive reporting of qualitative research (Tong et al., 2007).

### *Research team and reflexivity*

The research team consists of the primary researcher (EP), primary supervisor (AF), methodology supervisor (HB), researcher and expert by experience (MC). It was important to all members of the research team that analysis of the data was not performed solely by non-autistic researchers. It was felt that the autistic voice is not as widely represented as it could be within the empirical literature, which reflects a wider movement generally in research in terms of the importance of patient and public involvement in research (Morgan et al., 2016). Two of the research team have experience of working clinically with autistic people, one member has experience performing research with autistic people and this could bring potential biases. One member of the research team does not have experience or work with autistic people and so their voice was important in counterbalancing discussions.

Reflexivity is regarded as the gold standard for ensuring rigour, quality and determining trustworthiness in qualitative research (Teh & Lek, 2018). A reflective journal was kept from conception to the end of the research process and assumptions and possible biases were reflected on openly within the team throughout (Nowell et al., 2017).

In the interest of transparency, which is also important for reflexivity to permeate the whole research endeavour (Dodgson, 2019), the primary researcher is a middle aged, white, non-autistic woman who is a clinician and doctoral student. From her experiences working with autistic people EP observed that empathy was not absent from their experiences, contrary to the empirical literature, which led to the current study. In fact, through relationships with autistic people and clinical work, empathy was observed to sometimes be in abundance and to lead to distressed states in some autistic people. To offer an example from the reflective journal, researcher bias towards the expected presence of empathy within the autistic population was continuously reviewed in relation to coding and building themes, preserving objectivity as far as possible.

It is important to hold this perspective in mind and to consider who the primary researcher is in relation to the participants and when reading this research (Dodgson, 2019). There was no prior relationship of the participants and the primary researcher. The expert by experience researcher (MC) knew one participant personally and three other participants heard of the study through MC distributing the study information.

### *Ethical considerations*

Ethical approval was granted by the University of Liverpool Central University Research Ethics Committee (Appendix 3). A participant information sheet (Appendix 4) was provided, and informed consent was gained from participants at least 48 hours in advance of the interview. A distress policy (Appendix 5) was devised should any of the participants experience distress in

relation to their interview, identifying a course of action depending on the severity of the distress (this did not need to be employed). Time was provided at the beginning and end of each interview for questions and space to debrief. All participants were provided with EP's email address should further questions or need to communicate arise.

### *Expert by experience consultation*

Consultation was sought initially from the Liverpool Experts by Experience (LExE) group for the research design and aims. It was decided from the outset that inclusion of an expert by experience at every stage of the research was essential and so MC was approached via a mutual connection within the University. MC agreed to join the team and consulted throughout impacting the research at each stage through contributing both her research experience and perspective as an autistic adult. This added an additional level of rigour in checking interpretations of the data and ensuring that as far as possible the research was grounded in the lived experience of people with autism.

### *Study design*

Previous research has typically been professional led and this paper is regarded as an exploratory opportunity to capture the voice and experience of autistic people. A qualitative study incorporating semi-structured interviews was selected to capture the lived experience of autistic people in their own words. Thematic analysis when used robustly allows the researcher to stay true to the words of the participants and is described as an appropriate approach for those new to qualitative research (Braun & Clarke, 2006). The inductive analysis embedded in this approach allows a process of coding the data without trying to fit it into pre-existing ideas or the researcher's analytic preconceptions, allowing the process to be data-driven (Braun & Clarke, 2006). The process of familiarising oneself with the data and coding across the data set allows

for a richness which could potentially get lost in the split focus of the individual and linear coding of Interpretative Phenomenological Analysis (IPA) which tends to focus on smaller numbers in more interpretative depth. IPA is also primarily an interpretative approach (Hefferson & Gil-Rodriguez, 2011) and though TA involves interpretations it also semantic in nature and aims to group the participants' experiences semantically across the data set (Braun & Clarke, 2006). This served as another reason to use thematic analysis over IPA as it offers more opportunity to preserve the voices of the autistic participants, alongside the inclusion of an expert by experience, and offers further protection from the biases and interpretation of a largely neurotypical research team.

We selected thematic analysis as it is a flexible approach and unlike other approaches, it is considered a method in its own right and is not tied to any specific epistemological approaches allowing the researcher choice (Braun & Clarke, 2006). The analysis is inductive and allows new knowledge to emerge without relying on existing frameworks which suits our research question (Willig, 2013). The research remains with the words of the participants by synthesising the data into a meaningful account (Boyatzis, 1998). Other methodologies were considered, for example interpretative phenomenological analysis. Staying with the words of the participants is the essential criterion for the selection of this research, as the voice of autistic people is missing from the empathy literature.

### *Participants*

Recruitment took place through an advert (Appendix 6) that was placed on social media, and also shared with an existing pool of people participating in autism research at the University of Liverpool. Interested autistic adults were invited to contact EP via email. Convenience sampling (Eitkan et al., 2016) was employed; applicants responding to the advert, or through hearing of the study via word of mouth and who met the eligibility criteria were recruited on a

first-come-first served basis (Robinson, 2014). Eleven autistic adults participated in the study (see Table 4 for participant demographics). Two further participants expressed initial interest but did not commit to a final interview. All participants were required to meet the following inclusion criteria for the study; (1) Aged over 18 (2) Formal diagnosis of ASD, ASC or Asperger Syndrome (without accompanying intellectual or language impairment) (3) Fluent in English (4) Capacity to consent.

Table 4. Participant demographics

	Gender	Age	Country	Employment	Education
Participant 1	M	49	UK	No	City and Guilds
Participant 2	M	35	UK	Yes	GCSE
Participant 3	F	37	UK	Yes	GCSE
Participant 4	Non-Binary	48	UK	Yes	PGCE/Degree
Participant 5	M	36	UK	No	B.S
Participant 6	M	38	Norway	Student	B.A.
Participant 7	F	38	UK	Student	Degree/Ma
Participant 8	M	51	UK	Employed	BTEC
Participant 9	F	21	UK	Student	A-level
Participant 10	Non-Binary	39	UK	Self-employed	Post Grad
Participant 11	F	35	Denmark	FT – Self-employed	B.A

### *Interview settings*

A variety of communication methods were offered to avoid excluding those who may struggle with face-to-face interviews, increasing the likelihood of engagement by adapting to individual needs (Elliott et al., 1999). Three participants chose face-to-face interviews, two of which took place at the University of Liverpool, one took place in the home of the participant and nine chose to use Skype, with one interview moving to telephone due to connectivity issues. Participant information sheets and consent forms (Appendix 7) were provided at least 48 hours in advance of the interviews. Time for questions was offered before and after the interviews alongside an optional debrief.

### *Data collection*

A semi-structured interview was developed by EP (Appendix 8) in consultation with the research team. The interview schedule was iterative in design and used flexibly, allowing for the participants to have freedom to move around the topic of interest. (DeJonckheere & Vaughn, 2019). Given the neurodiversity of the participant population, adaptations were made accordingly, for example sending the interview schedule in advance for the participants to familiarise

themselves with the questions and to use as a visual reference. Participants were reminded of their right to not answer questions, their right to withdraw, and to ask questions. Participants were provided with EP's contact details for any questions arising before and after the interview. Interviews lasted between one and two and a half hours. One interview was divided into two parts on the same day to allow for a medical appointment. The mean interview time was 87 minutes. By interview nine, data saturation was discussed by the research team. The remaining interviews were already scheduled and so went ahead. Though there is not an exact method to deciding on data saturation in qualitative research, the research team agreed that no new themes, directly relating to our research questions, were emerging from the interviews (Lowe et al., 2018).

### *Data analysis*

Data gathered from the interviews was digitally audio-recorded and transcribed verbatim by EP and a university approved transcriber. To maintain a systematic approach to data analysis, the six phases of thematic analysis as described by Braun and Clarke (2006) were followed. The transcripts were read and re-read by EP and MC which supported familiarisation with the data. Line by line the data was coded with data driven descriptive words of features from the transcript. EP and MC met to discuss the preliminary codes once four transcripts had been coded. This provided a good opportunity to check interpretations and think about how similar codes may group together. Alongside supporting quotes, this was then discussed with all authors present. The remaining transcripts were coded as they were completed with two more meetings between EP and MC where further discussion and editing of the codes took place. Codes were discussed by the team along with emerging themes to verify the coding strategy and interpretation of data as recommended (Barbour, 2001). A further meeting with EP and MC was also held once the data and themes had been further explored by both and then further discussed

with AF and HB. This was followed by the presentation of a list of defined themes and the preliminary naming of themes which was further refined through team discussion (all authors). Throughout the process, the primary researcher moved between the full transcripts, codes and themes. This was part of the iterative process as a means of staying close to the data and to adjust and strengthen the process with frequent discussion with the research team. Triangulation of coding and theme development with the research team was designed to make the trustworthiness and credibility of the analysis rigorous (Lincoln & Guba, 1985).

## Results

Analysis of the interviews led to the identification of three main themes; Empathetic identity; similarity, difference and influencing factors; connectivity and other consequences. Several sub-themes make up each main theme (see Figure 2). Themes and sub themes will be presented below with excerpts of raw data to support (for further examples of theme development see Appendix 9).

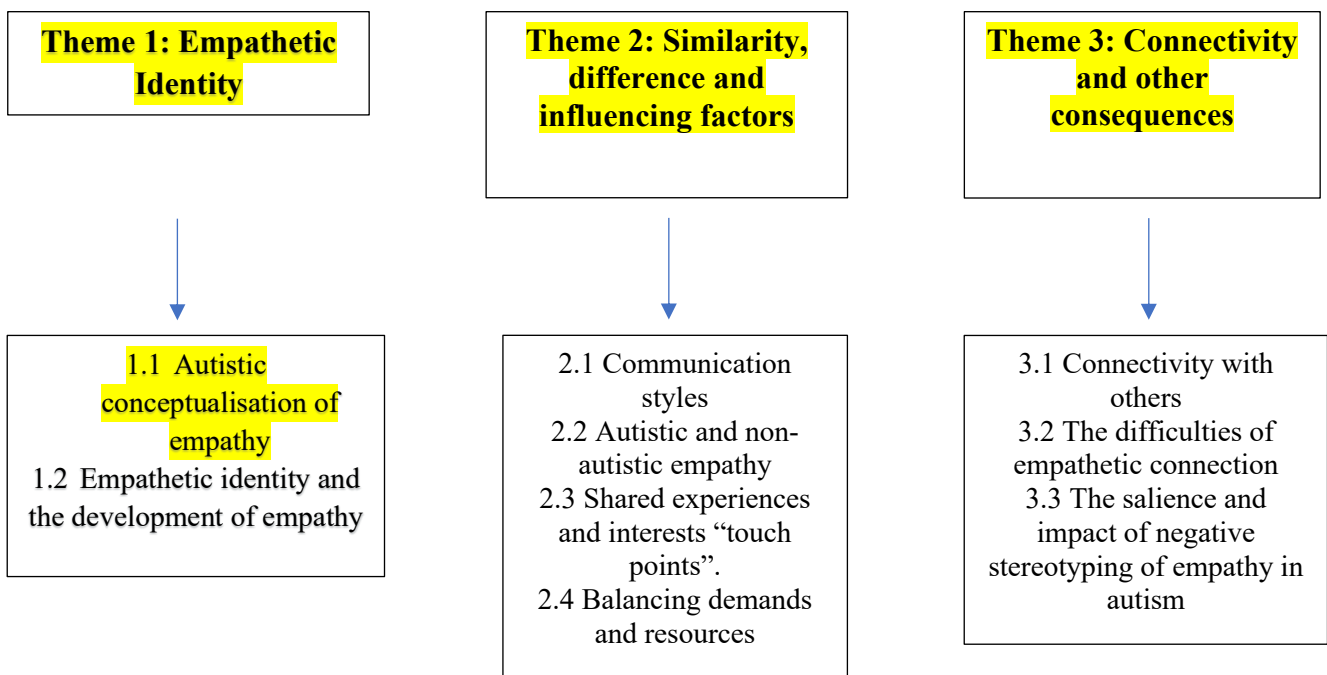


Figure 2. Theme map



## **Theme 1: Empathetic Identity**

Participants shared their theoretical understanding of empathy, and whilst they described similar key facets of empathy, their descriptions were offered tentatively. This suggested a lack of confidence about the boundaries of empathy as a clearly defined construct from the perspective of these participants. The descriptions of empathy appeared to reflect those most often described in the literature of cognitive empathy and affective empathy. Participants discussed where they believe empathy comes from and whether they, in line with their own descriptions, identified as having empathy.

### *1.1 Autistic conceptualisation of empathy*

Across all descriptions, a shared conceptual understanding of empathy was articulated. The core features of this understanding were a recognition of how others are thinking and feeling, and that this may be different to how they themselves are, or would be, feeling: *“Empathy is whenever you can either see what other people feel or intellectualise enough that you have an idea, that even if you don’t experience their exact feeling for yourself”*, (P3). The knowledge of a possible difference could, for some, lead to a sense of anxiety about getting the interaction wrong. Several participants summarised this as the ability to put themselves in *“someone else’s shoes”*.

From the interviews, there was a description that sometimes empathy moves beyond an internal, felt experience, to behaviours that communicate empathy bidirectionally; *“Thing’s people say or putting their hand on my arm or something”*, (P5). These empathetic communications could include offering a cup of tea, physical touch/a hug or validation, and even an awareness to provide another with ‘space’. Many spoke of being unsure of the social rules that govern empathetic gestures, which sometimes leads to distress. This reported sense of ‘getting it wrong’ could also occur when in receipt of empathetic gestures from others, for

example, when what someone else would find empathetic not being perceived as such by the autistic person:

*“Um, It’s such a big thing it almost... I always feel thrown by the word because I suppose on like a simple level it’s supposed to be around feeling what the other person is feeling or, you know, understanding where they’re coming from and, um, it’s supposed to be what makes us feel for people when we see someone suffering”, (P5).*

### *1.2 Empathetic identity and the development of empathy*

Whilst all participants identified as empathetic, descriptions varied in how well they felt they could empathise with others. Many described empathy as innate but also as something that is developed through experience, modelling from others, research, reading, and talking to others to learn more about their perspectives.

One participant reflected on identifying as empathetic as she shares in the emotional response of others when she would not have those emotional responses herself: *“if someone shows me a picture of a baby, I’m like yep that’s a baby. I have nothing in terms of my own feelings about them. I don’t think they’re cute . . . but I’m so excited about how she’s feeling, so I’m feeling it with her” (P11).* Another participant spoke of empathy as a natural innate process but that also draws upon their own life experiences: *“I think I’ll naturally stop and think well ‘what’s that person going through’ because I am aware of how many hidden battles people can have” (P9).* This echoed the descriptions of others who drew upon their own experiences to empathise.

There was also a rich narrative of relationships both within and outside of families developing empathy. P11 described her family as ‘low’ in empathy and described the

importance of *“friends . . . teachers and the people I met outside of my family”* in developing her empathy.

Some of the participants felt they were not very empathetic and yet rich examples of empathy in their narratives were clear. P2 felt they could only empathise with one person, when in fact their transcript captured other examples of empathy. For instance, they described an effortful interaction with a new person at his workplace who was struggling: *“ . . . he opened up to me a bit . . . it went from a one-sided conversation and me asking him questions constantly to by the end of the day him opening up to me and talking er . . . I genuinely wanted to help him . . . ”*.

Empathetic identity was described as being formed through reflecting on their experience, receiving feedback from others, or observing empathetic qualities in others and relating to and learning from this. There were rich examples of people recognising their empathy through relational interactions: *“Would that have happened if I lacked empathy?” (P5)*.

## **Theme 2: Similarity, difference and influencing factors**

Empathy was widely described as something that can fluctuate and be affected by internal and external factors i.e., communication styles, emotional state, sensory experiences. These factors were sometimes described as facilitating autistic people’s ability to empathise and at other times, were captured as hindering their empathy. Descriptions of differences between autistic and non-autistic people and the impact this has on each individual empathising with the other were prominent. It was noted that shared experiences and time spent together appeared to positively impact this communication difference between autistic and non-autistic people.

## 2.1 Communication styles

There was clear description of differences between how autistic and non-autistic people communicate with each other. These differences were thought to hinder the expression of empathy between the two groups. Though the key features of empathy may be similar to both groups, it appeared that differences in communication styles, empathetic cues and expression, could account for the between-group difficulties described. Participants spoke about there being more directness in within-group autistic communication, and how they felt they missed subtle, non-verbal communications of non-autistic people, which could lead to cues for empathy being missed. Anxiety around communicating empathy correctly to non-autistic people was described as fear the communication would be wrong or mistimed.

*“Yes and I think there’s this understanding that when you’re being direct about something it’s because you don’t want to leave it to chance. Whereas if you do that with people who don’t understand about autism or aren’t on the spectrum, people just take offense”, (P8).*

Participants described different ‘short-hand’ uses when talking about differences between autistic and non-autistic communication. Non-autistic ‘short-hand’ was depicted as something which was difficult to follow as an autistic person, leaving them feeling side-lined from the interaction:

*“small talk really is short-hand, and it really is to allow people to feel comfortable with each other . . . the thing that always gets me is if I’m asked how I am, I have to*

*really work to not tell people how I am. That's not really what's being asked! People are really just having a conversational tennis", (P8).*

This was described to potentially lead to reduced opportunities for empathetic connections as they were not involved in the conversations and as such, communication of cues for empathy could be missed.

A number of participants focused on the difficulty of non-verbal cues, describing them as subtle and therefore difficult to notice or understand. Facial expressions, especially if subtle, stood out as being something participants feared they missed. This was a bidirectional difficulty as participants also described how non-autistic people may not always recognise the emotions displayed by autistic people: *"people not always responding how I needed them to because if you can't show it on your face, then you can say I'm very sad right now but that's going to come across as fake, so people thought I was faking it" (P11).*

## *2.2 Autistic and non-autistic empathy*

Several participants described empathy as being easier, more intuitive, within the autistic population and more difficult with non-autistic people. They described interacting with other autistic people as affecting their bidirectional experience of empathy positively, for example, more relational ease, and less need to explain visible differences when with other autistic people:

*"The autistic people that I have met when I've known they're autistic have sometimes tried to explain to me 'well I'm a bit weird because I do this and I do this', and I'm like, 'no you're not weird, I also do all of those things, you don't have to explain anything'. So, there's an easy short-hand because they don't have to feel like they*

*have to explain this or she's not going to know why I do things or how to react",*  
(P11).

Some participants described these differences impacting even at a family level. Many participants grew up in non-autistic families and described this could, at times, lead to them not feeling understood and empathised with, their emotions sometimes seemingly invisible to non-autistic family members. Family environments could lack an “intuitive understanding”, that would perhaps be shared with other autistic people, thus hampering empathic processes:

*“I thought I grew up with sociopaths because of how bad neurotypical people are at guessing what an autistic person is feeling and thinking, but somehow it's not a deficit when they do it. It's like why aren't they bad at understanding other people. Am I not other people?”* (P11).

One participant articulated that they had been “late diagnosed” and, speaking to others who had been diagnosed later in life, this had led to a discussion of a shared sense of “liminality” between the autistic and non-autistic communities at times. Despite this, the same participant still maintained empathy as more intuitive within the autistic community:

*“ . . . when I've been meeting autistic people in the last couple of years, we do kind of, a lot of the time not all the time, just intuitively get along and we can kind of tell things that are stressing each other out or we communicate in a similar way”,* (P5).

### *2.3 Shared experiences and interests “touch points”*

In contrast to the theme of difference between communities of autistic and non-autistic people, there were positive descriptions of when the groups were joined together, for example, in a theatre group. These groups were usually based around shared interests and

identities. These intersections appeared to facilitate an opportunity for both autistic and non-autistic people to form better understandings of each other, to improve communication and empathy. A theme of similar experiences was also described as “*touchpoints*”, (P11) from which they could generalise to how others may be thinking or feeling:

*“Mmm hmmm yeah so I think it has helped me being part of that group . . . half of us as autistic and half of us not and we all actually get on really well and understand each other really well. I think we are really good example of how communication can work between the communities”, (P4).*

This suggests that communication challenges between autistic and non-autistic people can be reduced where there are opportunities to spend time together with shared interests and identities. The social expectations and needs can begin to be understood and ways of navigating these interactions/relationships emerge.

#### *2.4 Balancing demands and resources*

Two areas of demands that were felt to significantly impact their empathetic capacity were clearly described by the participants. Firstly, the sensory environment for example, noise, light, smell and emotional state. One participant summarised this clearly in a situation where a family’s child screaming on a flight led to ‘sensory overload’. Though initially very empathetic, citing her experiences in similar situations with her own child, the sensory demand reduced her empathetic capacity: *“I could not cope with it any longer. I couldn’t take it. Even though I felt empathetic I started to feel really angry. Not at her, just the sensory overload . . .”, (P7).*

Secondly, emotions were described as adding to the demands the person had to cope with and reducing their capacity for empathy. Emotions also impacted when triggered internally as well as externally as a sensory experience: *“I think it’s important I can understand...I know if I’m angry or scared, I’m less empathetic. If I disagree with someone, I’m less empathetic . . . all kinds of things that make me less empathetic”, (P6).*

Some participants also described processing social information slower than non-autistic people, in that more time was needed to put together the information they have and apply it to others:

*“. . . is times when I know that I’ve seemed careless towards people . . . because a lot of empathy is actually being able to interpret someone else’s behaviour . . . sometimes it’s like I’ve seen all of the evidence, but it seems like I can’t put it together in a coherent way, so I don’t realise that someone’s behaviour implies something about their state of mind or they are busy and they don’t want to be interrupted, or you know things like that, (P3).*

These subtle nuances in communication styles and internal experiences could lead to the differences being located in the autistic person, rather than as a difference between people: *“Yeah I think NT’s show it in a much more overt sort of way and more immediate, and with my empathy I do, I do feel it but I might not feel it until a day later or something. . . So I think I have like a delayed response to it if that makes sense”, (P4).*



### **Theme 3: Connectivity and other consequences**

Participants reflected on both the positive and negative impact empathy had on their lives. Many described a sense of belonging through acceptance that comes with connecting with others through empathy. In contrast there was also a strong description of feeling overwhelmed and distressed by their experience of empathy for others, particularly if suffering was observed in others and the autistic person feels helpless to act.

#### *3.1 Connectivity with others*

Many participants reflected on the beneficial impacts of empathy, describing empathy as leading to a sense of belonging, deepening relationships, motivation to act in line with their values and connecting to others.

There was a perception that empathy helps motivate actions towards helping others and to hold others in mind pushing their focus outwards from themselves, *“I think it helps us work together, it helps us to build communities, erm, it helps us push out of our own little bubble, otherwise we are just in our own little world all the time” (P4)*. Many described the importance of empathy in the building of relationships and the positive impact of feeling connected to others, *“... it’s extremely important. I think maybe because the social relationship almost doesn’t exist without empathy, and actually, being accepted ...”, (P6)*.

Some participants also described empathy strengthening their relationship with their children. P6 felt empathy maintains curiosity about the other person’s perspective: *“...when I interact with my daughter, it occurs to me much less that I know better than her. Or that I understand her automatically”*.

### 3.2 *The difficulties of empathetic connection*

Many descriptions of empathy were accompanied by distress, worry, anxiety and feeling overwhelmed. Worry and anxiety were often reported in response to being unsure of ‘the rules’ around how to express empathy socially. Participants spoke of feeling overwhelmed with the emotions that their empathy for others could elicit, articulating a difficulty in tempering their emotional responses. *“It should be possible to feel empathy without being engaged to the point where you are really distressed a lot of the time” (P3).*

Many described feeling over-empathetic, and that once elicited, emotions could feel uncontained and overwhelming, *“... once the emotions are tripped up it’s hard to put them down again. So, you know I have to be careful about how I consume the news for instance” (P3).* This description of limiting the news, or what is read, was to ‘protect’ themselves from the emotional distress elicited by their empathy, *“It’s just too distressing . . . I feel like I’m getting overwhelmed by what’s happening in the world. ... I can’t deal with it I can’t cope with it . . .” (P7).*

One participant described, *“... empathy can be overwhelming. . . why it’s overwhelming, and it usually is, is that it’s impossible to know what to do with it”, (P6).* P1 described feeling unsure about how to express empathy interpersonally, and that when they had, it had not been understood as empathy, or well received by others leading to confusion and distress for them both: *“in some respects possibly seen as, dare I say it some kind of attack or assault, you know, you’ve invaded my personal space invaded and I don’t want my personal space invaded, and they are not thinking that that person is trying to help them”.*

### 3.3 *The salience and impact of negative stereotyping of empathy in autism*

Despite the described positive value of empathy and the sense that they are empathetic, the impact negative stereotyping of empathy in autism was pervasive in the

accounts captured. Participants spoke of how this stereotyping can be seen as a way of devaluing autistic people, leading to them being positioned as outside of the ‘norm’: *“and then with autistic people we're supposed to lack empathy or have impaired theory of mind and then you kind of see that used in ways that devalue us as kind of fellow humans and make us kind of different and outside of the moral culture of society”* (P5).

For some participants despite clearly identifying as empathetic, there was on occasion an internal narrative around a lack of empathy, or a coldness, being associated with autistic traits, *“My gran ...I think she would have got a diagnosis because she was cold. She was very un-empathetic”* (P8).

One of the difficulties described by participants was that stereotypical views around autism, including a ‘lack of empathy’, was felt to influence how they are viewed by others, including medical professionals and the impact this could have on them being seen as individuals:

*“I felt very misunderstood, and she was obviously great psychiatrist, but I just got the feeling that she’d read some stuff in some books that just isn’t true to life and that made it very difficult for her to provide therapy, to disconnect her mind from those books and look at me”,* (P11).

The view that autistic people may lack or have a deficit of empathy was also reported as a barrier in relating to being autistic for some participants, *“I’d always heard that ‘they don’t feel empathy’, and I thought I feel a lot of empathy, I feel a crushing amount of empathy, so therefore that can’t be me”,* (P3). For others it was perceived as a barrier to receiving a diagnosis: *“ . . . but they were told because they had empathy they couldn’t be diagnosed . . . they couldn’t be autistic”,* (P9).

## Discussion

This study aimed to explore autistic adults' understanding and lived experience of empathy and the relationship of this experience to personal distress. A strength of the research is that it centred on the perspectives of autistic people, on their lived experience and understanding. The qualitative data was analysed using Braun and Clarke's (2006) thematic analysis which identified three overarching themes. The first theme described the participants' understanding of empathy, how they identified as empathetic, to what extent they felt able to empathise with others and how their empathy is developed. The second theme described what facilitates or hinders their empathy. The third theme described how empathy affects them.

The majority of the participants identified as empathetic and despite being uncertain about the comprehensiveness of their knowledge, described empathy in a way that appears to map onto the most widely used constructs; cognitive and affective empathy (Baron-Cohen & Wheelwright, 2004; Hoffman, 1984; Mehrabian & Epstein, 1972). Many felt that empathy was innate to a degree, but that empathy also develops through relational interactions.

Analysis of the data demonstrated that what may be different or difficult amongst this group of participants was not necessarily the key facets of empathy but the bidirectional communication of empathy, particularly with non-autistic people. Distress was particularly triggered through over-empathising and anxieties around having missed cues for empathy and worries regarding how to respond empathetically. Being in receipt of empathy from others was also experienced as unhelpful at times, suggesting that empathetic communication from non-autistic people to autistic people would also need adaptation. This is in line with findings from Crompton et al., (2019) who found that interactions between autistic people paired together showed higher rapport than when autistic and non-autistic persons are paired. The theme of autistic people finding communication and empathy with other autistic people easier

than with non-autistic people was frequently described in social contexts and within families also.

Traditionally, empirical literature has largely focused on there being a deficit located in the autistic individual, as opposed to interactional differences between individuals (Harmsen, 2019). This current research highlights that many of the well documented differences in autistic people, for example non-verbal communication, emotions, sensory processing (Arnaud, 2020; Klin et al., 2003; Lee et al., 2020; Robertson & Simmons, 2015), could impact on the autistic person's ability to see cues for empathy, to experience and show empathy when interacting with non-autistic people. These differences may serve to make empathy less visible to non-autistic people causing a bidirectional confusion in empathetic communication. This aligns with Milton's (2012) theory, 'The double empathy problem'.

There has also been research that has shown that non-autistic people can struggle to identify emotions in autistic people that further reflects the narratives of this study's participants (Brewer et al., 2016). The theme of shared interests and spaces appeared to offer hope in bridging these differences which suggests these difficulties can be reduced. Participants appeared to describe increased ease and understanding when smaller communities of autistic and non-autistic people spent time together with shared focus. This echoes the work of Bloom (2017) who talks about in-group biases positively impacting empathetic processes.

Negative stereotyping of empathy in autism was a strong theme and felt to place autistic people outside of the 'normal' moral culture and was experienced as dehumanising. This aligns with Milton's theory around the 'othering' of autistic and marginalised people (Milton & Lyte, 2012; Nicolaidis et al., 2018). The stereotype of reduced empathy can bring prejudice (Bäckström & Björklund, 2007) and this could contribute to some of the stigmatising beliefs around a 'lack of empathy' in autistic people. There were some

descriptions of coldness, and lack of empathy associated with autistic traits by some of the participants. This was in direct contradiction to their own empathetic identity and assertion that autistic people are empathetic, possibly indicative of internalised stigma.

Research suggests that public stigma, negative attitudes, prejudice and stereotypes held by members of the public about marginalised groups can become internalised by the individuals themselves (Rüsch et al., 2005; Puckett & Levitt, 2015;). Internalised and public stigma have been associated with negative outcomes, including reduced self-esteem, employment, and mental health (Alonso et al., 2009; Evans-Lacko et al., 2012). This could have important clinical implications for autistic people and the impact of these ‘myths’ that are perpetuated about them. With prevalence rates of mental health difficulties typically higher in the autistic population (Lugnegård et al., 2011; Mattila et al., 2010) it is essential to explore day to day experiences that can impact wellbeing.

The salience of the stereotype of autistic people lacking empathy was also linked to difficulty in identifying as autistic for some participants. Identifying as empathetic themselves meant that they were cautious about whether they would then meet the criteria for autism. Holding the belief that autistic people simply lack empathy could shape how a person might be referred, diagnosed and also identify with the autistic community. This could be an interesting avenue for future research. Promoting a model of difference rather than viewing differences as deficits, may not only improve people’s identification with autism but potentially have a wider positive impact on quality of life, mental health and reduce internalised stigma (Bacchman et al., 2019).

Participants described protecting themselves from distress by limiting social interactions or avoiding triggers for ‘empathetic distress’ in order to protect themselves from feeling overwhelmed. This could reflect Smith’s (2009) imbalance theory which suggests that autistic people may avoid some interactions due to an overwhelming emotional empathetic

response. This is also supported by Bastiaansen et al., (2008) who suggest some autistic people engage less socially not because it does not interest them but because it can overwhelm them.

### *Clinical implications*

This study adds the voices of autistic people to the evidence base. If empathy is not absent, or in deficit, but merely different than how viewed through the lens of a non-autistic society expects then it is important for us to be continuing the dialogue about this. This will have potential implications for clinical work, family relations, identifying autism, people identifying as autistic and reducing stigmatised views of autism. Echoing the work of Milton (2012), the data in this study described a reciprocal difference leading to difficulty in communicating empathy highlighting the need to be curious about this systemically and refrain from locating difficulties within individuals. There were indications that this internalised stigma may have been a factor for some participants. This warrants further exploration and could be a useful direction for future research. Stigma-focused interventions with clinicians, social care and education/employment professionals could be of benefit. Screening-focused training and wider awareness in the general public where assumptions about empathy skills may possibly rule out consideration of autism spectrum condition could also be beneficial. Importantly those who affect the lives of autistic people should be encouraged to think critically about the way autism is understood and formulated especially by those in positions of power. This has wide implications not just clinically but also in education and employment settings and for the evolution of societal discourses on autism and disability. In terms of therapeutic interventions, the findings suggest that increased focus on relational experiences rather than relying upon individualised skill-building for the autistic person could yield wider benefits to quality of life. Creating more shared space or “touch

point” opportunities for autistic and non-autistic people to develop better internationality could also reduce some of the difficulties described in this paper.

### *Strengths and limitations*

To our knowledge, this is the first research study to ask autistic adults what their experience of empathy is and how this experience affects them. The current culture of how knowledge is produced about autistic people often leaves their voice invisible (Milton, 2012). A clear strength of this study is that the methodology supports staying true to the words of the participants. On reflection the themes remained somewhat close to the domain summaries of the research interview schedule. Though interpretation (anchored with [an](#) autistic perspective via the collaboration of the expert by experience) is present, it was important to preserve the voices of the participants throughout. At times this led to a difficult balance between interpretation and remaining representative of the narratives present, this needs to be acknowledged as it is possible that the interpretation could have been taken further. That our team included an expert by experience researcher who actively participated meaningfully throughout each stage is another strength of this study. Commitment to participatory research was a priority for this research. The research and data analysis were led by the primary researcher but each stage was in collaboration with and supervision of the team and expert by experience. The expert by experience independently coded several transcripts and formed thematic maps which were then shared and compared in research meetings with the primary researcher and then the rest of the team. The expert by experience was well equipped to contribute to this level of research and was involved at every stage of the analysis. This level of expert by experience involvement is a clear strength of the research and a very necessary component in autism research, as argued by Milton (2014) who states the meaningful inclusion of autistic scholars is essential when capturing the phenomenological



lived experience of autistic people. The participants also spoke positively of their interview experiences.

Limitations of the study are that results of small qualitative studies cannot be assumed to be generalisable to the wider autistic population. They do however loan some support to current theories gaining traction in the empirical literature and provide a thick, rich description of the lived experience of empathy. This research lacks diversity as the sample represents a small group of primarily white autistic adults, although one person identified as being from a dual heritage background. The methodology of this study may not have captured subtle differences in the experience of the participant who identified as mixed heritage, or the two participants who were from outside of the UK.

Recommended future research could consider how people from different cultural and racial backgrounds may report different experiences of empathy in relation to autism and wellbeing. This study relied on participant self-selection which could overrepresent the views of certain groups and future research might include different recruitment strategies (snowballing) that may be more effective at accessing hard to reach groups (Noy, 2008; Etikan et al., 2016). In retrospect, the research could have been made more robust if the themes and subthemes had been sent out to the participants and their opinion sought on the framework during its development (Nowell et al., 2017). It is also important to reflect on the abilities of those who have taken part in this research and to think about how further empirical studies could include people with non-verbal communication skills or those who would struggle to take part without support. The findings also allude to interactional difficulties between the autistic and non-autistic populations but to fully understand this, future studies may need to consider observational methods.

## *Conclusion*

This study found rich descriptions of empathy from all the autistic adults participating. Despite identifying as empathetic, they spoke of many challenges. These challenges largely stemmed from interacting with non-autistic people, or people not well known to them where many factors can lead to differences in communication. These differences could lead to empathy being invisible to the neurotypical gaze and though historically there is much focus on a deficit being located within autistic people, current research is building a bidirectional model of differences that provides a better platform for understanding and interacting with the difficulties described. This paper has added a rich and valuable description of the lived experience of empathy as an exploratory step that serves to challenge some of the assumptions about empathy and autism that can influence future research and clinical practice.

## References

- Aarons, M., & Gittens, T. (1999). *The handbook of autism: A guide for parents and professionals* (2nd ed.). Electronic book.
- Alonso, J., Buron, A., Rojas-Farreras, S., de Graaf, R., Haro, J. M., de Girolamo, G., Bruffaerts, R., Kovess, V., Matschinger, H., & Vilagut, G. (2009). Perceived stigma among individuals with common mental disorders. *Journal of Affective Disorders, 118*(1), 180–186. <https://doi-org.liverpool.idm.oclc.org/10.1016/j.jad.2009.02.006>
- American Psychiatric Association. (1980). *Diagnostic and statistical manual of mental disorders* (3rd ed.). Washington, DC: APA Press.
- American Psychiatric Association. (1994). *Diagnostic and statistical manual of mental disorders* (4th ed.). Washington, DC: APA Press.
- Arnaud, S. (2020). A social–emotional salience account of emotion recognition in autism: Moving beyond theory of mind. *Journal of Theoretical and Philosophical Psychology*. <https://doi-org.liverpool.idm.oclc.org/10.1037/teo0000174>
- Asperger Syndrome Foundation. (n.d.) *What is Asperger Syndrome?* Retrieved from: [http://www.aspergerfoundation.org.uk/what\\_as.htm](http://www.aspergerfoundation.org.uk/what_as.htm)
- Asperger/Autism Network (n.d.) *Asperger Profiles: Emotions and empathy*. Retrieved from: <http://www.aane.org/emotions-and-empathy/>
- Bachmann, C. J., Höfer, J., Kamp-Becker, I., Küpper, C., Poustka, L., Roepke, S., Roessner, V., Stroth, S., Wolff, N., & Hoffmann, F. (2019). Internalised stigma in adults with autism: A German multi-center survey. *Psychiatry Research, 276*, 94–99. <https://doi-org/10.1016/j.psychres.2019.04.023>
- Bäckström M, Björklund F. (2017) Structural modeling of generalized prejudice: The role of social dominance, authoritarianism, and empathy. *Journal of Individual Differences; 28*(1):10–17.

- Barbour, R. S. (2001). Checklists for improving rigour in qualitative research: a case of the tail wagging the dog? *British Medical Journal*, 322(7294), 1115–1117.
- Baron-Cohen S (2000) Is Asperger syndrome/high-functioning autism necessarily a disability? *Development and Psychopathology* 12: 489–500. DOI: 10.1017/S0954579400003126
- Baron-Cohen, S. (2003). *The essential difference: The truth about the male and female brain*. Basic Books.
- Baron-Cohen, S., & Wheelwright, S. (2004). The Empathy Quotient: An Investigation of Adults with Asperger Syndrome or High Functioning Autism, and Normal Sex Differences. *Journal Of Autism And Developmental Disorders*, 34(2), 163-175. Retrieved from: doi: 10.1023/B:JADD.0000022607.19833.00
- Bastiaansen, J., Thioux, M., & Keysers, C. (2008). *Mirror neuron system not broken in adults with autism spectrum disorder for viewing emotions of others*. Cognitive Neuroscience Society Annual Meeting Program, p. 276.
- Begon, R., & Billington, T. (2019). Between category and experience: constructing autism, constructing critical practice. *Educational Psychology in Practice*, 35(2), 184–196. <https://doi-org.liverpool.idm.oclc.org/10.1080/02667363.2019.1571481>
- Blee, K. M., & Taylor, V. (2002). Semi-structured interviewing in social movement research. *Methods of social movement research*, 16, 92-117.
- Bloom, P. (2017). Empathy and Its Discontents. *Trends in Cognitive Sciences*, 21(1), 24–31.
- Boyatzis, R. E. (1998). *Transforming qualitative information: Thematic analysis and code development*. London: Sage.
- Braun, V. & Clarke, V. (2006) Using thematic analysis in psychology. *Qualitative Research in Psychology*, 3(2): 77-101.
- Braun, V. & Clarke, V. (2013) *Successful Qualitative Research: A Practical Guide for Beginners*. London: Sage.

- Brewer, R., Biotti, F., Catmur, C., Press, C., Happé, F., Cook, R., & Bird, G. (2016). Can neurotypical individuals read autistic facial expressions? Atypical production of emotional facial expressions in autism spectrum disorders. *Autism Research, 9*(2), 262-271.  
<https://doi.org/10.1002/aur.1508>
- British Psychological Society (2014) *Code of human research ethics*. Leicester: The British Psychological Society.
- Broderick, A. A., & Ne'eman, A. (2008). Autism as metaphor: Narrative and counter-narrative. *International Journal of Inclusive Education, 12*(5–6), 459–476.
- Brugha, T., Cooper, S. A., McManus, S., Purdon, S., Smith, J., Scott, F. J., ... & Tyrer, F. (2012). *Estimating the Prevalence of Autism Spectrum Conditions in Adults: Extending the 2007 Adult Psychiatric Morbidity Survey*. Retrieved from:  
<http://digital.nhs.uk/catalogue/PUB05061>.
- Chambers, B., Boden, Z. V. R., Murray, C. M., & Kelly, M. P. (2020). ‘Sometimes labels need to exist’: exploring how young adults with Asperger’s syndrome perceive its removal from the Diagnostic and Statistical Manual of Mental Disorders fifth edition. *Disability and Society, 35*(4), 589–608.
- Combs, G., & Freedman, J. (2012). Narrative, Poststructuralism, and Social Justice: Current Practices in Narrative Therapy. *Counseling Psychologist, 40*(7), 1033–1060.
- Crane, L., Goddard, L., & Pring, L. (2009). Sensory processing in adults with autism spectrum disorders. *Autism: The Inter-national Journal of Research and Practice, 13*(3), 215–228.  
<http://doi.org/10.1177/1362361309103794>.
- 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:*

*The International Journal of Research and Practice*, 24(6), 1438–1448. DOI:

10.1177/1362361320908976

Davis, M. H. (1983). Measuring individual differences in empathy: Evidence for a multidimensional approach. *Journal of Personality and Social Psychology*, 44(1), 113-126. doi:10.1037/0022-3514.44.1.113.

DeJonckheere, M., & Vaughn, L. M. (2019). Semistructured interviewing in primary care research: a balance of relationship and rigour. *Family Medicine and Community Health*, 7(2).  
<https://doi.org/10.1136/fmch-2018-000057>

Dell'Osso, L., Dalle Luche, R., Gesi, C., Moroni, I., Carmassi, C., & Maj, M. (2016). From Asperger's Autistischen Psychopathen to DSM-5 autism spectrum disorder and beyond: A Subthreshold Autism Spectrum Model. *Clinical Practice and Epidemiology in Mental Health* doi: 10.2174/1745017901612010120

Dodgson, J. E. (2019). Reflexivity in Qualitative Research. *Journal of Human Lactation*, 35(2), 220–222.

Elliott, R., Fischer, C. & Rennie, D. (1999) Evolving Guidelines for Publication of Qualitative Research Studies in Psychology and Related Fields. *British Journal of Clinical Psychology*. 38: 215-229. DOI: 10.11648/j.ajtas.20160501.11

Etikan, I., Musa, S. A., & Alkassim, R. S. (2016). Comparison of convenience sampling and purposive sampling. *American Journal of Theoretical and Applied Statistics*, 5(1), 1-4. DOI: 10.6224/JN.61.3.105

Evans-Lacko, S., Brohan, E., Thornicroft, G., & Mojtabai, R. (2012). Association between public views of mental illness and self-stigma among individuals with mental illness in 14 European countries. *Psychological Medicine*, 42(8), 1741–1752. <https://doi-org/10.1017/S0033291711002558>

- Fletcher-Watson, S., & Bird, G. (2020). Autism and empathy: What are the real links? *Autism: The International Journal of Research & Practice*, 24(1), 3–6. <https://doi-org/10.1177/1362361319883506>
- Fletcher-Watson, S., Adams, J., Brook, K., Charman, T., Crane, L., Cusack, J., Leekam, S., Milton, D., Parr, JR., & Pellicano, E. (2019). Making the future together: Shaping autism research through meaningful participation. *Autism*, 23(4), 943-953. DOI: 10.1177/1362361318786721
- Gillberg, C. (1992). The Emanuel Miller Lecture, 1991: Autism and autistic-like conditions: Subclasses among disorders of empathy. *Journal of Child Psychology and Psychiatry*. 33, 813–842.
- Gillespie-Lynch, K., Daou, N., Obeid, R., Reardon, S., Khan, S., & Goldknopf, E. J. (2020). What contributes to stigma towards autistic university students and students with other diagnoses? *Journal of Autism and Developmental Disorders*, 1–17. Advance online publication. <https://doi.org/10.1007/s10803-020-04556-7>
- Gregoire, C. (2016) *We may have been wrong about autism and empathy*. Huffington Post Science. Retrieved from: [http://www.huffingtonpost.co.uk/entry/autism-empathy-brain-research\\_us\\_56f92575e4b014d3fe237413](http://www.huffingtonpost.co.uk/entry/autism-empathy-brain-research_us_56f92575e4b014d3fe237413)
- Harmsen, I. E. (2019). Empathy in Autism Spectrum Disorder. *Journal of Autism and Developmental Disorders*, 49(10), 3939. <https://doi-org/10.1007/s10803-019-04087-w>
- Hefferon, K., & Gil-Rodriguez, E. (2011). Methods: Interpretative Phenomenological Analysis. *The Psychologist*, 24, 756-759.
- Hoffman, M. L. (1984). *Interaction of affect and cognition in empathy*. In C. E. Izard, & R. B. Kagan (Eds.), *Emotions, cognition and behavior* (pp. 103–131). Cambridge: Cambridge University Press.
- Jackson, L. (2002). *Freaks, geeks and Asperger Syndrome: A user guide to adolescence*. London, Jessica Kingsley Publishers.

- 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: The International Journal of Research and Practice*, 20(4), 442–462. DOI: 10.1177/1362361315588200
- Khanjani, Z., Mosanezhad Jeddi, E., Hekmati, I., Khalilzade, S., Etemadi Nia, M., Andalib, M., & Ashrafian, P. (2015). Comparison of Cognitive Empathy, Emotional Empathy, and Social Functioning in Different Age Groups. *Australian Psychologist*, 50(1), 80-85. doi:10.1111/ap.12099.
- Kim, H., & Han, S. (2018). Does personal distress enhance empathic interaction or block it? *Personality and Individual Differences*, 12, 77-83. DOI: 10.1016/j.paid.2017.12.005
- Kite, D. M., Gullifer, J., & Tyson, G. A. (2013). Views on the diagnostic labels of autism and Asperger's disorder and the proposed changes in the DSM. *Journal of Autism and Developmental Disorders*, 43(7), 1692. DOI 10.1007/s10803-012-1718-2.
- Klin, A., Jones, W., Schultz, R., & Volkmar, F. (2003). The enactive mind, or from actions to cognition: Lessons from autism. *Philosophical Transactions of the Royal Society of London, Series B: Biological Sciences*, 358, 345–360. DOI 10.1098/rstb.2002.1202
- Kok, F. M., Groen, Y., Becke, M., Fuermaier, A. M., & Tucha, O. (2016). Self-reported empathy in adult women with autism spectrum disorders—A systematic mini review. *Public library of science*. 11(3).
- Lake, J. K., Perry, A., & Lunskey, Y. (2014). Mental Health services for individuals with high functioning autism spectrum disorder. *Autism Research and Treatment*. Volume 2014, Article ID 502420. Retrieved from: <http://doi.org/10.1155/2014/502420>
- Landau, E. (2010). *Move to merge Asperger's, autism in diagnostic manual stirs debate*. Retrieved from: <http://edition.cnn.com/2010/HEALTH/02/11/aspergers.autism.dsm.v/index.html>



- Lawson, W., & Prior, M. R. (2001). *Understanding and working with the spectrum of autism: an insider's view*. Jessica Kingsley Publishers, London.
- Lee, M., Nayar, K., Maltman, N., Hamburger, D., Martin, G. E., Gordon, P. C., & Losh, M. (2020). Understanding social communication differences in autism spectrum disorder and first-degree relatives: A study of looking and speaking. *Journal of Autism and Developmental Disorders*, *50*(6), 2128–2141.
- Lincoln, Y., & Guba, E. G. (1985). *Naturalistic inquiry*. Newbury Park, CA: Sage.
- Lowe, A., Norris, A. C., Farris, A. J., & Babbage, D. R. (2018). Quantifying Thematic Saturation in Qualitative Data Analysis. *Field Methods*, *30*(3), 191–207.
- Lugnegård, T., Hallerbäck, M. U., & Gillberg, C. (2011). Psychiatric comorbidity in young adults with a clinical diagnosis of Asperger syndrome. *Research in Developmental Disabilities*. doi:10.1016/j.ridd.2011.03.025
- MacKay, T., Knapp, M., Boyle, J., Iemmi, V., Connolly, M., & Rehill, A. (2018). *The microsegmentation of the autism spectrum: Economic and research implications for Scotland*. The Scottish Government.
- Mattila, M., Hurtig, T., Haapsamo, H., Jussila, K., Kuusikko-Gauffin, S., Kielinen, M., & ... Moilanen, I. (2010). Comorbid psychiatric disorders associated with Asperger syndrome/high-functioning autism: A community and clinic-based Study. *Journal of Autism & Developmental Disorders*, *40*(9), 1080-1093. doi:10.1007/s10803-010-0958-2
- Mayer, J. L., Hannent, I., & Heaton, P. F. (2014). Mapping the developmental trajectory and correlates of enhanced pitch perception on speech processing in adults with ASD. *Journal of Autism and Developmental Disorders*, 1–12. DOI 10.1007/s10803-014-2207-6
- Mead, G. H. (1934). *Mind, self, and society*. Chicago: University of Chicago Press.
- Mehrabian, A., & Epstein, N. (1972). A measure of emotional empathy. *Journal of Personality*, *40*(4), 525–543.

- Milton, D. E. M. (2012). On the ontological status of autism: The “Double Empathy Problem.” *Disability & Society*, 27(6), 883–887.
- Milton, D., & Moon, L. (2012). The normalisation agenda and the psycho-emotional disablement of autistic people. *Autonomy, the Critical Journal of Interdisciplinary Autism Studies*, 1(1). <https://orcid.org/0000-0003-3825-6194>
- Milton, D. E. M. (2014). Autistic expertise: A critical reflection on the production of knowledge in autism studies. *Autism: The International Journal of Research and Practice*, 18(7), 794–802. DOI: 10.1177/1362361314525281
- Milton, D., & Sims, T. (2016). How is a sense of well-being and belonging constructed in the accounts of autistic adults? *Disability and Society*, 31(4), 520–534. DOI: 10.1080/09687599.2016.1186529
- Morgan, H., Thomson, G., Crossland, N., Dykes, F., & Hoddinott, P. (2016). Combining PPI with qualitative research to engage ‘harder-to-reach’ populations: service user groups as co-applicants on a platform study for a trial. *Research Involvement and Engagement*, 2(1), 1-26. <https://doi.org/10.1186/s40900-016-0023-1>
- Nicolaidis, C., Milton, D., Sasson, N. J., Sheppard, E., & Yergeau, M. (2018). An expert discussion on autism and empathy. *Autism in Adulthood*, 1(1), 4-11. <https://doi.org/10.1089/aut.2018.29000.cjn>
- Nowell, L., Norris, J., White, D., & Moules, N. (2017). Thematic Analysis: Striving to Meet the Trustworthiness Criteria. *International Journal of Qualitative Methods*. 16(1), doi:10.1177/1609406917733847
- Noy, C. (2008). Sampling Knowledge: The hermeneutics of Snowball Sampling in qualitative research. *International Journal of Social Research Methodology*, 11(4), 327–344. <https://doi.org/10.1080/13645570701401305>
- Piaget, J. (1932). *The moral judgment of the child*. New York: Free Press.

- Pohl, A. L., Crockford, S. K., Blakemore, M., Allison, C., & Baron-Cohen, S. (2020). A comparative study of autistic and non-autistic women's experience of motherhood. *Molecular Autism*, *11*(1), 1–12. <https://doi-org.liverpool.idm.oclc.org/10.1186/s13229-019-0304-2>
- Puckett, J. A., & Levitt, H. M. (2015). Internalized stigma within sexual and gender minorities: Change strategies and clinical implications. *Journal of LGBT Issues in Counseling*, *9*(4), 329–349. <https://doi.org/10.1080/15538605.2015.1112336>
- Robertson, A. E., & Simmons, D. R. (2015). The sensory experiences of adults with autism spectrum disorder: A qualitative analysis. *Perception*, *44*(5), 569–586. <https://doi-org.liverpool.idm.oclc.org/10.1068/p7833>
- Robinson, O. (2014). Sampling in Interview-Based Qualitative Research: A Theoretical and Practical Guide. *Qualitative Research in Psychology*, *11*(1), 25–41. DOI: 10.1080/14780887.2013.801543
- Robson, C. (2002). *Real world research: A resource for social scientists and practitioner-researchers* (2nd edn.). Oxford, UK: Blackwell.
- Rogers, K., Dziobek, I., Hassenstab, J., Wolf, O. T., & Convit, A. (2007). Who cares? Revisiting empathy in Asperger syndrome. *Journal of Autism and Developmental Disorders*, *37*(4), 709–715. doi:10.1007/s10803-006-0197-8
- Rüsch, N., Angermeyer, M. C., & Corrigan, P. W. (2005). Mental illness stigma: Concepts, consequences, and initiatives to reduce stigma. *European psychiatry*, *20*(8), 529–539.
- Sahar, N. (2017). Cognitive Milestones on Mutual Paths towards Empathy: A Four-Step Model. *At The Interface / Probing The Boundaries*, (92), 107–129. doi:10.1163/9789004360846\_007
- Sasson, N. J., Faso, D. J., Nugent, J., Kennedy, D. P., Lovell, S., & Grossman, R. B. (2017). Neurotypical peers are less willing to interact with those with autism based on Thin Slice Judgments. *Scientific Reports*, *7*.

- Seventh Voice (n.d.) *Simply my take on living life as a female with Asperger's Syndrome*. Retrieved from: <https://seventhvoice.wordpress.com>
- Silverman, D. (2010). *Doing qualitative research: A practical handbook*. London : SAGE, 2010.
- Smith, A. (2006). Cognitive empathy and emotional empathy in human behaviour and evolution. *Psychological Record*, 56(1), 3.
- Smith, A. (2009). Emotional empathy in autism spectrum conditions: weak, intact, or heightened? *Journal of Autism And Developmental Disorders*, 39(12), 1747-1748.  
doi:10.1007/s10803-009-0799-z
- Teh, Y. Y., & Lek, E. (2018). Culture and reflexivity: Systemic journeys with a British Chinese family. *Journal of Family Therapy*, 40, 520–536. doi:10.1111/1467-6427.12205
- The National Autistic Society (2016). *What is Autism?* Retrieved from:  
<http://www.autism.org.uk/about/what-is/asd.aspx>
- Tong, A., Sainsbury, P., & Craig, J. (2007). Consolidated criteria for reporting qualitative research (COREQ): A 32-item checklist for interviews and focus groups. *International Journal for Quality in Health Care*, 19(6), 349–357.
- Willig, C. (1999). *Beyond appearances: a critical realist approach to social constructionism*. In Nightingale, D.J. and Cromby J. (Ed.). *Social constructionist psychology: a critical analysis of theory and practice*. Open University Press, 37/51.
- Willig, C. (2013). *Introducing qualitative research in psychology*. McGraw-Hill Education.
- Wing, L. (1981). Asperger's syndrome: A clinical account. *Psychological Medicine*, 11(1), 115-129.  
doi:10.1017/S0033291700053332
- Wing, L. (1996). *The autistic spectrum: a guide for parents and professionals*. London, Constable and Company Ltd.
- World Health Organisation (1994). *International classification of diseases (10th ed.)*. Geneva, Switzerland.

World Health Organization. (1992). *The ICD-10 classification of mental and behavioural disorders: Clinical descriptions and diagnostic guidelines*. Geneva: World Health Organization.

## List of tables

Table 1. SPIDER tool for the identification of search terms .....	9
Table 2. CASP quality assessment of included studies .....	13
Table 3. Study characteristics .....	16
Table 4. Patient demographics .....	56

## List of figures

Figure 1. PRISMA flowchart of study selection process.....	11
Figure 2. Theme map .....	58

## **Appendices**

### *List of appendices*

Appendix 1: *CASP example*

Appendix 2: *Data extracts illustrating diagnosis theme*

Appendix 3: *Ethical approval*

Appendix 4: *Participant Information Form*

Appendix 5: *Distress Policy*

Appendix 6: *Advert*

Appendix 7: *Consent Form*

Appendix 8: *Interview Schedule*

Appendix 9: *Code and theme development example and extract from reflective diary.*




Appendix 10: *Autism Journal guidelines*

*Appendix 1 CASP example*



**CASP Checklist:** 10 questions to help you make sense of a **Qualitative** research

**How to use this appraisal tool:** Three broad issues need to be considered when appraising a qualitative study:

-  Are the results of the study valid? (Section A)
-  What are the results? (Section B)
-  Will the results help locally? (Section C)

The 10 questions on the following pages are designed to help you think about these issues systematically. The first two questions are screening questions and can be answered quickly. If the answer to both is “yes”, it is worth proceeding with the remaining questions. There is some degree of overlap between the questions, you are asked to record a “yes”, “no” or “can’t tell” to most of the questions. A number of italicised prompts are given after each question. These are designed to remind you why the question is important. Record your reasons for your answers in the spaces provided.

**About:** These checklists were designed to be used as educational pedagogic tools, as part of a workshop setting, therefore we do not suggest a scoring system. The core CASP checklists (randomised controlled trial & systematic review) were based on JAMA ‘Users’ guides to the medical literature 1994 (adapted from Guyatt GH, Sackett DL, and Cook DJ), and piloted with health care practitioners.

For each new checklist, a group of experts were assembled to develop and pilot the checklist and the workshop format with which it would be used. Over the years overall adjustments have been made to the format, but a recent survey of checklist users reiterated that the basic format continues to be useful and appropriate.

**Referencing:** we recommend using the Harvard style citation, i.e.: *Critical Appraisal Skills Programme (2018). CASP (insert name of checklist i.e. Qualitative) Checklist. [online] Available at: URL. Accessed: Date Accessed.*

©CASP this work is licensed under the Creative Commons Attribution – Non-Commercial-Share A like. To view a copy of this license, visit <http://creativecommons.org/licenses/by-nc-sa/3.0/> [www.casp-uk.net](http://www.casp-uk.net)

Paper for appraisal and reference:

Section A: Are the results valid?

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

Yes	<input checked="" type="checkbox"/>
Can't Tell	<input type="checkbox"/>
No	<input type="checkbox"/>

HINT: Consider

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

Comments: **Mapping the Autistic Advantage from the Accounts of Adults Diagnosed with Autism: A Qualitative Study.** they were looking for adaptive autistic abilities

2. Is a qualitative methodology appropriate?

Yes	<input checked="" type="checkbox"/>
Can't Tell	<input type="checkbox"/>
No	<input type="checkbox"/>

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: **they wanted the voices of the population to answer this question**

Is it worth continuing?

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

Yes	<input checked="" type="checkbox"/>
Can't Tell	<input type="checkbox"/>
No	<input type="checkbox"/>

HINT: Consider

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

Comments: **they haven't really explored why not other approaches though, they've stated that they don't like the philosophical underpinning of some but not named it.**

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

Yes	<input checked="" type="checkbox"/>
Can't Tell	<input type="checkbox"/>
No	<input type="checkbox"/>

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: **but more could have been said here about the other hint topics for example**

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

Yes	<input checked="" type="checkbox"/>
Can't Tell	<input type="checkbox"/>
No	<input type="checkbox"/>

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	<input checked="" type="checkbox"/>
Can't Tell	<input checked="" type="checkbox"/>
No	<input type="checkbox"/>

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: **It's a bit of a yes and no really as they have in some ways but not in others, unless the use of deductive and a nod to the theories was their way of doing this perhaps. I feel it could be more reflexive.**

Section B: What are the results?

7. Have ethical issues been taken into consideration?

Yes	<input checked="" type="checkbox"/>
Can't Tell	<input type="checkbox"/>
No	<input type="checkbox"/>

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: **Again they have but they could have done more! they have done okay actually re-read it**

8. Was the data analysis sufficiently rigorous?

Yes	<input checked="" type="checkbox"/>
Can't Tell	<input type="checkbox"/>
No	<input checked="" type="checkbox"/>

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: **lacked reflections on personal bias and influence in the analysis and discussion section**

9. Is there a clear statement of findings?

Yes	<input checked="" type="checkbox"/>
Can't Tell	<input type="checkbox"/>
No	<input type="checkbox"/>

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:

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: **this is there but not in a clear ring fenced way it's organically spread throughout the article.**

Appendix 2 Data extracts illustrating diagnosis theme

Diagnosis

1 Bargiela Et Al., 2016	x ". . . If I had known and people had helped me out earlier on then life would have been a whole lot easier".
2 Camm-Crosbie Et Al., 2019	
3 Forster An & Pearson Et Al., 2019	x "I'm not being hard, but I want to be on the mainstream side, not the learning disabled side" - distancing self from disablilty.
4 Griffith, Totsika Et Al., 2011	X
5 Hickey Et Al., 2018	x "well you have an explanation of why it is that you find it difficult to meet people or relate to them", for ome it was painful "great feelings of inadequacy"
6 Kapp Et Al., 2019	
7 Kock Et Al., 2019	x "" . . . Theres definitely been a lot of worry about getting it wrong, more since the diagnosis" - relationships. "It was a relief when I did get the diagnosis because it's like okay, I understand why I do this, this and while everyone else does soemthign different . . . " - relationships.
8 Leedham Et Al., 2020	<i>... you sort of realise that you're stuck like this forever really, so that's a bit ... It's a bit overwhelming ... I'm going to struggle with things for the rest of my life, that's hard.</i>

9 Powell & Acker, 2016	x "I was relieved to have it confirmed" "not to be labelled a weirdo" "I was happy . . . I feel validated . . . Liberated" I feel "shocked . . . Daunted . . .confused" "very depressing to realise that I will never change or get better"
10 Robertson & Simmons, 2015	
11 Rodgers Et Al., 2019	'I worry about whether to tell people or not [about diag- nosis]. . . . So do I explain myself so that explains why I don't want to do these things or will that isolate me even more?
12 Russell Et Al., 2019	X
13 Stagg & Belcher, 2019	It really was like a sort of eureka moment ... it was kind of a relief ... and it wasn't my fault, and that was one of the biggest things, that I realised it wasn't my fault. (Brenda) It's the relief of knowing what's wrong, or what has been wrong. (Linda) A relief, because 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. (Debra) So it was a real (sighs) I mean 'revelation' is not even the word, really, it was (sighs) I was just stunned, really, to think that I could have gone through life potentially having Asperger's and never having realised. (Mary)
14 Treweek Et Al.,	X





## Appendix 3

### *Ethical approval*

17 January 2019

Dear Dr Flood

I am pleased to inform you that your application for research ethics approval has been approved. Application details and conditions of approval can be found below. Appendix A contains a list of documents approved by the Committee.

#### **Application Details**

Reference:  
Project Title:  
Principal Investigator/Supervisor: Co-Investigator(s):  
Lead Student Investigator: Department:  
Approval Date:  
Approval Expiry Date:

3906  
Exploring the understanding and experience of empathy in adults diagnosed with Asperger Syndrome. Dr Andrea Flood  
Miss Lisa Powney, Dr Helen Brooks  
-  
School of Psychology (including DClinPOsych)  
17/01/2019  
Five years from the approval date listed above

Central University Research Ethics Committee A

The application was **APPROVED** subject to the following conditions: **Conditions of approval**

All serious adverse events must be reported to the Committee ([ethics@liverpool.ac.uk](mailto:ethics@liverpool.ac.uk)) in accordance with the procedure for reporting adverse events.

If you wish to extend the duration of the study beyond the research ethics approval expiry date listed above, a new application should be submitted.

If you wish to make an amendment to the study, please create and submit an amendment form using the research ethics system.

If the named Principal Investigator or Supervisor leaves the employment of the University during the course of this approval, the approval will lapse. Therefore it will be necessary to create and submit an amendment form within the research ethics system.

It is the responsibility of the Principal Investigator/Supervisor to inform all the investigators of the terms of the approval.

Kind regards,

Central University Research Ethics Committee A [ethics@liverpool.ac.uk](mailto:ethics@liverpool.ac.uk)  
CURECA

## **Appendix 4**

### *Participant Information Form*

**V3 LEP 11.01.2019**

#### Participant Information Sheet

## Exploring the understanding and experience of empathy in adults diagnosed with Asperger Syndrome.

*Thank you for expressing interest in taking part in this research. This information sheet contains information about why the research is being done and what it will involve so you can make a decision about whether to take part. Please read through the following information and you can ask me any questions you may have in a telephone appointment or via email. It is fine to talk this through with your friends and family and to ask me about anything you don't understand.*

*There is no obligation to take part in the research.*

*Thank you for reading this.*

### **What is the purpose of this research and why have I been chosen to participate?**

The research is being completed as part of a doctoral thesis by myself, Ellie Powney, a trainee Clinical Psychologist. The research is focused upon your understanding and experience of empathy as someone who is diagnosed with Asperger Syndrome. We are also interested in whether you think your experience of empathy has any relationship to any distress you have experienced. You will need a formal diagnosis of Asperger Syndrome or Autism Spectrum Disorder without accompanying intellectual or language impairment (as this meets criteria for Asperger Syndrome). You will also need to be over the age of 18. This research will help us begin to capture what people with a diagnosis of Asperger Syndrome think about empathy and what they experience. Exclusion criteria; certain conditions mean that we cannot use your data for this study. Therefore if you do not speak fluent English, have no formal diagnosis of Asperger Syndrome or ASD, have a diagnosis of ASD but with accompanying intellectual or language impairment, have serious mental illness such as Psychosis or Bipolar disorder then there is no need to participate any further, but we sincerely thank you for your interest in this study.

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

If you decide you would like to participate in this research I will contact you by email or telephone, depending on your preference, and I will organise a time and place that suits you to hold the interview. This can be at the University of Liverpool, or a local meeting room of your choice as long as the place we meet allows us to talk without being overheard. It may also be possible to complete the interview via Skype. When we meet I will explain the nature and purpose of the research again. You will have the opportunity again to ask any questions you may have. I will explain confidentiality and its limitations and then ask you to give informed consent to taking part in the research.

The interview can last from an hour to an hour and a half. The interview will be recorded and will be stored securely on the university's secure server until they are transcribed. You can be provided with a transcript of the interview if you would like one once it is completed. Your consent forms will also be secured securely on the university's secure server.

The data from the interviews will be used to form a doctoral thesis, articles, reports and potentially be presented at conferences. If you would like a summary of the findings of the study these can be provided to you. You will need to provide contact information for this information to be sent out, this information will also be stored securely and destroyed once the information has been sent.

Though the interview should not elicit any distress we will discuss before hand how best to manage this should it arise. Should you become distressed at any point during the interview we can pause the interview until you feel okay to continue or we can stop the interview if you do not wish to continue. There is a debriefing process that we will follow should you experience any significant distress, if there are any significant concerns we may contact your GP to ensure that you are as well supported as you can be. There will be an opportunity to discuss any questions you have regarding this when we initially discuss your participation and it can be revisited at any point during the process of the interview.

### **What will I gain for participating?**

It is unlikely that you will experience any direct benefits from taking part. However the research will be contributing to the evidence base about empathy and Asperger Syndrome. The approach used is different to previous research, which has tended to use pre-existing ideas about empathy, or attempted to measure it in a way that may not reflect the experience of people with an Autism Spectrum Condition. The intention of this research is to understand how autistic people experience empathy using their own words and ideas.

A £15 Love to Shop voucher will be given to those who take part in our research as a way of thanking you for your contribution and for giving up your time to assist in this research.

### **Can I change my mind?**

This research is entirely voluntary. You can choose not to take part or withdraw from the research at any time. You can also pause or stop the interview at any time. You can withdraw your data (the interview transcription and recording) up to two weeks after your interview has been completed; after that point it will have been anonymised and analysed and will not be able to be withdrawn. The research team would like to be able to use quotations from your interview when reporting the research, but these will be anonymised (all identifiable information would be removed). You can also decide to take part but ask us not to use direct quotations.

### **What will happen to my personal data?**

The university processes personal data as part of it's research and teaching activities in accordance with the lawful basis of 'public task', and in accordance with the University's purpose of "advancing education, learning and research for the public benefit".

Under UK data protection legislation, the University acts as the Data Controller for personal data collected as part of the University's research. The (principle Investigator/supervisor) acts as the Data Processor for this study, and any queries relating to the handling of your personal data can be sent to ([Lep79@liverpool.ac.uk](mailto:Lep79@liverpool.ac.uk)/[amflood@liverpool.ac.uk](mailto:amflood@liverpool.ac.uk)).

*Further information on how your data will be used can be found in the table below".*

How will my data be collected?	Your data will be collected through the interview and the interview will be recorded.
How will my data be stored?	The data and all forms you fill in i.e. consent forms will be stored on the University Secure Server. Some interviews will be sent to be transcribed and these interviews will be stored by them on an encrypted drive until the interview has been transcribed at which point it will be destroyed. These companies also have their own confidentiality agreements. The confidentiality and storage have been approved by the University of Liverpool.
How long will my data be stored for?	Your interview data will be destroyed once the interview has been transcribed.
What measures are in place to protect the security and confidentiality of my data?	The data will be transcribed with all identifiable information removed and the audio data will then be destroyed. All forms will be held securely on the University Secure server and only the interviewer will have access to this data.
Will my data be anonymised?	Once transcribed the data will be fully anonymised. The audio files will then be destroyed.
How will my data be used?	Your data will be coded and themes will be developed. Once analysed the data will be compiled in the form of a university thesis, it will be sent for publication and may be presented at conferences. There will be no identifiable information used for any of these purposes.
Who will have access to my data?	The interviewer (Lisa Ellen Powney, Ellie) will have access to the data, Two supervisors and an Expert by Experience will have access to the anonymised data in order to also code and develop themes to help ensure this is a trustworthy and thoughtful process.

Will my data be archived for use in other research projects in the future?	Your anonymised transcripts will be held for ten years and consent forms will be held for one year. Both will be held on the University Secure Server. The data will not be used in other projects.
How will my data be destroyed?	The data will be deleted from the University Secure Server.

**What I am not happy with something about the research or the research process?**

The main point of contact for this research is (Ellie Powney: [lep79@liverpool.ac.uk](mailto:lep79@liverpool.ac.uk)).

If you are unhappy or if there is a problem during the process that you are not comfortable discussing with Ellie, then you can contact the principle researcher (Andrea Flood, [amflood@liverpool.ac.uk](mailto:amflood@liverpool.ac.uk)).

If you continue to be unhappy or you feel you cannot come to us with your complaint then you can contact the Research Ethics and Integrity Office at ([ethics@liv.ac.uk](mailto:ethics@liv.ac.uk)). You will need to provide the name of the study, the researchers involved and the details of your complaint.

If you have any further questions then please do not hesitate to contact me:

Ellie Powney

[lep79@liverpool.ac.uk](mailto:lep79@liverpool.ac.uk)

Doctorate in Clinical Psychology

University of Liverpool

School of Psychology

Ground Floor Whelan Building

Quadrangle

Brownlow Hil

**Appendix 5**  
*Distress Policy*

V3 LEP 11.01.2019

**Distress and/ or Risk Disclosure Protocol**

**Exploring the understanding and experience of empathy in adults diagnosed with Asperger Syndrome.**

**Distress identified and/or risk disclosure made.**



**Distress:** The participant verbalises or shows signs that they are experiencing an uncomfortable level of distress. This could be demonstrated through their behaviour (e.g. crying) or from the things they say during the interview. This indicates that the content of the interview may have become too stressful for the participant.

**Disclosure:** The participant discloses information during the interview that makes the researcher



**Step One:**

- Pause interview - Interviewer offers immediate emotional support
- Assess mental state:  
(Offer a tissue/drink of water and ask if there is anyone they would like to be contacted for them)  
What are you thinking right now?  
How do you feel right now?  
Do you feel safe?  
Do you feel able to carry on with your day?  
Offer a tissue/drink of water and ask if there is anyone they would like to be contacted for them
- Ask the participant if they would like to stop the interview: **If no, then resume the interview once they feel able and agree to proceed. If yes, then proceed to step two.**
- If applicable, discuss the process for referring on disclosures to practitioners with participant – refer to PIS.
- Highlight sources of support i.e. trusted friend or family member



**Step Two:**

- Discontinue the interview
- Ask the participant if they would like to remain in the room for a while to calm down and offer support
- Ask the participant if they would like us to contact anyone for them
- Inform my supervisors; issues can be discussed and subsequently monitored and dealt with.
- Researcher to also inform and debrief with identified principle lead on the study (Dr Andrea Flood, Clinical Psychologist)
- Highlight sources of support i.e. GP, Talk Liverpool.



**Follow up:**

- If the person consents, follow up via telephone the following day.  
AND
- Encourage the participant to talk to GP or Talk Liverpool if they experience increased distress in the hours/ days after the interview.

## Appendix 6

*Advert*

V3 LEP 11.01.2019

### **Exploring the understanding and experience of empathy in adults diagnosed with Asperger Syndrome.**

Have you been diagnosed with Asperger Syndrome or Autism Spectrum Disorder without accompanying intellectual or language impairment? Are you over the age of 18? Would you be interested in taking part in a research interview about your understanding and experience of empathy?

I am a trainee clinical psychologist completing research as a part of my training with the University of Liverpool. My interest is the understanding and experience of empathy for adults with a diagnosis of Asperger Syndrome. I am also interested in whether you think there is any link between your experience of empathy and any personal distress you may have experienced.

Interviews will be approximately one hour long and will be face to face or over skype.

**If you are interested in participating in this research please contact the researcher Ellie Powney, via: [Lep79@liverpool.ac.uk](mailto:Lep79@liverpool.ac.uk)  
All participants who participate will be given a £15 Love to Shop voucher to thank them for their time and participation.**

## Appendix 7

### Consent Form

#### Participant consent form

V3 LEP 11.01.2019

#### Exploring the understanding and experience of empathy in adults diagnosed with Asperger Syndrome.

Please initial box

1. I confirm that I have read and have understood the information sheet dated [DATE] for the above study, or it has been read to me. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily.
  
2. I understand that taking part in the study involves attending an interview that will be recorded and transcribed and anonymised.
  
3. I understand that my participation is voluntary and that I am free to stop taking part and can withdraw from the study at any time without giving any reason and without my rights being affected. In addition, I understand that I am free to decline to answer any particular question or questions.
  
4. I understand that I can ask for access to the information I provide and I can request the destruction of that information if I wish at any time prior to two weeks following the interview. I understand that following the two week period post interview I will no longer be able to request access to or withdrawal of the information I provide.



5. I will allow the use of direct quotes from my interview to be used. These quotes will be anonymised (all identifiable information will be removed).

6. I understand that the information I provide will be held securely and in line with data protection requirements at the University of Liverpool until it is [fully anonymised] and then deposited in the secure server until the research is complete.

7. I understand that signed consent forms and [original audio/ questionnaires] will be retained in the University's secure server until the audio is transcribed for audio files, consent forms will be held for one year, transcriptions of the interviews will be held for ten years, all on the university secure server.

8. I understand that the information I provide will be held securely at the University of Liverpool until it is fully anonymised and then deposited in the secure server for sharing and use by other authorised researchers to support other research in the future.

9. I understand that personal information collected about me that can identify me, such as my name or where I live, will not be shared beyond the study team.

#### *Audio recordings*

10. I understand and agree that my participation will be audio recorded and I am aware of and consent to your use of these recordings for the following purposes: completion of the researchers doctoral thesis, publications, conferences and presentations.

#### *Storage of documents*

11. I understand that signed consent forms and original audio/ questionnaires will be retained in the university server until transcribed for the audio recordings, one year for the consent forms, and ten years for the transcribed anonymised data.

12. I understand that a transcript of my interview will be retained for ten years on the university secure server.

*Exclusion criteria*

13. I understand that I must not take part as my data can not be used if I do not speak fluent English, if I do not have a formal diagnosis of Asperger Syndrome or Autism Spectrum Disorder (ASD), have a diagnosis of ASD but with accompanying intellectual or language impairment, have serious mental illness such as Psychosis or Bipolar disorder then there is no need to participate any further, but my interest is appreciated.

*Affording participants the opportunity to receive a copy of the report*

14. The information you have submitted will be published as a report; please indicate whether you would like to receive a copy.

*Confidentiality of the data*

15. I understand that my responses will be kept strictly confidential. I give permission for members of the research team to have access to my fully anonymised responses. I understand that 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.

16. I understand that confidentiality and anonymity will be maintained and it will not be possible to identify me in any publications

*Disclosure of criminal activity*

17. I understand that the confidentiality of the information I provide will be safeguarded and won't be released without my consent unless required by law. I understand that if I disclose information that raises considerations over the safety of myself or the public, the researcher may be legally required to disclose my confidential information to the relevant authorities.

18. I agree to take part in the above study.

\_\_\_\_\_

\_\_\_\_\_

Participant name

Date

Signature

\_\_\_\_\_

\_\_\_\_\_

Name of person taking consent

Date

Signature

**Principal Investigator**

Dr Andrea Flood  
Doctorate in Clinical Psychology  
University of Liverpool  
School of Psychology  
Ground Floor Whelan Building  
Brownlow Hill  
L69 3GB

**Student Investigator**

Ellie Powney  
Doctorate in Clinical Psychology  
University of Liverpool  
School of Psychology  
Ground Floor Whelan Building  
Brownlow Hill  
L69 3GB

**Appendix 8**  
*Interview Schedule*

V3 LEP 11.01.2019

**Semi structured Interview Schedule**  
**Empathy and personal distress: A thematic analysis of the lived experience of adults diagnosed with Asperger Syndrome.**

Hello and thank you for participating in this research. As you are aware I am Ellie a trainee psychologist studying at Liverpool University. I am interested in your own personal experience, which may be different to other people. So when I ask you questions tell me what things have been like for you. There are no right and wrong answers or opinions. I am talking to you because I want to find out what you think and experience. I will also ask you if empathy has ever led to any distress for you and I will ask you to tell me a little about this.

As we discussed I will be recording the interview. If you would like to hear the recording we can organise a time for that to happen.

You can stop the interview at any time. I will offer you a rest break after 30 minutes, when we have finished the question we are on. It is okay to take additional breaks, you just need to let me know if you would like to stop to take a break.

Our interview will remain confidential. All identifiable information will be removed from the transcripts before they are analysed by myself and some will also be analysed by my supervisors and an expert by experience who has a diagnosis of Autism Spectrum Condition.

Do you have any questions before we begin?

I am going to start by giving you some questions to answer about yourself. I might ask you some questions about your answers. You can ask me questions if anything isn't clear.

Hand out demographic and 'Getting to know you' form.

### **Section A. What is your understanding of empathy?**

Prompts will be used to facilitate a rich description i.e. can you tell me a bit more about that?

Can you give an example of that?

Can you tell me what your understanding of empathy is?

How do you think you learn how to be empathetic?

### **Section B. How do you know when you are being empathetic?**

Prompts will be used to facilitate rich description i.e. can you tell me a bit more about that?

Can you give an example of that?

Does it change the way you feel?

Does it change the way you act?

Does it change the way you think?

Does it make a difference if you know a person well i.e. do you find it easier to be empathetic with those you know?

### **Section C. How do you know when others are being empathetic with you?**

Prompts will be used to facilitate rich description i.e. can you tell me a bit more about that?

Can you give an example of that?

Can you tell me how you know when others are being empathetic towards you?

Do you ever notice if others are not empathetic towards you?

Does it have any impact on you when others are empathetic?

### **Section D. Do you think there are differences in empathy between people diagnosed with ASC and neuro-typicals?**

Prompts will be used to facilitate a rich description i.e. can you tell me a bit more about that?

Can you give an example of that?

### **Section E. Is empathy helpful?**

Prompts will be used to facilitate rich description i.e. can you tell me a bit more about that?

Can you give an example of that?

Do you think empathy is helpful? Or, Are there any advantages to empathy?

### **Section F. Is empathy ever unhelpful, does it ever cause distress?**

Prompts will be used to facilitate rich description i.e. can you tell me a bit more about that?

Can you give an example of that?

Do you ever feel that empathy is unhelpful? Or, Are there any disadvantages to empathy?

Has empathy ever led, or contributed, to you becoming distressed or upset?

### **Section G. Do you identify with the descriptions of cognitive and affective empathy?**

A prompt card will be given which will provide a brief simple description of the definitions for cognitive and affective empathy.

Do you have any questions about these descriptions?

Do you identify with either or both of these descriptions?

**Is there anything we've not talked about today that you think it would be important for me to know?**

Time at the end of the interview will be spent checking how the participant found the process and if they would like to hear about the results of the study, how they would like to receive feedback. If any distress is reported or observed the distress policy will have been

implemented and sources of support identified. I will also remind the participant of their right to withdraw and up to what time point they are able to withdraw their data.

## Appendix 9

Code and theme development example and extract from reflective diary.

Participants data, once extracted as quotes, were colour coded so that a visual representation of participants present in the code patterns and later the data was easy to view, move and discuss. This also ensured we could review visually if themes were well supported by several participants and not one strong and attractive narrative that perhaps speaks to researcher biases. At this point in the analysis we were clustering patterns across the data and building themes to see if the descriptions were rich and independent enough to build thick stories. This example was from before the final theme map was built and I will include a prior discussion map below where there were many more subthemes. In discussing this version and building the stories and going beyond the data this version did not stand as robustly as hoped and so the development and movement between the data, codes and theme maps continued. The maps were moved as quotes, patterns and stories were discussed until we reached our final map as the narratives began to richly tell the story of the participants.

Example of extracts with codes and beginning to be clustered into patterns and labelled tentatively.

Participant number and codes generated from quote	<i>2.1 Thoughts on theme: Communication, authenticity, cognitive latency</i>
Participant 1 – missing cues that are subtle Doubting own empathy Need to know them for empathy	<b>I</b> I wouldn't be able to empathise with somebody erm, but you see, I was about to say I don't think I can empathise with somebody that I've met for the first time but then again, because I would need to know quite a bit about their life or their character, I'd also say it's to do with, erm, do you get on with that person
Participant 4  Missing cues – facial expression I won't see	<b>4 Cause we don't pick up on the facial cues and the little subtle expressions so er . .</b>  Erm, do you think, why is that important for empathy do you think?  <b><u>Sorry why is what important?</u></b>  The little facial expressions and cues  <b><u>Well cause I suppose people don't always say, if someone says, 'oh I'm feeling upset', then you know they are feeling upset, but if they don't say I'm feeling upset a NT person might pick up how they are looking but I might not necessarily.</u></b>
	<i>Thoughts on theme: Double Empathy/In-Group Out Group culture</i>
Participant 5 – Double empathy Autistic to Autistic intuitive          In-Group/Out-Group	Yes it does feel like sometimes, when I've been meeting autistic people in the last couple of years, we do kind of, a lot of the time not all the time, just intuitively get along and we can kind of tell things that are stressing each other out or we communicate in a similar way.  And then sometimes I feel people who are really obviously not autistic I feel quite alien from them and they seem to get me less. So I feel like I see that double empathy problem thing in action [Yeah] in day to day...  I feel like quite a lot of intuitive connection with and some of the better friendships I've had in my life since becoming labelled as autistic and meeting people similarly. //  Yeah definitely. I was thinking, I took my mum shopping, I take her to Sainsbury's and there's always, at least in our town, there's always a lot of elderly shoppers and I was just thinking about age gaps and how we don't kind of really think old people or young people lack empathy even if



<p><i>Out group – communication – familiarity</i> <i>Cultural touchstones</i> <i>Milton</i></p> <p><i>Difference or deficit?</i></p> <p><i>Late diagnosed and so identifying in ways with NT and ASC and feeling liminal</i></p>	<p>they don't really relate to each other and maybe sometimes have hostile views towards each other as a group [<b>That's so true</b>] Its just because I don't know, people grew up in different eras, different experiences, different values, different cultural touchstones. Manners have changed. Things are polite now, well things are acceptable now that wouldn't have been in the past and things are old fashioned now that would have been normal. Or maybe I don't know if it was Damien Milton or someone else that was talking about...sorry my minds wandering let me just try to bring it back. About kind of being in a different country and the culture being different. We wouldn't think of that person as having a deficit, we'd think of them as foreign.</p> <p>when I'm around more visibly autistic people, I feel significantly neurotypical, but when I'm on the other side, I kind of feel the other way. Less so with the race thing. But when I'm around people who aren't autistic, then I feel super autistic. [<b>yeah</b>] And that kind of empathy thing is weird because I kind of have empathy to a certain degree for both sides, but it leads to a level of alienation as well. I suppose that's my final thought anyway, does that makes any sense?</p>
--	---

Below is an example of theme development between two mid-point meetings in the process - themes were being labelled as opposed to named at this stage to see if they built a robust description of the overall data. The final map is figure 1 in the paper.

Last viewed version	Latest Version
<p>AREA 1 My understanding</p> <p><i>1 What is empathy?</i></p> <p><i>1.1 Understanding others perspective/feelings/in their shoes – our own response – emotional/thoughts/behavioural</i></p> <p><i>1.2 Does this apply to me? AM I EMPATHETIC</i></p> <p><i>1.3 How do I know this? Research, others told me, my experience</i></p>	<p>AREA 1 My understanding</p> <p><i><u>1.1 What is empathy?</u></i></p> <p><i><u>1.2 My empathetic identity – am I? How do I know?</u></i> <i>How is it developed? Exposure; family friends</i></p>
<p>AREA 2 What effects my empathetic experience?</p> <p><i>2.1 Communication, authenticity, cognitive latency</i></p> <p><i>2.2 Double Empathy and the in-group out-group effect</i></p> <p><i>2.3 Processing capacity; sensory and emotional</i></p> <p><i>2.4 Shared experiences “touch point”</i></p> <p><i>2.5 Exposure; family friends (modelling and knowing well), writing, acting, interviewing</i></p>	<p>AREA 2 What effects my empathetic experience?</p> <p><i>2.1 Communication, authenticity, Autistic Processing speeds</i></p> <p><i><u>2.2 Double Empathy</u></i></p> <p><i>2.3 Multiplicity? writing, acting, interviewing shared identity: Shared experiences “touch point”</i></p> <p><i>2.3 Processing capacity; sensory and emotional</i></p>
<p>AREA 3 The impact of Empathy</p> <p><i>3.1 Connectivity; builds relationships, communities, connections</i></p> <p><i>3.2 Promotes values congruent behaviour (over dispositional nature?)</i></p> <p><i>3.1 Connectivity and values congruent living</i></p> <p><i>3.3 Comfort, support, shared happiness</i></p> <p><i>3.4 Distress, anxiety, overwhelmed</i></p> <p><i>3.5 Stigma, devalue, identity (Internal and external)</i></p>	<p>AREA 3 The impact of Empathy</p> <p><i><u>3.1 Connectivity; valued living and belonging</u></i></p> <p><i><u>3.2 Distress, anxiety, overwhelmed</u></i></p> <p><i><u>3.3 Stigma, devalue, identity (Internal and external)</u></i></p>

--	--

**Conversations from the reflective diary – typed up as the diary is hand-written and usually in rough bullet pointed form.**

Today MC and I (EP) discussed the language in the paper generally and the results section. Melissa has emailed her maps across and I shared mine and we looked at similarities and differences in the maps and language used and what had struck us from the data.

Language is a constant worry and as a team we (all authors) spend quite a lot of time thinking about what language to use and the impact that language could have on the participants and the readers. Melissa shared a reference for an article that explored autistic peoples and non-autistic people’s preferences regarding their thoughts on descriptive language. We will follow this for our paper, it has been widely cited in other papers since it was published.

Where there were difficult experiences to describe we stuck more closely to the actual words of the participants to ensure that views were fairly represented. This came up with the descriptions of an association of coldness and a ‘lack of empathy’ and autism which contradicted the participants stronger narrative of autistic people being empathetic. It gave rise to the biases of the researchers and this was managed through careful discussion, and keeping thoughts and feelings in a diary so as not to project them onto the data without thought. This was felt to be important to include but was managed carefully in order to preserve the voice of the participants

From earlier discussions about biases and attention in both interviewing and coding: Three of the research team hold opinions that autistic people have empathy based on their experience of knowing and working with autistic people and from lived experience. This mismatch from the literature is what sparked interest and collaboration with the topic in the first place. One of the team does not have experience and their voice will need to be listened to carefully as we are all aware that there is some level of expectation that many of the participants will identify as empathetic. The second interview was interesting in that the person did not feel they were very empathetic, and that they could only empathise with one person, their son. and yet had plentiful examples of empathy in their interview. We discussed the importance of representing both the persons narrative about themselves but also our interpretation of their other descriptions that suggest a more flexible hypothesis of the empathetic experience. Not seizing upon that which supports our own expectations and experience.

## Appendix 10

### *Autism Journal guidelines*

#### 4.1 Formatting

Autism asks that authors use the [APA style](#) for formatting. The [APA Guide for New Authors](#) can be found on the APA website, as can more general [advice for authors](#).

#### 4.2 Artwork, figures and other graphics

For guidance on the preparation of illustrations, pictures and graphs in electronic format, please visit SAGE's [Manuscript Submission Guidelines](#).

#### 4.3 Supplementary material

This journal is able to host additional materials online (e.g. datasets, podcasts, videos, images etc) alongside the full-text of the article. For more information please refer to our [guidelines on submitting supplementary files](#).

#### 4.4 Terminology

Autism has researched and compiled their own [Terminology Guidelines](#) which all authors should follow.

#### 4.5 Reference style

Autism adheres to the APA reference style. View the [APA](#) guidelines to ensure your manuscript conforms to this reference style.

#### SAGE: Preparing your manuscript

Where a journal uses double-blind peer review, authors are required to submit a fully anonymised manuscript with a separate title page. See <https://sagepub.com/Manuscript-preparation-for-double-blind-journal>

#### Formatting your article

When formatting your references, please ensure you check the reference style followed by your chosen journal. Here are quick links to the [SAGE Harvard](#) reference style, the [SAGE Vancouver](#) reference style and the [APA](#) reference style.

Other styles available for certain journals are: [ACS Style Guide](#), [AMA Manual of Style](#), [ASA Style Guide](#), [Chicago Manual of Style](#) and [CSE Manual for Authors, Editors, and Societies](#).

Please refer to [your journal's manuscript submission guidelines](#) to confirm which reference style it conforms to and for other specific requirements.

Equations should to be submitted using Office Math ML and Math type.

#### Microsoft Word guidelines

There is no need to follow a specific template when submitting your manuscript in Word. However, please ensure your heading levels are clear, and the sections clearly defined.

#### Artwork guidelines

Illustrations, pictures and graphs, should be supplied in the highest quality and in an electronic format that helps us to publish your article in the best way possible. Please follow the guidelines below to enable us to prepare your artwork for the printed issue as well as the online version.

- Format: TIFF, JPEG: Common format for pictures (containing no text or graphs). EPS: Preferred format for graphs and line art (retains quality when enlarging/zooming in).
- Placement: Figures/charts and tables created in MS Word should be included in the main text rather than at the end of the document. Figures and other files created outside Word (i.e. Excel, PowerPoint, JPG, TIFF and EPS) should be submitted separately. Please add a placeholder note in the running text (i.e. “[insert Figure 1.]”)
- Resolution: Rasterized based files (i.e. with .tiff or .jpeg extension) require a resolution of at least 300 dpi (dots per inch). Line art should be supplied with a minimum resolution of 800 dpi.
- Colour: Please note that images supplied in colour will be published in colour online and black and white in print (unless otherwise arranged). Therefore, it is important that you supply images that are comprehensible in black and white as well (i.e. by using colour with a distinctive pattern or dotted lines). The captions should reflect this by not using words indicating colour.
- Dimension: Check that the artworks supplied match or exceed the dimensions of the journal. Images cannot be scaled up after origination
- Fonts: The lettering used in the artwork should not vary too much in size and type (usually sans serif font as a default).