



School of Psychology

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**A Meta-ethnography of Autistic People’s Experiences of Social  
Camouflaging and a Delphi Study about Improving Eating  
Disorder Treatment for Autistic Women with Anorexia  
Nervosa**

Thesis submitted in partial fulfilment of the requirement for the degree of:

**Doctorate of Clinical Psychology (DClinPsy)**

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## **Preface**

This thesis presents two papers on topics which are relevant to the mental health of autistic adults. Autism is difference in the development of the brain. Autistic people may have differences in how they communicate and interact, may do the same things repeatedly, and have a preference for particular routines or interests. Research suggests autistic people might be more likely to have some mental health problems, and research into the mental health of autistic people is a priority for autistic people and their supporters. Paper one discusses social camouflaging, a concept which has been associated with mental health difficulties in autistic people. Paper two investigates treatment for autistic women with anorexia nervosa, an eating disorder which research suggests is more common in autistic people.

Paper one reviews the literature on social camouflaging. Social camouflaging is a process where autistic people might try and hide their autistic behaviour and appear more socially capable. Previous research has linked social camouflaging with mental health difficulties such as anxiety and depression in autistic adults. The relationship between social camouflaging and mental health difficulties is not fully understood. Meta-ethnography allows the findings of several papers discussing people's experiences to be considered together and used to develop new theories and ideas. Paper one systematically identified research about autistic people's experiences of camouflaging and synthesised them using an approach called meta-ethnography. The purpose of conducting a meta-ethnography about autistic people's experiences of social camouflaging was to identify what might cause the relationship between social camouflaging and poor mental health. Paper one identified, evaluated, and synthesised a total of 13 studies. The results of the meta-ethnography describe how autistic people may use social camouflaging as a way of coping with stress from social situations and the wider society around them which can be unaccepting of autistic behaviour. The social context itself can lead to stress and poor mental health for

autistic people. The meta-ethnography describes how many autistic people find their camouflaging strategies have negative unintended consequences which paradoxically makes the context around them more stressful. Some autistic people find they do not have negative unintended consequences from camouflaging, or that the negative consequences are not as severe as tolerating the context without camouflaging. The results of paper one describe a theory for understanding the relationship between social camouflaging and poor mental health. Paper one has implications for how clinicians support autistic people with mental health difficulties. It is important that clinicians consider the relative costs and benefits of camouflaging for autistic people. Clinicians can work sensitively with autistic people to formulate the ways that their camouflaging strategies might increase the stress they are experiencing, and enable autistic people to make informed decisions about when, where, and how they camouflage.

Paper two investigates how to improve treatment for autistic women with anorexia nervosa (AN). Research suggests that AN is more common in autistic women, and autistic women have worse outcomes from eating disorder treatment compared to non-autistic women. Despite this, there is little research into how to improve eating disorder treatment for autistic women with AN. When guidelines have been developed, this has been in the context of a service improvement project within a single service, with little detail about how recommendations were developed. There is a need for systematic research into how to improve AN treatment for autistic women. Paper two describes a Delphi study investigating how best to support autistic women with AN. Delphi studies allow the calculation of how much a group of experts agree on a topic without requiring them to meet and make a decision. A group of 49 researchers, clinicians, and people with lived experience of autism and eating disorders were asked what they thought would help autistic women with AN. Their responses were used to generate 56 suggestions that the experts agreed on. The results give a wide range of suggestions about how to support autistic women with AN. Many of the recommendations highlight the importance for staff and services to be able to tell the

difference between autism- and AN-related behaviours so they can avoid setting treatment targets which try and change autistic behaviour. Treatment for autistic women with AN may need to target a broader and different range of areas compared to non-autistic women with AN. In addition, the results suggest it is important for eating disorder treatment to accommodate autistic traits such as differences in communication and sensory sensitivities. Finally, the suggestions highlight the importance of involving autistic people in the development of services and contributing to their own care. The recommendations from the Delphi study could be used to develop a training package for staff.



Paper 1

# **A Meta-ethnography of Autistic People's Experiences of Social Camouflaging and its Relationship with Mental Health**

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## **Abstract**

Some autistic people report using strategies to hide autistic behaviour and appear more socially competent. Previous research has termed this 'social camouflaging' and linked it with mental health difficulties. This review aimed to systematically identify, appraise, and synthesise qualitative research about autistic people's experiences of social camouflaging. The purpose of this was to understand how autistic people experience camouflaging throughout the lifespan and identify potential mechanisms for the relationship between camouflaging and mental health. A total of 13 studies were identified, critically appraised, and synthesised using meta-ethnography. Four third-order concepts were developed, describing how autistic people camouflage to attempt to cope with the stressful social context. Depending on the context and camouflaging strategies used, many autistic people experience unintended negative consequences which increase the stress from the social context. This pattern should be investigated in future research and has potential implications for how clinicians support autistic people with mental health difficulties. Future research should explore camouflaging in autistic people with other stigmatised characteristics.

## **Lay Abstract**

Some autistic people describe trying to hide autistic behaviour and seem more socially capable. Researchers have called this 'social camouflaging' and have linked it with mental health difficulties. This review used a step-by-step approach to identify research where autistic people talk about their experiences of social camouflaging. The review aimed to gain a better understanding of how autistic people experience camouflaging over their lives, and identify what might cause the relationship between camouflaging and poor mental health. A total of 13 studies were identified, evaluated, and combined using a method called meta-ethnography. The results describe how autistic people camouflage to try and cope with stress from social situations and the society around them. Many autistic people find their camouflaging strategies have negative consequences which accidentally make the situation around them more stressful. This should be investigated further and may have implications

for how clinicians support autistic people with mental health difficulties. In the future, researchers should investigate how camouflaging might be different for autistic people who experience stigma for other reasons like ethnicity, sexuality, and disability.

## Introduction

Autism is a neurodevelopmental condition characterised by differences in social communication and restricted or repetitive interests and behaviour (American Psychiatric Association [APA], 2013). Autism is consistently diagnosed in a greater number of males than females, although estimates of male-to-female ratios vary (Fombonne, Du Mazaubrun, Cans, & Grandjean, 1997; Icasiano, Hewson, Machet, Cooper, & Marshall, 2004). Recent estimates suggest a gender ratio of 3:1, with 3 males diagnosed with autism for every 1 female diagnosed (Loomes, Hull, & Mandy, 2017). A variety of explanations have been proposed for the overrepresentation of autism in males. Potential contributors include phenotypic differences in how males and females present (Rubenstein, Wiggins, & Lee, 2015), and diagnostic instruments which are based on research which predominantly studies males (Kreiser & White, 2014).

Bargiela, Steward, and Mandy (2016) interviewed women about their experience of autism diagnosis and how they felt their gender impacted on this. Many women spoke of 'pretending to be normal' or 'wearing a mask' to fit in in social situations. Subsequent research has investigated this experience further, referring to it as 'masking' (A. Cook, Ogden, & Winstone, 2018) 'compensatory strategies' (Livingston, Shah, & Happe, 2019) or 'social camouflaging' (Hull et al., 2017). There is no agreed upon definition of this concept, with some researchers suggesting there are distinct differences between masking and compensation (Livingston et al., 2019). The current paper refers to social camouflaging or camouflaging as a set of strategies used in social situations to hide behaviours associated with autism and appear more socially competent or neurotypical (Hull, Mandy, et al., 2019; Hull et al., 2017; Livingston et al., 2019). Camouflaging strategies vary, with examples strategies including forcing eye contact, suppressing 'autistic' body movements and using conversational 'scripts' involving asking questions about others (J. Cook, Crane, Hull, Bourne, & Mandy, 2020; Hull et al., 2017; Livingston et al., 2019). Social camouflaging has

been suggested as a factor affecting the difference in diagnosis of autism between men and women (Lockwood Estrin, Milner, Spain, Happé, & Colvert, 2021).

Research into social camouflaging has sought to understand how it might differ between and impact individuals. Hull, Mandy, et al. (2019) developed the Camouflaging Autistic Traits Questionnaire (CAT-Q) to quantitatively measure self-reported camouflaging behaviours. The CAT-Q has been used to research the relationship between camouflaging and a variety of factors, including gender (Hull, Lai, et al., 2019) and personality traits (Robinson, Hull, & Petrides, 2020).

The CAT-Q has been used to investigate the hypothesised relationship between social camouflaging and poor mental health. Hull, Levy, et al. (2021) investigated the relationship between self-reported camouflaging and depression and anxiety in autistic adults. They found higher levels of camouflaging were associated with generalised anxiety, social anxiety, and depression, even when level of autistic traits was controlled for. Further research has found an association between social camouflaging and psychological distress (Beck, Lundwall, Gabrielsen, Cox, & South, 2020), depression, anxiety, and stress in adolescents (Bernardin, Lewis, Bell, & Kanne, 2021) and suicidal thoughts and behaviours (Cassidy et al., 2020). However, as this research is correlational it is not possible to determine the direction of the relationship between camouflaging and mental health.

Qualitative research has the potential to provide further insights into the relationship between social camouflaging and mental health. Many quantitative studies using the CAT-Q refer to qualitative literature when interpreting their findings (Beck et al., 2020; Hull, Lai, et al., 2019; Hull, Levy, et al., 2021; Hull, Petrides, & Mandy, 2021). However, theories about social camouflaging developed from qualitative studies vary, and it is unclear how quantitative studies select which theories to empirically validate. The CAT-Q was developed based on Hull et al.'s (2017) qualitative study of the experience of social camouflaging. Hull et al. (2017) developed a theoretical understanding of social camouflaging based on their definition of it and the experiences of formally diagnosed autistic adults. As a result, it is

likely that quantitative studies using the CAT-Q are most suited to investigate social camouflaging as defined by Hull et al. (2017). It is possible that qualitative studies which define camouflaging differently and investigate it in different demographics provide alternative theories which have not been explored in quantitative research so far. By synthesising multiple qualitative accounts of social camouflaging it may be possible to reach a richer theoretical understanding of the experience, particularly with regards to its relationship with mental health.

The present review aimed to explore autistic people's experiences of social camouflaging over time and across different contexts. The review aimed to systematically identify and synthesise qualitative research about autistic people's experiences of social camouflaging. A meta-ethnography was planned to investigate this topic, as meta-ethnographies take an interpretive rather than a merely aggregative approach (Noblit & Hare, 1988; Walsh & Downe, 2005). Meta-ethnography is one of the most commonly used methods of qualitative synthesis, with improvements in the transparency of the search criteria and critical appraisal of studies in meta-ethnographies over time (Dixon-Woods, Booth, & Sutton, 2007; Hannes & Macaitis, 2012). Meta-ethnography allows the generation of new models and theories (France et al., 2019; Sattar, Lawton, Panagioti, & Johnson, 2021) and is therefore suited to further explore the relationship between social camouflaging and mental health. The present meta-ethnography aimed to explore the following research questions:

1. How do autistic people experience social camouflaging across the lifespan?
  - a. How do autistic people camouflage themselves in social situations?
  - b. Are there differences in the lived experience of social camouflaging according to the type of strategy used?
  - c. Do autistic people's descriptions of their experiences suggest potential mechanisms for a relationship between social camouflaging and mental health?

## Methods

### ***Systematic literature search***

A systematic search was conducted in October 2021 using the databases PsycINFO, Scopus, Web of Science, ASSIA, and OpenGrey. The search terms used in PsycINFO are presented in Table 1. Equivalent search terms were used in the other databases. The reference lists of relevant studies were searched manually for additional papers.

**Table 1.**

*Search terms used in PsycINFO*

<b>Key concept relating to the review topic</b>	<b>Search terms used</b>
Autism	exp Autism Spectrum Disorders OR autis* OR asperger* OR "social communic*"
Social camouflaging	camo* OR mask* OR social strateg* OR social compensat* OR imitat* OR exp Impression Management OR identity manag*

### ***Study selection***

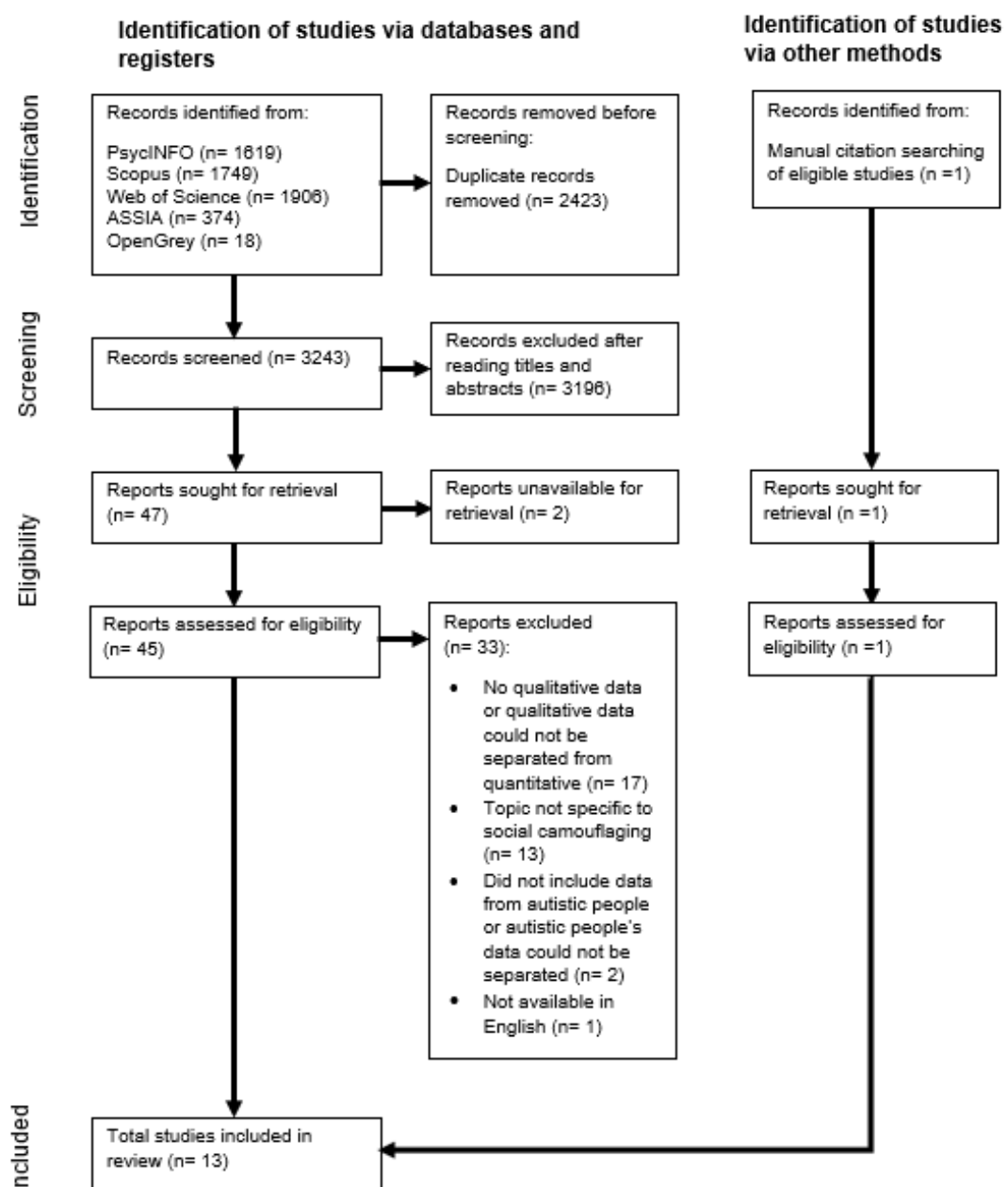
To be selected, retrieved studies were required to meet the following inclusion criteria: qualitative research on the topic of autistic people's experiences of social camouflaging; or qualitative research on the topic of autistic people attempting to change their behaviour in social situations. The following exclusion criteria were applied: where studies were mixed methods, if it was not possible to separate the qualitative and quantitative data; where studies included the experiences of family members or professionals, if it was not possible to separate them from the perspectives of autistic people; studies in languages other than English. There was no restriction on date published.

Figure 1 shows a PRISMA diagram (Page et al., 2021) illustrating the study selection process. The researcher (SF) screened the titles and abstracts of all retrieved studies to

remove duplicates and identify potentially relevant research. Once potentially relevant studies were identified SF retrieved them in full and applied the inclusion and exclusion criteria. A second trainee clinical psychologist independently screened 50% of the potentially relevant papers. Cohen's kappa was calculated as 0.77, representing a 'Moderate' level of agreement (McHugh, 2012). Any disagreements were resolved via discussion, with both reviewers needing to agree that the study met the criteria for it to be included.

**Figure 1**

*PRISMA diagram detailing search process and selection of studies*





### ***Data extraction***

Included studies were read in full with the following data extracted: authors, year, study aim, study setting, method of data collection, method of data analysis, sample characteristics and recruitment strategy (see Table 2).

### ***Critical appraisal***

The quality of the included studies was appraised using the Critical Appraisal Skills Programme (CASP, 2018). The CASP was selected as it is one of the most widely used tools for the evaluation of qualitative research (Dalton, Booth, Noyes, & Sowden, 2017; Hannes & Macaitis, 2012) and is recommended by the Cochrane Qualitative and Implementation Methods Group (Noyes et al., 2019). The CASP does not recommend a scoring system, but the present study followed previous meta-ethnographies in assigning studies a point for each criterion with a half point for criteria that was partially fulfilled or unclear (Graham, Tierney, Chisholm, & Fox, 2020). The CASP has a total of 9 scored criterion, meaning each study could score a maximum of 9. The checklist was completed to aid interpretation as part of the synthesis process and quality appraisal was not used to exclude studies. SF completed the CASP for all included studies and a second trainee clinical psychologist undertook an additional, independent quality appraisal of 50% of the studies using the CASP. Where SF and the second reviewer disagreed on a quality rating this was discussed in detail. The purpose of this was to identify additional information about the quality of the studies which could have been overlooked by a single reviewer.

### ***Data synthesis***

A meta-ethnography was conducted in line with the guidance developed by Noblit and Hare (1988). Meta-ethnography was selected as a synthesis approach because it can be used to develop new interpretations across studies, while preserving the relationship between concepts as described in the original studies (Britten, Campbell, & Pope, 2002; France et al., 2019). This was congruent with the aims of the systematic review to explore

autistic people's experiences of social camouflaging and identify potential mechanisms for the relationship between camouflaging and mental health. The systematic review followed Noblit and Hare's (1988) seven steps for conducting a meta-ethnography:

1. Getting started - identifying a research interest in social camouflaging and its relationship to mental health
2. Deciding what is relevant to the initial interest - defining the inclusion and exclusion criteria and carrying out systematic searches
3. Reading the studies - repeated reading of the selected studies, noting any interpretative metaphors
4. Determining how the studies are related - determining the relationships between the selected studies by creating a list of key metaphors, ideas or concepts in each study and comparing them. Studies are deemed directly comparable and therefore capable of being reciprocally translated into each other, or representative of a line of argument that can put any similarities and differences into a new interpretive context
5. Translating the studies into one another - Reciprocal translation to identify third-order concepts which are interpretations of the original authors' interpretations.  
Refutational translation to identify differences in the theories or ideologies of conflicting concepts
6. Synthesising translations - Comparing the translations from the previous phase to identify any common or overarching concepts and develop new interpretations from these
7. Expressing the synthesis via a written narrative and diagram

The review was conducted from an inductive critical realist position which presumes that knowledge is only capable of capturing a small part of reality. Knowledge is filtered through the lens of human experience and may be more or less close to reality itself (Fletcher, 2017). As a result, it is important to consider the background of the reviewers. The

synthesis was primarily conducted by a non-autistic trainee clinical psychologist (SF). SF is the sibling of an autistic person and has worked with autistic children and adults in a variety of contexts. The meta-ethnography was discussed by the research team at regular intervals to discuss the clarity of the results and ensure they addressed the research questions. A service user consultant with autism was employed to review the results to ensure they were coherent and reflected the perspectives of participants in the original studies. Previous qualitative research has also recruited autistic advisors to ensure themes accurately reflect the autistic voice (Babb et al., 2021).

## **Results**

### ***Characteristics of the included studies***

Following the study selection process, 13 studies were identified and included in the review. Details of the characteristics of each study are shown in Table 2. Each study is assigned a number which will be used to refer to it throughout the review. Across the 13 studies, data was collected from 1009 autistic people. Notably, two studies (4, 5) utilised data from the same sample of participants but applied different qualitative analysis methods. Where information about the gender of participants was given, 59.3% of participants identified as female, 35.9% identified as male, and 4.9% identified as 'other' or non-binary. Ages of participants ranged from 12 to 79, although as some studies only reported mean ages it is possible some participants were aged outside of this range. Four studies specifically studied camouflaging in adolescents and nine studied camouflaging in adults. Many studies did not report on the ethnicity of their participants and the terminology used to describe ethnicity varied widely between different studies. In all the studies where ethnicity was reported, the majority of participants were from a white background. Where information was given about whether autism diagnoses were formally given or self-identified, 88.3% had formal diagnoses of autism and 11.7% self-identified as being autistic.

**Table 2.**

*Characteristics of included studies. Quality appraisal score is as rated from the CASP and is out of a maximum of 9.*

<b>Study No.</b>	<b>Author(s) (year)</b>	<b>Aim</b>	<b>Setting</b>	<b>Data Collection Method</b>	<b>Data Analysis Method</b>	<b>Sample Characteristics</b>	<b>Recruitment Strategy</b>	<b>Quality Appraisal Score</b>
1.	Bernardin, Mason, Lewis, and Kanne (2021)	To explore adolescent experiences of camouflaging and how they differ by sex and diagnosis	Qualitative, online questionnaire and follow-up interviews for subset of sample, USA	Open-ended questions on online questionnaire and semi-structured interview for subset of participants	Inductive thematic analysis (Moustakas method)	Online questionnaire: 76 self-reported autistic adolescents aged 13-18 (23 female, 53 male, M age=15.07, SD=1.64)  Interviews: 10 self-reported autistic adolescents (5 female, 5 male, M age=15.7, SD=1.64)  No data on ethnicity	Database of autistic participants, email and social media adverts  Interviewed participants opted into further contact and were contacted in the order they participated up to a maximum of 5 for gender and diagnosis	6
2.	Bradley, Shaw, Baron-Cohen, and Cassidy (2021)	To explore autistic adults' experiences of camouflaging and its impact on mental health	Mixed methods, online questionnaire, UK-based	Open-ended questions within a wider online survey about mental health and autism	Inductive semantic-level thematic analysis (Braun and Clarke method)	277 autistic adults (206 diagnosed (128 female (M age=36.42, SD=10.57), 78 male (M age=42, SD=11.65)), 71 self-identifying (56 female (M age=39.34, SD=8.64), 15 male (M age=36.57, SD=9.83)) who reported camouflaging and completed open-ended questions  No data on ethnicity	UK database of autistic participants, social media adverts	8

Study No.	Author(s) (year)	Aim	Setting	Data Collection Method	Data Analysis Method	Sample Characteristics	Recruitment Strategy	Quality Appraisal Score
3.	Cage and Troxell-Whitman (2019)	To examine reasons, contexts, and consequences of camouflaging in relation to mental health	Mixed methods, online questionnaire, country not reported	One open-ended question within wider questionnaire of closed questions	Content analysis	262 autistic adults, M age=33.62, SD=11.52, 135 female 111 male 12 other, self-reported diagnoses verified using RAADS-14  85.8% 'White', 8.4% 'Mixed/Multi-ethnic', 2.7% 'Asian', 1.9% 'other', 1.1% 'prefer not to say'	Social media advert and recruitment via autism charities and organisations	5
4.	J. Cook, Crane, Bourne, Hull, and Mandy (2021)	To explore processes behind and experiences of camouflaging in autistic people during an everyday social situation	Qualitative, Interpersonal recall study, UK	Participants watched a video of themselves during recorded interaction with experimenter. Asked to stop video when they used or thought about camouflaging strategies and asked open questions	Thematic analysis, critical realist framework, (Braun and Clarke method)	17 autistic adults, (M age=44.53, SD=12.03) (8 female, 6 male, 3 other) all formally diagnosed  12 participants 'White British', 3 'White Other', 1 'Mixed Other' and 1 'Hispanic'	Social media advert and London-based autism support groups	9

<b>Study No.</b>	<b>Author(s) (year)</b>	<b>Aim</b>	<b>Setting</b>	<b>Data Collection Method</b>	<b>Data Analysis Method</b>	<b>Sample Characteristics</b>	<b>Recruitment Strategy</b>	<b>Quality Appraisal Score</b>
5.	J. Cook, Crane, Hull, Bourne, and Mandy (2020)	To identify and describe camouflaging behaviours used by autistic adults during everyday social interaction	As above	As above	Qualitative content analysis at surface level, (Graneheim and Landman method)	As above	As above	6
6.	Halsall, Clarke, and Crane (2021)	To examine whether autistic girls educated in resource bases used camouflaging strategies, and investigate the motivations and consequences of these	Qualitative, interviews with triads of girls, parents and educators with girls attending a resource base attached to one of three schools in South West England, UK	Separate face-to-face semi-structured interviews with girls, educators and a parent, prompted with a visual scaling activity based on the CAT-Q	Inductive thematic analysis, social constructionist perspective, (Braun and Clarke method)	8 autistic adolescent females, M age=13 years 7 months, SD=11.17 months, all formally diagnosed  7 participants 'White British', 1 'White European'	Purposive sampling of girls attending 3 schools	8

Study No.	Author(s) (year)	Aim	Setting	Data Collection Method	Data Analysis Method	Sample Characteristics	Recruitment Strategy	Quality Appraisal Score
7.	Hull et al. (2017)	To examine the motivations, techniques, and impact of camouflaging on autistic adults	Mixed methods, online questionnaire, international sample but UK-based	Open questions within online questionnaire	Inductive thematic analysis (Braun and Clarke method)	92 autistic adults, 55 females (M age=40.71, SD=14.14), 30 males (M age=48.03, SD=16.62), 7 other (M age=40.71, SD=14.29), formally diagnosed  No data on ethnicity but data on nationality - 51 participants 'British', 16 'North American', 15 'Western European' and 10 'Other'	UK database of autistic participants and social media adverts	7
8.	Jedrzejewska and Dewey (2021)	To examine online and offline camouflaging experiences of autistic adolescents	Mixed methods, semi-structured interview following a quantitative questionnaire, UK	Face-to-face semi-structured interviews	Thematic analysis (Braun and Clarke method)	6 autistic adolescents, 3 females 3 males, M age=13.75, SD=1.06, all with formal diagnoses  5 participants 'White British', 1 'Black British'	Set of schools, colleges, and charity in London, entire classes of autistic and non-autistic children completed questionnaire and autistic children who scored highest on CAT-Q invited for interviews until data saturation reached	8

Study No.	Author(s) (year)	Aim	Setting	Data Collection Method	Data Analysis Method	Sample Characteristics	Recruitment Strategy	Quality Appraisal Score
9.	Livingston et al. (2019)	To investigate social compensatory strategies in adults with and without diagnosis of autism	Mixed methods, online questionnaire, international sample but UK-based	Open questions within questionnaire with open and closed questions	Inductive thematic analysis at the semantic level (Braun and Clarke method)	58 formally diagnosed with autism (37 female, 13 male, 8 other, M age=35.8, SD=11.5), 19 self-identified as autistic (9 female, 8 male, 2 other, M age=40.2, SD=11.1)  No data on ethnicity but data on 'residence' – 53 'UK', 11 'USA or Canada', 6 'Europe', 6 'Australasia', 1 'Africa'	Social media advert and recruitment via UK autism charity	7.5
10.	Miller, Rees, and Pearson (2021)	To explore the experiences of masking in autistic and non-autistic adults	Qualitative, online questionnaire, country not reported	One open question within wider questionnaire	Inductive thematic analysis, critical realist approach (Braun and Clarke method)	144 self-reported autistic adults (101 female, 28 male, 15 nonbinary, M age=36.3, SD=10.9)  No data on ethnicity	Social media advert	8
11.	Ryan and Räisänen (2008)	To use a sociological approach to explore how people with Asperger's syndrome negotiate social life	Qualitative, semi-structured interviews, UK	Semi-structured face-to-face interviews except for one participant interviewed via email	Thematic analysis, constant comparative method, 'dialogue' between data and theories of interactionism and ethnomethodology	16 people with diagnoses of Asperger's syndrome, 4 of which were interviewed with their partners, no data on age or diagnostic source  No data on ethnicity	Support groups, online communities, charity advertising, and snowball sampling	6



<b>Study No.</b>	<b>Author(s) (year)</b>	<b>Aim</b>	<b>Setting</b>	<b>Data Collection Method</b>	<b>Data Analysis Method</b>	<b>Sample Characteristics</b>	<b>Recruitment Strategy</b>	<b>Quality Appraisal Score</b>
12.	Schneid and Raz (2020)	To explore the experience of the conflict of social interaction and impression management for autistic people	Qualitative, semi-structured interviews, Israel	Semi-structured interviews via telephone, email, or in person, co-created with academic and community partners	Constant comparative method (Denzin and Lincoln method)	24 people with Autism/Aspergers/PDDNOS (22 formally diagnosed and 2 self-diagnosed) aged over 16 (M age=31), 10 male, 13 female, 1 other  No data on ethnicity	Personal acquaintance, social networks, and snowball sampling	7
13.	Tierney, Burns, and Kilbey (2016)	To explore whether autistic adolescent females use social management strategies	Qualitative, semi-structured interviews, UK	Face-to-face semi-structured interviews, based on existing literature and piloted with autistic adolescents	Interpretive phenomenological analysis	10 autistic adolescent females (M age=14.4, SD=1.02) with formal diagnoses  No data on ethnicity	Referred by professionals at two CAMHS or via self-referral on two autism charity websites	8

*Note.* USA = United States of America; UK = United Kingdom; RAADS-14 = Ritvo Autism and Asperger Diagnostic Scale; CAT-Q = Camouflaging Autistic Traits Questionnaire; PDDNOS = Pervasive Developmental Disorder Not Otherwise Specified; CAMHS = Child and Adolescent Mental Health Services.

### ***Quality appraisal***

The included studies were assessed using the CASP checklist (CASP, 2018). Scores on the CASP are shown in Table 2, with studies receiving a maximum score of 9. Studies varied in quality. All but one (11) of the included studies gave a clear statement of their aims, and all the studies were appropriate in selecting a qualitative methodology. The majority of studies gave a clear statement of their findings with consideration of their credibility (1, 2, 3, 4, 5, 6, 7, 8, 9, 10). The most common weakness in the reviewed studies was a lack of explicit consideration of the researcher's role and potential bias, with 7 of the 13 studies not sufficiently considering author positionality (1, 3, 5, 7, 8, 9, 11). Some studies did not discuss their justification for aspects of their research design in detail (1, 3, 7, 10). Some mixed methods studies did not justify their approach over a purely quantitative or qualitative design, and others did not provide a rationale for using questionnaires over conducting interviews.

Scores on the CASP were not used to exclude studies but were used to aid understanding and interpretation. Where studies had methodological weaknesses this was considered during synthesis, particularly when considering the strength of researcher's second-order concepts.

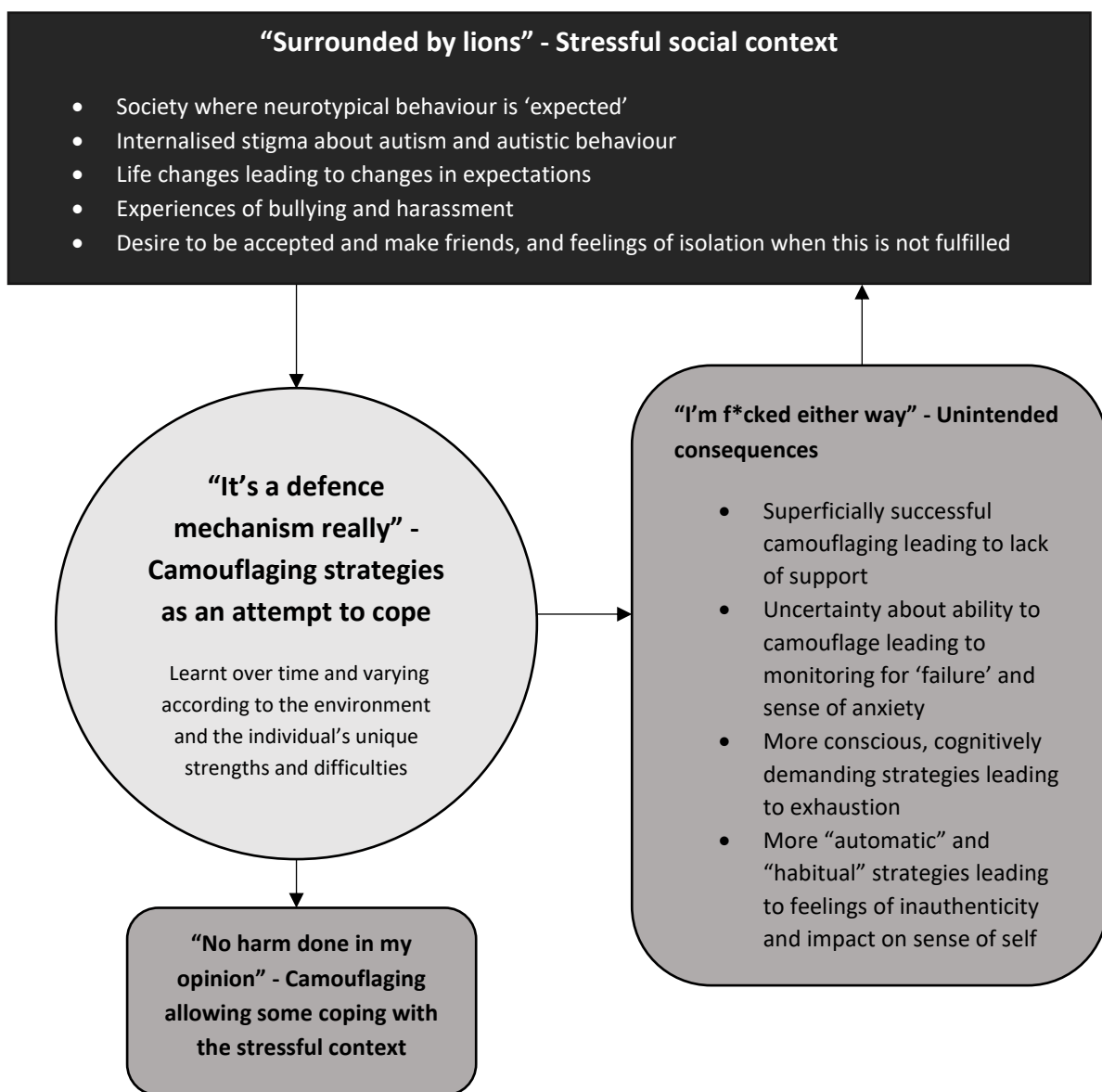
### ***Results of synthesis***

First-order constructs from participant accounts of their experiences and second-order constructs from researcher's interpretations of accounts were extracted and compared across studies. Reciprocal translation was used to identify similar concepts across the studies which could be grouped together under either an existing or new concept. Refutational synthesis was used to explore contradictory concepts. The meta-ethnographic process resulted in the development of four third-order concepts describing the experiences of autistic people using social camouflaging. These third-order concepts were generated from the synthesis and reorganisation of second- and first-order concepts. A line-of

argument synthesis was used to draw the third-order concepts together and determine how they relate to each other. Figure 2 shows a diagrammatic representation of the third-order concepts and line-of-argument synthesis. The following section will discuss the concepts in more detail.

**Figure 2.**

*A diagrammatic representation of the third-order concepts and line-of-argument synthesis from the meta-ethnography*



**“Surrounded by lions” - Stressful social context.** Across the reviewed studies autistic people described a constantly present stressful social and societal context which is like being “surrounded by lions” (Tierney et al., 2016). This context has the potential to impact autistic people’s mental health via internalised stigma about autism, and experiences of rejection and bullying.

Autistic participants in several studies (2, 3, 4, 7, 9) describe the social context as one where people “expect neurotypical behaviour” (Bradley et al., 2021) and “connections have to be made initially on neurotypical terms” (Hull et al., 2017). Participants describe a pressure to change autistic behaviour to be “more socially acceptable” (J. Cook et al., 2021). Schneid and Raz (2020) emphasise how this pressure feels “coercive” to autistic people. Autistic people in the studies described how “you have no choice but to change” and “it’s not possible to be ‘out’... without incurring stigma and disapproval” (Bradley et al., 2021). There was a sense in many autistic people’s accounts that if they did not conform to neurotypical social norms they would experience negative consequences such as being perceived as “rude, ‘sick’ or ‘shifty” (J. Cook et al., 2021). Autistic people in many studies (1, 2, 4, 7, 8, 11, 12) made references to being “abnormal” or “weird”, suggesting that the context negatively affects how they perceive themselves. One participant in Schneid and Raz (2020) described the relationship between societal views of autism and their view of themselves: “all these years I have been judging myself because I was judged by others”. Cage and Troxell-Whitman (2019) refer to stigma about autism becoming “internalised” and autism being associated with a sense of “shame”.

Participants in the majority of studies (1, 2, 3, 6, 7, 9, 10, 13) described experiences of bullying and harassment. Autistic people also described or displayed a desire for friendships and connection (1, 2, 4, 6, 7, 8, 9, 13). In addition, multiple studies (1, 2, 9, 11, 13) discussed autistic people’s experiences of social rejection and isolation and the impact of this on mental health. One participant in Ryan and Räisänen (2008) discusses their

experiences of isolation: "...sometimes it feels that it is just happening all over there somewhere and I am living in a bubble or living on the other side of a plate glass window to everybody else... it is kind of like really hard being alive sometimes... I really don't want all this pain in my life".

Some studies (1, 7, 8, 13) considered how gender influenced autistic people's experiences of the social context. Bernardin, Mason, et al. (2021) suggested that "social landscapes for adolescent females are more complex... which may make it more difficult for autistic females to fit in with peers". In addition, participants in Jedrzejewska and Dewey (2021) noted how their gender affected whether others perceived them as being autistic: "girls are expected to be quiet, so when they're quiet people don't really recognise autism as much in them". Autistic participants in Jedrzejewska and Dewey (2021) also felt their gender affected how they were "allowed" to act, with "a perception of... women being more like hysterical than boys... so like if they're upset they wouldn't be like a problem more". It is possible that gender expectations affect the neurotypical social expectations placed on autistic people. For example, it may be considered acceptable for girls to be quieter and for boys to be more outspoken, meaning that if an autistic girl behaves in a more outspoken way this might be perceived as being odd. This is likely to vary depending on subtle aspects of the context, as highlighted by the fact that autistic participants in Jedrzejewska and Dewey (2021) simultaneously felt girls are expected to be "quiet" and "hysterical". There was a lack of consideration in the literature of how other aspects of autistic people's identities might affect their experience of the social environment, with only one mention of sexuality (13), and no discussion of race or disability.

Multiple studies (1, 6, 9, 12, 13) noted changes in the social context being linked to increased stress for autistic people. Some studies linked this to increased or changed expectations being placed on autistic people, such as "major unspoken changes in social etiquette" (Tierney et al., 2016) during adolescence and "applying for jobs and being in the

real world” (Livingston et al., 2019) during adulthood. These changes in expectations led to increased stress due to autistic people being expected to need less support, or because they meant that their current coping or camouflaging strategies were no longer sufficient for them to meet neurotypical social norms.

Overall, the literature describes several aspects of the social and societal context which are inherently stressful for autistic people. Autistic people are expected to behave in neurotypical ways and autistic behaviour is perceived as “abnormal”. Autistic people described being aware of this and internalising this stigma. Autistic people described experiences of bullying and social rejection if they do not conform to social norms, which impacts upon mental health. Stress was often exacerbated by transitions such as starting secondary school or living more independently which led to higher expectations being placed on autistic people. All of these aspects of the context have the potential to impact on autistic people’s mental health.

**“It’s a defence mechanism really” - Camouflaging strategies as an attempt to cope.**

Across the reviewed studies, camouflaging was framed as a “defence mechanism” (Hull et al., 2017) used to overcome and adapt to the stressful context. Autistic people (1, 2, 3, 6, 7, 9) described camouflaging as an attempt to “protect [themselves] from violence, intimidation, bullying and harassment” (Cage & Troxell-Whitman, 2019). Additionally, participants and researchers (2, 3, 6, 7, 8, 9, 10, 11, 12, 13) described camouflaging being used to “fit in” to the “neurotypical world”. For some autistic people (1, 2, 7, 9, 13) camouflaging was used to attempt to access opportunities such as relationships and work. Although two studies (1, 13) described autistic adolescents as “develop[ing] strategies in order to establish friendships” (Tierney et al., 2016), none of the studies described adolescents using camouflaging to obtain other opportunities such as at school. Some studies (4, 7, 9, 10, 11, 12) described camouflaging being learnt or ‘refined’ over time. Miller et al. (2021) particularly emphasised that camouflaging may be learnt during childhood. It is possible that using camouflaging to

obtain opportunities beyond friendships may be a particularly complex skill. This may mean that autistic adolescents have not sufficiently 'refined' their camouflaging skills to be able to use them to obtain further opportunities.

Some researchers (5, 7, 9, 12) attempted to categorise camouflaging into different types, with some suggesting particular categories might be related to different outcomes. However, none of the suggested categories appeared consistently and categorically across all of the studies. J. Cook et al. (2021) and J. Cook et al. (2020) describe camouflaging as a wide range of diverse "idiosyncratic solutions" to an individual's unique social difficulties. Both studies suggest camouflaging strategies may exist on a "continuum". Some studies (5, 7, 10, 11, 13) described autistic people using areas of strength, such as memory and observation, to compensate for areas of difficulty as part of camouflaging. Autistic people in the majority of studies (1, 2, 4, 6, 7, 8, 9, 11, 12) described camouflaging to different extents in different relationships and contexts. For example, some autistic people reported that "at home I can be myself" (Halsall et al., 2021) although researchers noted that this did not apply to all autistic people and depended on the individual's living situation (11). Other contexts where some autistic people reported camouflaging less include with close friends and family (7, 8), when communicating online (8, 11), and when communicating with other autistic people (2, 11, 12). It appears that camouflaging strategies are adjusted to both the autistic individual's unique strengths and weaknesses, and the demands of the context they are in.

Overall, the literature suggests camouflaging as an attempt to cope with the stressful context experienced by autistic people. Camouflaging strategies vary between individuals according to their unique strengths and difficulties and the pressures they're experiencing in the environment.

**“I’m f\*cked either way” - Unintended consequences.** Although camouflaging is an attempt to cope with the stressful context, many studies suggested camouflaging has unintended consequences. This is described as leaving autistic people “f\*cked either way” (Livingston et al., 2019) as they either suffer negative consequences from the stressful social context or suffer negative consequences from social camouflaging. Some of the negative consequences of camouflaging appear to be related to the qualities of the strategies being used. Many of these unintended consequences lead to the context becoming paradoxically increasingly stressful.

Participants in many studies (2, 7, 8, 9, 10, 13) described not having their needs recognised because of using social camouflaging. Researchers felt autistic people “fail[ed] to receive adequate support or allowances” (Hull et al., 2017) because of camouflaging. Some participants linked camouflaging with a “delay in formal diagnosis” (Bradley et al., 2021) which made it more difficult to access support. Other participants discussed how camouflaging post-diagnosis led to others invalidating them or telling them they were “faking being autistic” (Miller et al., 2021). This appeared to be an unintended consequence of camouflaging strategies which were superficially successful and made autistic people appear to not have difficulties with the social context. J. Cook et al. (2021) felt participants’ experiences suggested they “[continue] to experience social cognition difficulties while engaging in camouflaging”. Autistic people’s descriptions also suggested that appearing to cope with the social context meant others “don’t think [they] need the help that [they] sometimes do” (Bradley et al., 2021). As a result of superficially appearing to cope, the context around autistic people can become increasingly unsupportive, inflexible, and unresponsive to their needs, causing additional stress.

Some autistic people may feel “uncertain” about their ability to camouflage (1, 4, 6, 7). “Continuous” monitoring of their own behaviour and other’s social cues during interactions was part of the camouflaging process for some autistic people (4, 7, 11). Autistic



people appeared particularly aware of and anxious about signs of camouflaging “failing” (2, 4, 7, 9, 11); for example, “I go over and over and over what they said and what I said. Did I understand them correctly, did I respond appropriately, did I make a gaffe? Have I offended anyone?” (Hull et al., 2017). Ryan and Räisänen (2008) and J. Cook et al. (2021) hypothesised that this “consciousness” of interactions may paradoxically make it more difficult for autistic people to become fully spontaneously involved in them. Although continuously monitoring social cues may allow autistic people to adjust their behaviour to avoid harassment and build friendships, this may result in an alertness to signs that interactions are going poorly. When camouflaging is perceived to be ‘failing’ this may result in increased anxiety and the context being perceived as increasingly stressful.

Autistic people in several studies (2, 4, 7, 9, 11) described camouflaging as conscious and cognitively demanding “like trying to solve mathematical equations in your head all day long while carrying on as normal” (Bradley et al., 2021). The consequence of this in the majority of studies (1, 2, 4, 6, 7, 9, 10, 11, 12) was a feeling of “exhaustion” or feeling “drained” after camouflaging. Autistic people were described as needing time to “recover” after camouflaging (2, 7, 9). Some studies (2, 9) linked exhaustion to other negative unintended consequences such as feeling “burnt out” and unable to do “simple” things like eating and washing. Exhaustion from cognitively demanding camouflaging may make autistic people less able to meet the demands of the context, leading to increased stress.

Contrastingly, autistic people in some studies (2, 3, 4, 7, 10) reported that over time their camouflaging strategies had become more “automatic”, “habitual”, and “involuntary”. Camouflaging did not become more automatic for all autistic people. Notably, none of the studies of adolescents described camouflaging becoming more habitual over time. Miller et al. (2021) noted that for some participants the more “instinctual” camouflaging became the more difficult it became to “work out where they ended and the mask begun”. Additional

studies (1, 2, 4, 7, 9, 10, 12, 13) discussed feelings of “inauthenticity” or, more acutely, changes in their sense of self due to camouflaging. Schneid and Raz (2020) note that camouflaging to “pass as normal” appears to increase autistic people’s “sense of alienation”. Where camouflaging becomes more habitual and automatic, this appears to be associated with feelings of inauthenticity which have a cumulative impact on autistic people’s sense of identity. This sense of alienation may contribute to autistic people’s shame and stigma about autism, making the context increasingly stressful.

Although autistic people use camouflaging to cope with the stressful context, many camouflaging strategies have unintended consequences which may make the context more stressful in the long term. When camouflaging is perceived as being “successful”, autistic people receive less support, making it more difficult for them to cope. Autistic people have understandable doubts about their ability to camouflage and may closely monitor their behaviour and the responses of others. They may be particularly alert to signs that their camouflaging is “failing”, simultaneously increasing their anxiety and decreasing their ability to engage with interactions. Many autistic people find camouflaging a cognitively demanding and conscious process which leads to exhaustion. This exhaustion makes it more difficult for autistic people to care for themselves and meet the demands of the context. Conversely, some autistic people find camouflaging becomes more habitual and automatic over time. This automatisisation of camouflaging appears to be associated with feelings of inauthenticity and an impact on identity over time. This affects how autistic people experience the social context and may increase their internalised stigma about autism.

**“No harm done in my opinion” - Camouflaging allowing some coping with the stressful context.** Across the reviewed literature, some autistic people reported that camouflaging was helpful overall, and in some cases that there was “no harm done” (Bernardin, Mason, et al., 2021). In Bernardin, Mason, et al. (2021), some adolescent autistic boys did not feel there were any negative consequences to camouflaging, and

reported feeling positive or neutral afterwards. For example, one participant reported feeling “Happy, because I’m out having fun”, while another reported “I feel I still have enough of my personality that I don’t feel like a different person, but just enough so... it’s proper for the situation.” None of the other studies and none of the studies of autistic adults described a complete absence of negative consequences.

In other studies (7, 9), autistic people reported some negative consequences of camouflaging but felt these were either minor or not as severe as the consequences of not camouflaging: “It cuts down the pain and makes me employable. ...To not compensate would make life more unhappy for me” (Livingston et al., 2019). Livingston et al. (2019) linked participants reporting more positive outcomes from camouflaging to autistic people refining their strategies, choosing environments where their strategies were more successful, or balancing the time they spent camouflaging with time where they are not. Both Hull et al. (2017) and Bernardin, Mason, et al. (2021) noted that positive feelings about camouflaging appeared to be more common in autistic males than females. Hull et al. (2017) hypothesised that camouflaging is more likely to have positive consequences for males due to “present gendered socio-cultural contexts”.

It may be that camouflaging is a more positive experience for some autistic people because of differences in the demands that the context places on them. Alternatively, some autistic people might find their camouflaging strategies are suited to the context they are in or attempt to select contexts where their strategies are more suitable. It’s worth noting that although camouflaging was viewed as positive overall by some autistic people, there were usually some negative consequences associated with it. The costs of camouflaging strategies were often regarded as not as negative as tolerating the stressful context without them. Camouflaging strategies themselves did not resolve the social context being one where neurotypical behaviour was expected and stigma was associated with autistic behaviour.

## **Discussion**

The present systematic review identified 13 qualitative studies of varying quality which explored autistic people's experiences of social camouflaging. These studies were synthesised using meta-ethnography to produce four third-order concepts, "stressful social context", "camouflaging strategies as an attempt to cope", "unintended negative consequences" and "camouflaging allowing some coping with the stressful context". These third-order concepts relate to each other in a line-of-argument synthesis which describes how the social context and autistic people's use of social camouflaging affects their mental health.

The meta-ethnography describes how autistic people experience social and societal contexts which are stressful and may impact on their mental health. This includes the experience of living in a society where neurotypical behaviour is expected and there is stigma about autistic behaviour. Autistic people experience bullying and harassment while simultaneously desiring and struggling to obtain friendships and connection. Social camouflaging is an attempt to cope with the stressful social context and varies depending on features of the context, and the strengths and difficulties of the individual autistic person. Many autistic people experience unintended negative consequences, where camouflaging makes one aspect of the social context easier to manage while paradoxically making another more stressful. The unintended negative consequences of camouflaging vary depending on the qualities of the strategies being used. Some autistic people find that overall camouflaging is beneficial for them, or that the negative consequences of camouflaging are not as significant as those they would face if they did not camouflage.

## ***Stigma***

The results of this meta-ethnography bear similarities to the wider literature about stigma and mental health. Autistic people in the reviewed studies discussed how the social

context was stressful for them, particularly due to societal stigma about being autistic. Autistic people in the wider literature also describe experiencing stigma about autism (Botha, Dibb, & Frost, 2022). Botha and Frost (2018) suggested that autistic people can be viewed as an identity-based minority who may be affected by minority stress. The Minority Stress Model (Meyer, 2003) would suggest that due to being an identity-based minority, autistic people are vulnerable to social stigma, rejection, and victimisation which can impact on their health (Botha & Frost, 2018). Botha and Frost (2018) found that minority stressors such as experiences of discrimination significantly predicted poor mental health in autistic adults. This is consistent with the present meta-ethnography, where autistic people linked their experiences of bullying and rejection with their mental health.

Additionally, Pearson and Rose (2021) and Perry, Mandy, Hull, and Cage (2022) both attempt to apply Social Identity Theory (Tajfel & Turner, 1979) as a way of understanding social camouflaging. Social Identity Theory suggests that when there is stigma associated with a group, group members may attempt to gain a more positive identity by disassociating from the stigmatised identity and attempting to 'pass' in a group with higher status (Perry et al., 2022). Individuals might attempt to avoid stigma by monitoring how they might be appearing to others (Pearson & Rose, 2021). This is similar to descriptions of social camouflaging in the reviewed studies, where camouflaging could be considered an attempt to avoid stigma by 'passing' as non-autistic.

DeJordy's (2008) model of "unintended consequences of passing" describes how people with invisible social identities (e.g. LGBT people) may choose to keep these identities private, or 'pass' at work. DeJordy (2008) discusses how individuals may choose to pass at work to avoid negative responses, but that this might result in unintended consequences. These include cognitive or "ego"-depletion which makes it difficult to engage with work, and cognitive dissonance between the person's actual identity and the identity they are enacting. These unintended consequences are similar to the unintended consequences identified in

this meta-ethnography; the ego-depletion DeJordy (2008) describes appears similar to the feeling of exhaustion described by autistic participants in the included studies, and the cognitive dissonance appears similar to feelings of inauthenticity.

Given that the current meta-ethnography and previous literature suggests camouflaging and the mental health of autistic people is influenced by stigma (Botha & Frost, 2018; Pearson & Rose, 2021; Perry et al., 2022), it is important to consider how this may differ for autistic people who experience stigma for other reasons. The present meta-ethnography suggests autistic women experience different pressures from their social context which may influence their use of social camouflaging and the impact it has on them. The reviewed studies did not discuss how stigma from other characteristics may affect autistic people. The Minority Stress Model was initially developed to explain higher levels of mental health difficulties in lesbian, gay, and bisexual people (Meyer, 2003). Rogers, Hom, Janakiraman, and Joiner (2021) found that higher levels of harassment, rejection, and discrimination was associated with higher levels of suicidal ideation in LGBT people. Other researchers have investigated how the Minority Stress Model can be applied to other groups, with Wei et al. (2010) finding that higher levels of minority stress was associated with higher levels of depressive symptoms in ethnic minorities. Some researchers suggest there could be an additive effect of belonging to multiple minorities on mental health, although this is not necessarily observed in the data (Hayes, Chun-Kennedy, Edens, & Locke, 2011). It remains unclear from the current meta-ethnography how belonging to other stigmatised identities may affect autistic people's mental health and use of camouflaging.

### ***Social Anxiety***

Autistic people's descriptions of social camouflaging in the current meta-ethnography also bear similarities to cognitive-behavioural models of social anxiety. Individuals with social phobia experience anxiety about social situations and worry that they will behave in a way

that will lead others to evaluate them negatively (APA, 2013). Clark and Wells's (1995) cognitive model of social phobia suggests people with social anxiety have higher self-focussed attention and closely monitor how they are coming across. This appears similar to the close monitoring described as part of camouflaging by some autistic people in the current meta-ethnography. Clark and Wells (1995) hypothesise that self-focussed attention is unhelpful because it prevents the individual from discovering how others are responding and learning others do not respond negatively or not as badly as they feared. Self-focussed attention is hypothesised to increase the salience of negative self-perceptions (Kashdan & Roberts, 2004), similarly to how autistic people in the reviewed studies appeared sensitised to signs of their camouflaging 'failing'. Finally, self-focussed attention is hypothesised to make it more difficult for people to engage with social situations, making it more likely for feared negative responses to occur (Clark & Wells, 1995; Hofmann, 2007). This is similar to the hypotheses of researchers in the reviewed studies that autistic people may find it more difficult to engage in interactions if they use monitoring as part of their camouflaging. A substantial body of research supports the hypothesised role of self-focussed attention in maintaining social anxiety (Norton & Abbott, 2016). It is possible that when autistic people monitor their own behaviour as part of social camouflaging that this sensitises them to signs of camouflaging failing and makes it difficult for them to engage with interactions. This maintains their perception of the social context as stressful and reinforces the need to camouflage.

Although there are similarities between autistic people's monitoring during social camouflaging and self-monitoring in social anxiety, there are also important differences to consider. Autistic people in the present research described closely monitoring the responses of others as well as their own behaviour. This directly contrasts with Clark and Wells's (1995) theory as they describe a lack of attention to others leading to a failure to learn that they do not reject them in the way that they feared. In addition, the autistic people in the current

meta-ethnography described using camouflaging as a result of multiple experiences of rejection, bullying, and harassment. Autistic children and adolescents are significantly more likely to be bullied than typically developing children and children with learning disabilities, with between 46.3% and 94% of autistic children experiencing bullying (Humphrey & Hebron, 2015). Autistic adults are also more likely to experience emotional bullying or teasing than non-autistic adults (Weiss & Fardella, 2018). Frequent experiences of bullying are associated with poorer quality of life for autistic adults (Hong, Bishop-Fitzpatrick, Smith, Greenberg, & Mailick, 2016). This high prevalence of bullying suggests that autistic people do experience high levels of social rejection. Although self-monitoring and self-focussed attention may make autistic people more aware of signs of their camouflaging 'failing', autistic people are also likely to be attending to other's reactions to them. Given the high prevalence of bullying of autistic people, it is likely that autistic people will find others rejecting of them and this may further reinforce camouflaging.

### ***Clinical implications***

The current meta-ethnography has implications for the understanding of the relationship between social camouflaging and mental health, and how clinicians work with autistic people with mental health difficulties. This meta-ethnography suggests camouflaging is an understandable response to attempt to cope with a difficult and stressful social context. For some autistic people, social camouflaging allows some coping with the stressful context, or has negative consequences which are considered not to be as harmful as tolerating the context without camouflaging. For other autistic people social camouflaging has negative unintended consequences which make the context more stressful.

This research suggests one of the most effective ways to improve the mental health of autistic people would be to improve the social and societal context. This would involve creating a context where autistic behaviour is accepted and neurotypical social norms are



not considered the only way to make social connections. Some autistic people in the current meta-ethnography described particular contexts where they felt more accepted, such as with close friends or other autistic people. Schneid and Raz (2020) describe autistic people “reframing” situations by explicitly asking neurotypical people to explain social situations. Schneid and Raz (2020) described this being difficult due to the risk of being exposed to stigma, but simultaneously helping autistic people understand the situation and highlighting their needs to others.

Both finding contexts where they feel accepted and reframing situations create temporarily less stressful contexts for autistic people. However, more permanent change of the wider societal context is likely to be a lengthy and ongoing process. As a result, autistic people are likely to continue to feel the need to camouflage to cope with the context and may experience unintended negative consequences as a result. The present meta-ethnography suggests it is important for clinicians to be aware of the relative costs and benefits of camouflaging for autistic people. Some autistic people may wish to camouflage less because of the unintended consequences they experience, whereas others may feel these are less significant than the impact if they did not camouflage. It is important for clinicians to work sensitively with autistic people to formulate the ways their camouflaging strategies might increase the amount of stress they are experiencing. This may allow autistic people to make informed decisions about when, where, and how they camouflage.

Future research should further investigate how particular qualities of social camouflaging might lead to negative unintended consequences and mental health difficulties for autistic people. For example, quantitative research could explore whether autistic people who use more cognitively demanding strategies experience higher levels of exhaustion than autistic people who use less demanding strategies. In addition, research could explore whether self-monitoring during camouflaging is linked to anxiety in the same way as it is in

social anxiety. Finally, future research could investigate the apparent relationship between more automatic strategies and feelings of inauthenticity.

### ***Strengths and limitations***

The present meta-ethnography represents a systematic search of the literature on autistic people's experiences of social camouflaging. The meta-ethnography synthesises data from multiple studies of adolescents and adults to generate a new model to describe camouflaging and how it may impact on mental health. Meta-ethnography is a commonly used and well-established method of qualitative synthesis with multiple guidelines on improving their quality (Dixon-Woods et al., 2007; France et al., 2019; Hannes & Macaitis, 2012; Sattar et al., 2021). Strengths of the present study include the use of multiple reviewers to select and appraise included studies in order to reduce bias.

This review has methodological weaknesses which it is important to acknowledge. As this is a review of qualitative research, it is not possible to conclude causal relationships between the concepts generated from the meta-ethnography. Many of the reviewed studies describe relationships between concepts but it is important that these are empirically validated via further research. In addition, many of the reviewed studies do not adequately consider the potential biases of the researchers when choosing their research questions and conducting their qualitative analysis. Finally, it is important to note the diversity of participants in the reviewed studies. Many studies did not report on the ethnicity of their participants, and when this was reported the majority of participants were from a white background. The majority of studies did not collect other demographics such as sexuality, education, and employment. Several studies acknowledge that their participants were of average intelligence or above and therefore do not represent autistic people with learning disabilities. As a result, the present meta-ethnography may not describe the experience of camouflaging for all autistic people, particularly autistic people of different ethnic

backgrounds or with learning disabilities. Future qualitative research should explore social camouflaging in autistic people with diverse backgrounds, particularly people with other stigmatised characteristics, and social camouflaging in autistic people with learning disabilities.

### ***Conclusions***

The present meta-ethnography systematically identified and synthesised 13 qualitative studies on autistic people's experiences of camouflaging. The review frames social camouflaging as an attempt to cope with a stressful context where autistic behaviour is stigmatised. Camouflaging has negative unintended consequences for some autistic people. Other autistic people feel the negative consequences they experience from camouflaging are not as severe as the consequences of tolerating the stressful context without camouflaging. The meta-ethnography proposes several ways camouflaging may unintentionally cause the context to become more stressful and lead to poor mental health. These include autistic people being provided with less support because of apparently successful camouflaging, autistic people experiencing anxiety because of monitoring themselves as part of camouflaging, exhaustion due to cognitively demanding camouflaging, and feelings of inauthenticity due to more habitual camouflaging. This review suggests it is important for clinicians working with autistic people with mental health difficulties to carefully consider the role of camouflaging. Clinicians should support autistic people to consider the relative costs and benefits of camouflaging in different contexts for them personally. Future research should empirically investigate the relationships between these concepts and investigate how camouflaging may be different in autistic people with other stigmatised characteristics.

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**Paper 2**

**“Work WITH us”: A Delphi Study about Improving Eating Disorder Treatment for Autistic Women with Anorexia Nervosa**

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## **Abstract**

Research suggests an increased prevalence of anorexia nervosa (AN) in autistic women, and poorer treatment outcomes compared to non-autistic women with AN. However, there is little research into how to improve eating disorder treatment for autistic women. This study investigated how best to support autistic women with AN. A three-stage Delphi study was conducted with 49 participants with relevant expertise as a researcher, clinician, or expert by experience. A total of 70 statements were generated, with 56 reaching consensus after the final round. Statements that reached consensus made recommendations for adaptations to treatment, staff training, and service organisation. The results highlight the need to distinguish between autism- and AN-related difficulties, accommodate autistic traits such as sensory sensitivities and communication differences, and include autistic people in the development and delivery of care. Future research should investigate the impact of these adaptations on outcomes. The applicability of these recommendations to autistic people with other eating disorders and of other genders needs to be investigated further.

## **Lay Abstract**

Autistic women are more likely to have anorexia nervosa (AN) than non-autistic women. Autistic women with AN can find eating disorder treatment unhelpful and need adaptations to treatment. This study asked a group of 49 researchers, staff, and people with personal experience of autism and eating disorders what they thought would help autistic women with AN. This study used a Delphi study method, which allows the calculation of how much participants agree without them needing to meet and make a decision. The study created 56 suggestions that the participants agreed on. The results give different suggestions for changing treatment, training staff, and changing how services work to be better for autistic women. The suggestions highlight the importance of being able to tell the difference between autism- and AN- related behaviour, adjusting care to accommodate autistic traits,

and involving autistic people in care. Many of the suggestions recommend that changes need to be flexible to the individual autistic person. Some suggestions included changes to how staff communicate with autistic people, and changes to the environment and food so it is less triggering to sensory sensitivities. In the future, research should check if these changes are helpful for autistic women with AN, and if they would be helpful for autistic people who are not female or have other eating disorders.

## Introduction

Autism is a neurodevelopmental condition characterised by difficulties with social interaction, communication and restricted or repetitive interests or behaviour (American Psychiatric Association [APA], 2013). Research into the prevalence of autism has consistently suggested a higher prevalence in males (Fombonne, Du Mazaubrun, Cans, & Grandjean, 1997; Icasiano, Hewson, Machet, Cooper, & Marshall, 2004) with a recent meta-analysis suggesting a ratio of 3:1 males diagnosed for each female (Loomes, Hull, & Mandy, 2017). However, in clinical samples the gender ratio decreases with increasing age, with a ratio of 1.2:1 in people over 40 (Rutherford et al., 2016). Rutherford et al. suggested that this reflects the delayed diagnosis and under-identification of autism in females. Several explanations have been suggested for this, including possible phenotypic differences in how autistic<sup>1</sup> males and females present (Rubenstein, Wiggins, & Lee, 2015). Hull, Petrides and Mandy's (2020) review of the literature suggested that compared to autistic males, autistic females may be more likely to present with internalising problems such as eating disorders. When autistic people and other stakeholders are consulted, one of their top priorities is research into the mental health of autistic people (Roche, Adams, & Clark, 2020).

Anorexia nervosa (AN) is an eating disorder (ED) characterised by restricted food intake and an intense fear of or behaviour to prevent gaining weight (APA, 2013). AN has a significant impact on individuals' functioning and quality of life, with high levels of mortality (Demmler, Brophy, Marchant, John, & Tan, 2020). Over the last decade, the years lived with disability have decreased for other mental health conditions but increased for individuals with AN (van Hoeken & Hoek, 2020). Autistic women are overrepresented amongst people receiving treatment for AN (Huke, Turk, Saeidi, Kent, & Morgan, 2013; Westwood, Mandy, & Tchanturia, 2017). There are multiple factors which may increase autistic women's risk of

<sup>1</sup> The current paper refers to 'autistic people' instead of 'people with autism' as this is preferred by the majority of the autistic community in the UK (Kenny et al, 2016). Individuals may have their own preferences.



developing AN. Brede et al.'s (2020) autism-specific model of restrictive eating difficulties suggests autism-related traits can both directly and indirectly lead to restricted eating. Autism-related traits such as special interests related to food and exercise can directly lead to restricted eating. Other traits may indirectly lead to restricted eating as a way of coping with the negative emotional consequences of autism-related difficulties like social rejection (Brede et al., 2020).

Outcomes for autistic people with AN are particularly poor compared to people with AN who are not autistic; for example, people with AN with higher levels of autistic traits have longer illness durations (Saure et al., 2020). Adults with higher Autism Quotient (AQ-10) scores had higher levels of ED psychopathology when admitted to inpatient ED care (Tchanturia, Adamson, Leppanen, & Westwood, 2019). When followed up over a 30 year period, autistic adolescents with AN had worse outcomes than non-autistic adolescents with AN in terms of mental state, independence from their families, social contact, and employment (Nielsen et al., 2022).

Qualitative research suggests clinicians lack confidence and experience working with autistic people with AN (Kinnaird, Norton, & Tchanturia, 2017). In addition, clinicians identified difficulties differentiating between autistic characteristics and symptoms of AN (Kinnaird et al., 2017). Autistic women with AN report being refused treatment by ED services and being viewed as uncooperative because of their difficulties with traditional treatments (Babb et al., 2021; Kinnaird, Norton, Stewart, & Tchanturia, 2019).

Despite emerging research into the prevalence, impact, and lack of effective treatment for AN in autistic women, there is little research into how AN treatment can be improved for this population. Qualitative research suggests service users and clinicians feel autistic women would benefit from adaptations in communication and the environments they are seen in (Babb et al., 2021). Currently, there is only one set of guidelines on treatment adaptations for autistic people with AN (Li, Halls, Byford, & Tchanturia, 2021); The Pathway for Eating Disorders and Autism developed from Clinical Experience (PEACE) pathway

(Tchanturia, 2021; Tchanturia, Smith, Glennon, & Burhouse, 2020) is a practice-based guideline developed as a coproduced quality improvement project involving patients, clinicians, carers and researchers within South London and Maudsley NHS Trust Eating Disorder Services. Recommendations from the PEACE pathway include training for staff on the interaction between autism and EDs, training on adapting therapies, the addition of autism screening as part of ED assessment, adaptation of the ward environment, and the provision of a specialist food menu for autistic patients (Tchanturia et al., 2020). As the PEACE pathway has only recently been developed there is limited research into its impact on outcomes. However, Tchanturia et al.'s (2021) preliminary investigation found the length of inpatient admission for autistic people with AN was reduced after the PEACE pathway was developed.

Due to the nature of quality improvement projects, there is limited detail on how the PEACE pathway guidelines were developed. For example, it is unclear to what extent different stakeholders contributed to the development of the guidelines, the diversity of stakeholder's experiences, and at which stages input was provided. Given that the project was developed within a specific service, it is unclear whether the recommendations would generalise to other services or if additional recommendations would be suggested by services elsewhere. The only evaluation of outcomes of the PEACE pathway was conducted in the same service where the pathway was developed and does not provide any details of outcomes for outpatients (Tchanturia et al., 2021). Systematic research is required to explore how treatment for autistic women can be improved.

The present study aimed to develop a consensus on how to improve treatment for autistic women with AN. Delphi studies are recommended when there is not an accepted body of knowledge on a topic (Sumsion, 1998). Delphi studies emulate group decision making in a controlled context with the aim of reducing the impact of biases (Dalkey & Helmer, 1963). An advantage of this is experts from different backgrounds have an equally

weighted impact on the results. Delphi studies provide a more transparent view of the decision-making process and how strongly participants agree with the results.

Delphi studies vary methodologically; they typically involve participants rating their agreement with a set of statements generated from a literature search (Bond et al., 2017; Byrne & Morrison, 2014) or qualitative responses from a group of experts (Heather, Dallolio, Hutchings, Kaner, & White, 2004; Mitchell, Shannon, Mulholland, & Hanna, 2020). A facilitator provides participants with anonymous feedback on how their ratings compare to the group and allow them to revise their responses. Over several rounds of questionnaires, responses converge and a statistical criterion is used to define which statements meet consensus (Jorm, 2015).

As Delphi studies rely on group decision making, the quality of the decision depends on the expertise of the participants (Okoli & Pawlowski, 2004). Diversity of experience is also important; groups with diverse expertise make better decisions, providing a rationale for recruiting experts from a variety of professional backgrounds (Jorm, 2015). To encourage diversity of experience in the panel, participants in the present study were from a variety of backgrounds in the areas of autism and EDs. There is a growing emphasis on increasing the meaningful participation of autistic people in research (Fletcher-Watson et al., 2018; Poulsen, Brownlow, Lawson, & Pellicano, 2022) and participatory research can improve the relevancy and quality of research (Forsythe et al., 2019). As a result, it was important to include autistic people as experts in the present Delphi study. To be eligible to participate, experts needed to have knowledge about autism, EDs, or both, as a researcher, clinical staff member, or expert by lived experience (EbE). Demographic information was collected to ensure participants were appropriately knowledgeable.

A Delphi study was planned to develop a consensus on the best ways to support autistic women with AN while receiving treatment for an ED. The study aimed to recruit participants with a wide range of personal and professional experiences to reach a high-

quality consensus. By using a Delphi methodology the research aimed to generate suggestions in a transparent and systematic way.

## **Method**

### ***Participants***

Participants were recruited via adverts on social media in groups for autistic people, people with eating disorders, and healthcare professionals. Participants were also identified via the researchers' personal contacts and knowledge of people with expertise in the area. Participants self-identified as experts in the areas of autism, EDs, or both. Participants reported whether their expertise was via academic research, clinical work, or personal experience as a carer, autistic person and/or person with an ED. Individuals with personal experience will be referred to as experts by experience (EbE). If their expertise was from multiple sources, participants were instructed to select the area in which they felt they had the most expertise.

The aim was to recruit a maximum of 54 experts. This was to ensure there were 10-18 experts in each expertise-type 'panel' according to recommendations from Okoli and Pawlowski (2004). The different expertise 'panels' were researchers, clinicians, and EbE. The purpose of this was to ensure different groups of experts had equal contributions to the final consensus by aiming to recruit equal numbers of participants to each panel.

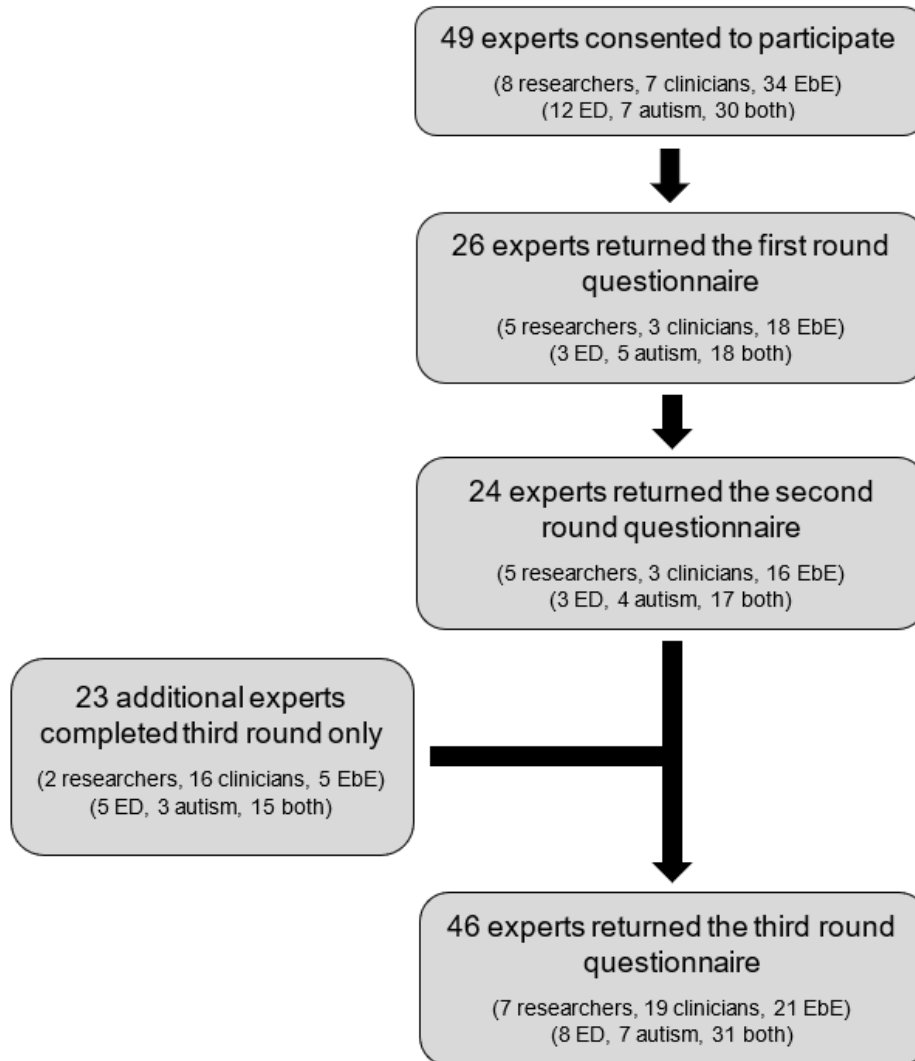
Demographic information was gathered to ensure potential experts were suitably qualified, including the number of years of research, clinical, or service development/advocacy experience each expert had. Participants were asked which country they lived or worked in with an aim to recruit an international sample.

At the initial recruitment phase 49 experts consented to participate. Following the recruitment phase, 26 experts returned the first-round questionnaire. Figure 1 shows the number of experts participating at each stage of the Delphi study.

**Figure 1**

*A flowchart showing the number of experts participating at each stage of the Delphi study.*

*Brackets show the number of experts per expertise type at each stage.*



*Note.* EbE = expert by experience; ED = eating disorder.

As a result of the level of attrition in the first round, additional participants were recruited during the third round. It was hoped that stakeholders who may have found it difficult to give open responses would be more likely to participate in the third round by rating their agreement with others' responses. Previous Delphi studies have used separate

samples of experts for different stages of the study (Byrne & Morrison, 2014) with some combining ratings across multiple stages when calculating consensus (Tierney & Fox, 2009). During the third round, 23 additional experts were recruited and completed this stage only. In total, 46 experts completed the third stage of the Delphi study.

### ***Procedure***

The present study used a three-stage Delphi method based on the steps described by Heather et al. (2004) and Tierney and Fox (2009). Experts provided informed consent to participate and the research was reviewed and approved by the Cardiff University School of Psychology Ethics Committee (see Appendix B). At each stage participants received either an editable document or a link to an online survey to complete at their own convenience over a period of a couple of weeks.

During round one, participants were emailed an editable document containing six open-ended questions (see Table 1). Responses to the first questionnaire were interpreted using conventional content analysis at a conceptual level (Hsieh & Shannon, 2005). The content analysis was conducted by reading the participant responses repeatedly in order to develop a familiarity with and immersion in the data (Hsieh & Shannon, 2005). Phrases which described possible key concepts were identified in a systematic way by working through the data participant by participant. Exact phrases which described common and key concepts were highlighted (Hsieh & Shannon, 2005). Once concepts were identified from the phrases they were compared back to the wider dataset, similarly to the 'reviewing themes' stage of thematic analysis (Braun & Clarke, 2006).

A set of statements was composed based on the concepts from the content analysis. To adhere with the research aims of exploring adaptations to treatment for autistic women with AN, concepts were configured into statements recommending particular ways of working (e.g. "Eating disorder staff should provide autistic women with more written information during treatment") (similarly to Kelly, Jorm, Kitchener and Langlands, 2008).

Some themes did not contain clear recommendations, and instead reflected knowledge participants felt staff would need (e.g. “Autistic women with anorexia might find weight gain distressing because of changes in their sensory experiences of their clothes or bodies”). The statements were created by looking back at the original quotes representing each concept and using experts’ own wording as far as possible. The research team met regularly to discuss the content analysis and ensure the statements generated were relevant and did not contain unnecessary overlap. Full details of the results of the content analysis are given in the results section.

**Table 1**

*Open-ended Questions in Round One Questionnaire*

1	What do you see as the specific needs of autistic women with anorexia nervosa?
2	How are these different to neurotypical women with anorexia nervosa?
3	What do you think would help an autistic woman recover from anorexia nervosa?
4	What is the best way for staff to support an autistic woman with anorexia nervosa?
5	What are the challenges for staff to work with an autistic woman with anorexia nervosa?
6	What would a training package for staff working with autistic women with anorexia nervosa need to achieve?

During the second round, participants from round one were emailed a link to an online questionnaire with the statements generated from the content analysis. Participants were asked to rate their agreement with each statement on a 7-point scale from 1 (strongly disagree) to 7 (strongly agree).

During the third round, participants from the second round were emailed a link to an online questionnaire with the same set of statements alongside the median group rating for each item and a reminder of their individual previous rating. Participants were asked to re-rate each statement on the 7-point Likert scale and prompted to give their reasoning if their rating differed by more than one from the median (as in Heather et al., 2004). Participants

who had not completed the previous rounds clicked on a link to an online questionnaire and were asked to rate each item on the 7-point Likert scale without any information about the median group ratings. Following round three, items with a median of six or greater (labelled as “agree”) and an interquartile range of less than or equal to one were considered to have reached consensus (as in Heather et al., 2004).

## Results

### *Participant demographics*

Table 2 reports the duration of the relevant expertise of the participants who completed the round one questionnaire and the additional participants who were recruited during round three. It is not possible to provide data on the duration of expertise at each different stage as individual data on duration of expertise was required to be deleted at particular stages to maintain confidentiality. For EbE, data was collected regarding whether they had prior experience of service development or advocacy and the duration of this experience. As a result EbE (n=11) who did not have experience of service development or advocacy are excluded from the data in Table 2. During round 3, 7 experts were primarily researchers, 19 were primarily clinicians, and 21 were EbE. Data regarding the expertise types of participants at different points in the study are given in Figure 1. Participants were living or working in the United Kingdom (n=40), United States of America (n=5), and Canada (n=4).

**Table 2**

*Mean years of experience by expertise type for participants who completed the round one questionnaire and participants recruited during round three.*

<b>Type of expertise</b>	<b>Mean years of experience (SD, range)</b>
Research (n=7)	7 (5.61, 2-20)
Clinical (n=19)	8.89 (8.75, 1-30)
Expert by experience (n=10)	6.38 (5.03, 1-18)
Total sample (n=36)	7.75 (7.31, 1-30)



### **Round 1**

Ninety concepts were generated using conventional content analysis. These concepts were configured into statements to be fed back to experts in the second round of the study. The statements were examined for overlap, and 20 were removed in favour of similar but more concrete statements about improving treatment. For example, the statement “Autistic women might be sensitive to particular noises, smells, or visual input, like lights around them” was removed as it was captured by the statement “Buildings which are used for eating disorder treatment should be adapted to be more autism-friendly and less triggering to sensory sensitivities. This could be done by designing spaces together with autistic people.” A total of 70 statements were retained for use in the second round questionnaire (see Appendix C).

### **Round 2**

Participants’ median agreement for each statement in round 2 was calculated to be provided to participants to aid their decision-making in round 3. The majority of statements had a high median agreement of six or more at this stage. For the median agreement in round 2, see Appendix C.

### **Round 3**

Statements were considered to have reached consensus if they had a median of six (labelled as “agree”) or greater and an interquartile range of one or less. Statements are considered to have met consensus strongly if they have an interquartile range of less than one. Of the original 70 statements, 56 reached consensus. For the medians and interquartile ranges of all 70 statements, see Appendix C.

Table 3 shows the statements meeting consensus regarding the needs of autistic women with AN and recommendations for treatment. The statements refer to a variety of needs including difficulties with switching tasks and distress when unable to keep to meal

plans. The consensus-reaching statements recommend a broad range of treatment approaches and targets. Several treatment targets focussed on supporting women with managing aspects of being autistic, such as cognitive differences, the demands of social relationships, regulating sensory needs, and managing the impact of past social experiences. Some treatment targets related to supporting autistic women to separate features of autism from ED difficulties, for example by developing routines which are unrelated to the ED, and exploring special interests which are unrelated to food.

The statements meeting a strong consensus (with an interquartile range of less than one) referred to autistic women with AN finding it difficult to manage changes in staff and benefiting from being treated by teams with autistic staff members and staff with experience working with autistic people. The statements with strong consensus regarding treatment suggested meal plans should be adapted to avoid sensory sensitivities, psychological therapies should be adapted for autistic women, and treatment should draw on autistic women’s strengths.

**Table 3**

*Statements reaching consensus about the needs of autistic women with anorexia nervosa, what they might benefit from, and recommendations for treatment. Statements were considered to have reached consensus if they had a median of six or greater and an interquartile range of one or less.*

Statement	Interquartile range
<b>Autistic women with anorexia might...</b>	
...feel they have to stick rigidly to meal plans given to them by services, which can be distressing when the meal plan can't be kept to.	1
...be more likely to have other physical or mental health conditions which need considering during treatment	1
...need more time to complete and switch between tasks.	1
...find changes in staff or unfamiliar staff more difficult to work with	0
...might be labelled as being 'resistant' due to not benefitting from traditional treatments	1

<b>Autistic women with anorexia might benefit from...</b>	
...being supported to explore their special interests which are separate from food.	1
...being treated by teams which have autistic staff members and therapists.	0.75
...being treated by staff who are experienced in working with autistic people	0
...support and mentorship from other autistic people	1
<b>Eating disorder treatment for autistic women should</b>	
...involve support in a broader range of areas compared to non-autistic women with anorexia. Autistic women may benefit from support accessing education and employment, finding suitable accommodation, and finding support with daily tasks	1
...support autistic women to learn how to manage difficulties they might have with their attention, memory and organisational skills	1
...provide autistic women with information about the effects of starvation and refeeding on their bodies and minds	1
...support autistic women to understand what parts of their experiences are related to their autism and what parts are related to their eating disorder	1
...support autistic women with anorexia to develop new routines and rituals to replace unhelpful routines which are related to their eating disorder	1
...support autistic women to manage the demands of social relationships	1
...provide some autistic women with a trauma-informed approach or therapy to manage their past social experiences i.e. experiences of living in a society that can be negative about autism and autistic behaviour	1
...ensure that any specific psychological therapies like CBT are adapted for autistic women with anorexia.	0.75
...support autistic women to explore their self-esteem and identity. This might involve exploring their identity as an autistic person.	1
...support autistic women to identify what hunger cues feel like in their body	1
...adapt meal plans for autistic women to avoid their sensory sensitivities.	0
...support autistic women to learn the best ways to regulate their sensory needs. This might involve using aids like weighted blankets, stim toys or headphones/ear plugs and allowing these to be used during mealtimes.	1
...support autistic women to develop coping strategies that can be used in lots of different environments	1
...draw on the individual's strengths to help them recover	0
...include education and support for autistic women's families where possible.	1

Table 4 shows the statements meeting consensus referring to how ED staff work with autistic women with AN and how staff should be trained. The statements provide a variety of suggestions about how staff can adjust their communication by asking more specific questions, asking autistic women to do things in a less directive way, using more written communication, and using communication passports to document each individual's unique communication needs.

Several statements relating to staff reached a strong consensus, with an interquartile range of less than one. All but one of the statements relating to training met a strong

consensus. Statements recommended a training package is provided to all staff and is developed and delivered together with autistic women. The training package was recommended to draw attention to autistic strengths, and to contain information about meltdowns, shutdowns, adapting interventions, and how autism and AN interacts so treatment does not aim to change autistic behaviour. The statements meeting consensus referred to the importance of building trusting relationships with autistic women, although this may take longer compared to with non-autistic women with AN. A further statement meeting strong consensus referred to the need for staff to be accepting of autistic women's need to 'stim' by making repetitive movements to gain regulating sensory input.

**Table 4**

*Statements reaching consensus about the experiences of eating disorder staff, how they can work with autistic women with anorexia nervosa and how they should be trained. Statements were considered to have reached consensus if they had a median of six or greater and an interquartile range of one or less.*

Statement	Interquartile range
<b>Eating disorder staff might...</b>	
...have concerns that non-autistic patients will think it is unfair that autistic women with anorexia receive different treatment	1
...find it difficult to work with autistic women with anorexia because of pressure on services and a lack of time	1
<b>Eating disorder staff should...</b>	
...change how they communicate with autistic women. Staff should try and ask specific questions instead of open ones. Staff should try and be clear about what they mean and check they have been understood.	1
...develop 'communication passports' with autistic women so that all staff know the individuals' unique communication needs	1
...be aware that some autistic women benefit from staff communicating with them in a way that puts less pressure on them. This might involve asking them to do things in a less directive or demanding way.	1
...provide autistic women with more written information during treatment	1
...be accepting of autistic women's need to stim (make repetitive actions/movement in order to get regulating sensory input)	0
...develop trusting and empathetic therapeutic relationships with autistic women with anorexia nervosa.	0
...be aware that it might take more time to develop therapeutic relationships with autistic women with anorexia compared to with non-autistic women with anorexia.	0.75
...be aware that autistic women with anorexia may be more likely to feel blamed by staff and should try and communicate information in a sensitive, non-blaming way.	1

A training package for eating disorder staff should...	
...be developed and delivered together with autistic women	0
...be delivered to all eating disorder staff so that they have a better understanding of autism	0
...teach staff about how autism might look different in women compared to men	0.25
...draw attention to autistic people's strengths and theories of neurodiversity instead of just deficit-based information.	0
...ensure staff are able to screen patients for autism	1
...ensure staff are able to distinguish between anorexia and ARFID (avoidant/restrictive food intake disorder, where a person finds eating particular foods very aversive due to things like texture and taste).	0.75
...teach staff about the ways that anorexia and autism may interact and affect each other	0
...ensure staff are able to distinguish between eating disorder behaviour and autistic behaviour, and train them to avoid setting treatment goals which aim to change autistic behaviour	0
...teach staff about meltdowns and shutdowns that autistic women may experience when overwhelmed, and how to avoid and respond to these	0
...teach staff how to adapt interventions so they are more suitable for autistic women	0

Table 5 shows the statements meeting consensus which made recommendations about service-level changes to support autistic women with AN. The statements make a variety of recommendations, including to adapt buildings to be less triggering to sensory sensitivities and to develop online information specifically aimed at autistic women with AN.

The statements meeting strong consensus (with an interquartile range of less than one) suggest autistic women would benefit from services being more flexible and transparent by providing more warning about changes to treatment, ensuring service rules are fully explained, and treatment plans are clear and broken into steps. A further statement with a high consensus recommends that services work collaboratively with autistic women to tailor treatment to the individual's needs.

**Table 5.**

*Statements reaching consensus about how services can support autistic women with anorexia nervosa. Statements were considered to have reached consensus if they had a median of six or greater and an interquartile range of one or less.*

Statement	Interquartile range
<b>Eating disorder services should...</b>	
...support autistic women with anorexia to manage changes in treatment. This might involve having more warning about changes or having longer transitions between teams.	0
...ensure that any rules (including 'unwritten' rules) are fully explained and justified, as autistic women may find it difficult to adjust to different rules in different services.	0.75
...provide autistic women with anorexia with structured, clear treatment plans with goals which are broken into achievable steps.	0.75
...work collaboratively with autistic women to tailor treatment to their individual needs, as what is helpful for one autistic woman may be unhelpful for another.	0
...ensure different staff to have a consistent approach with autistic women with anorexia	1
...ensure staff working with autistic women with anorexia need regular supervision to discuss their work.	1
...adapt buildings to be more autism-friendly and less triggering to sensory sensitivities. This could be done by designing spaces together with autistic people.	1
...be adapted to be more accessible for autistic people, i.e. communicating via text messages and emails as well as phone calls	0
...provide more online information aimed at autistic women with anorexia i.e. educational information, blog posts, community spaces	1
...use the PEACE pathway (Pathway for Eating disorders and Autism developed from Clinical Experience, developed by Kings College London and South London and Maudsley NHS Trust).	0.75
...be aware that traditional treatment and environments which are aimed at neurotypical people can be harmful to autistic women with anorexia	1
...be aware that some changes to treatment that would be helpful for autistic women might also be helpful for non-autistic women.	1

Across all the statements meeting consensus, there were recommendations made for treatment, the training of staff, and the organisation of services. Across the different groups of statements there were some similarities in the statements reaching consensus; statements referred to a need to distinguish between autistic and AN behaviours, a need to accommodate autistic traits, and the need to include autistic people in the development and delivery of care.

Many statements suggested treatments and staff should attempt to differentiate between behaviours relating to autism and those relating to AN. This was reflected by statements with strong consensus (with an interquartile range of less than one) which

recommended that staff receive training on the interaction of autism and AN and set treatment goals which do not aim to change autistic behaviour. Statements recommended supporting autistic women to cope with autistic traits which might affect their ED by exploring different ways to manage difficulties with attention and memory and regulate their sensory needs. This was also reflected by topics which occurred over multiple consensus-reaching statements, such as supporting autistic women to develop new routines and explore special interests which are unrelated to their ED.

Many statements referred to the need for staff, services, and treatments to accommodate autistic traits. This was reflected in statements with strong consensus (with an interquartile range of less than one) which advised that meal plans should avoid sensory sensitivities, staff should accept autistic women's need to 'stim', and services should be more transparent by providing more warning about changes and ensuring treatment plans are clear and structured. This was also reflected in topics which did not necessarily reach a strong consensus but reoccurred over multiple consensus-reaching statements, such as communication from staff needing to be adapted.

Finally, many statements emphasised the importance of including autistic people in training and treatment. This was reflected by statements with strong consensus (with an interquartile range of less than one) which recommended that autistic women are included in the development and delivery of training, for staff teams to have autistic staff members, and for services to work with autistic women to tailor treatment to their individual needs.

## **Discussion**

The present research systematically explored the views of researchers, clinicians, and EbE on how to support autistic women with AN receiving treatment for an ED. Based on the responses of participants, 70 statements were generated which provide suggestions about adaptations when providing treatment for autistic women with AN. Following three Delphi study rounds, 56 of these statements reached consensus. These statements made

recommendations for treatment, the training of staff, and the organisation of services. Many of the statements recommended that treatment distinguish between autism- and AN-related behaviours, autistic traits are accommodated, and autistic people are included in the development and delivery of care. The following section will discuss these recommendations in detail, their relation to theory and the broader literature, and their clinical implications.

### ***Distinguishing between autism and anorexia nervosa***

Several statements meeting consensus emphasised the importance of distinguishing between behaviours relating to autism and those relating to AN. Statements highlighted that treatment should avoid attempting to change autistic behaviour, although some statements identified that autistic women may require support to cope with autistic traits which might indirectly affect their AN.

Experts in the current study agreed that it is important for staff to be trained to distinguish between ARFID, autism- and AN-related behaviours in order to avoid setting treatment targets which aim to change autism-related behaviours. Additionally, experts suggested it is useful for autistic women to be supported to understand which of their experiences are related to autism and which are related to an ED. Brede et al.'s (2020) autism-specific model of restrictive eating provides a potential framework for distinguishing between autism- and AN-related behaviours. This model suggests autism-related traits can lead to restricted eating through a direct pathway, such as food-related sensory sensitivities leading to the avoidance of certain foods. In addition, autistic traits can lead to EDs indirectly, with food restriction as a way of coping with negative emotions arising from autism-related difficulties. For example, an autistic person might find it difficult to tolerate uncertainty, leading to feelings of anxiety. In this case restricted eating might develop as a way of 'numbing' anxiety, with control over calorie intake also providing a sense of control and predictability which reinforces the restricted eating (Brede et al., 2020). The indirect pathway between autistic-traits and ED symptoms is partially supported by research suggesting this relationship may be mediated by social anxiety (Kerr-Gaffney, Halls,



Harrison, & Tchanturia, 2020). Further empirical investigation of the pathways within Brede et al.'s (2020) model is required. It is worth noting that the same autism-related trait may lead to restricted eating via both direct and indirect pathways (Brede et al., 2020). This may make it challenging for staff to distinguish between autism- and AN-related behaviours in the way suggested by the present study.

Some of the statements meeting consensus suggested autistic women with AN might benefit from treatment which targets a different range of difficulties compared to treatment for non-autistic women with AN. Many of these additional treatment targets involved supporting autistic women to cope with autistic traits. Participants in the Delphi study suggested autistic women might benefit from support with daily tasks, managing difficulties with attention and organisational skills, regulating their sensory needs, and managing the impact of past traumatic social experiences. These autism-related experiences may indirectly affect autistic women by causing negative emotions which are coped with by restricting eating in the way described by Brede et al. (2020). Some statements also suggested that autistic women would benefit from support to develop new routines and rituals and explore special interests which are unrelated to their ED. AN-related routines and special interests are an example of a direct effect of autistic traits on ED symptoms as described by Brede et al. (2020). The statements meeting consensus suggested that autistic women should be supported to cope with autistic traits which might affect their AN, but that treatment should not attempt to change autistic traits.

The treatment targets proposed in the current study contrast with traditional ED treatments such as Enhanced Cognitive Behaviour Therapy (CBT-E) and the Maudsley Model of Anorexia Nervosa Treatment for Adults (MANTRA). Traditional ED treatments typically focus on addressing overevaluation of weight and shape, pro-anorectic beliefs, perfectionism, cognitive inflexibility, low self-esteem, difficulty coping with emotions, and difficulties with relationships (Cooper & Fairburn, 2011; Fairburn, Cooper, & Shafran, 2003; Murphy, Straebl, Cooper, & Fairburn, 2010; Schmidt et al., 2015; Treasure & Schmidt,

2013; Wade, Treasure, & Schmidt, 2011). These difficulties would be viewed as maintaining factors for an ED in a CBT model (Cooper & Fairburn, 2011; Fairburn et al., 2003) and are therefore recommended treatment targets, whereas Brede et al.'s (2020) autism specific model would suggest that some of these differences may be precipitating factors for autistic people with AN.

Neither CBT-E nor MANTRA would expect people with ED to require long-term support with daily tasks, attentional, or organisational skills, as cognitive difficulties would be expected to improve with weight restoration (Bodell et al., 2014; Lozano-Serra, Andrés-Perpiña, Lázaro-García, & Castro-Fornieles, 2014; Pender, Gilbert, & Serpell, 2014). Contrastingly, for autistic women with AN cognitive difficulties might be a feature of autism (Demetriou et al., 2018), which precipitates the development of an ED by leading to anxiety which is coped with by restricting eating (Brede et al., 2020). As a result, learning to cope with cognitive differences may be an important part of AN treatment for autistic women.

Trauma therapy and trauma informed treatment are not a standard feature of CBT-E or MANTRA (Cooper & Fairburn, 2011; Fairburn et al., 2003; Murphy et al., 2010; Schmidt et al., 2015; Treasure & Schmidt, 2013; Wade et al., 2011) despite the association between experiences of trauma and EDs (Trottier & MacDonald, 2017). Participants in the current study felt autistic people may have experienced additional trauma because of their socio-cognitive differences and experiences in a society which can be unaccepting of autistic behaviour. Similarly, these difficult experiences may cause negative emotions which are coped with by restricting eating (Brede et al., 2020). The results of this Delphi study suggest that autistic women with AN may benefit from support which target a wider range of difficulties than non-autistic women with AN.

### ***Accommodating autistic traits***

Many statements reaching consensus recommended that women's autistic traits should be accommodated during ED treatment instead of staff and services attempting to

change them. Statements which discussed the accommodation of autistic traits during treatment for AN discussed this in relation to adapting treatment to avoid sensory sensitivities, adapting communication for autistic women, and being flexible to the individual needs of autistic women.

Experts in the current study agreed that meal plans and treatment environments should be adapted to avoid autistic women's sensory sensitivities. This is consistent with previous research where autistic people reported that sensory inputs such as certain lights, colours, noises, and disliked food tastes and textures can trigger anxiety (MacLennan, O'Brien, & Tavassoli, 2021). Previous research also suggests autistic women might restrict food intake in response to sensory sensitivities (Brede et al., 2020). MacLennan et al. (2021) found many autistic people avoided aversive sensory stimuli to cope, and being unable to avoid these stimuli was distressing. Some autistic people in MacLennan et al.'s research reported they had adapted to some sensory inputs over time, but this was not a universal experience.

A statement which recommended that autistic women should be encouraged to try new food and textures did not meet consensus. Standard ED treatments such as CBT-E would formulate the avoidance of certain foods as relating to the over-evaluation of weight and shape (Cooper & Fairburn, 2011; Murphy et al., 2010). As a result, CBT-E would recommend the reintroduction of 'feared foods' (Cooper & Fairburn, 2011; Murphy et al., 2010). However, taken together with the literature, the present research would suggest many foods avoided by autistic women with AN are avoided due to sensory sensitivities which may not resolve with repeated exposure and will be distressing for the autistic person to be exposed to (MacLennan et al., 2021). The present research suggests treatment should be alert to and accommodate sensory sensitivities, while attempting to differentiate between sensory-based avoidance of foods and avoidance based on features of AN, such as weight restriction.

Individual differences are relevant when considering how to adapt menus to avoid autistic women's sensory sensitivities. Crane, Goddard, and Pring (2009) found high levels of within-group variability in autistic people's sensory processing differences, with different people having very different sensory sensitivities. Despite this, the PEACE pathway (Tchanturia, 2021; Tchanturia et al., 2020) only provides one menu which is designed to accommodate common sensory sensitivities by utilising bland, low odour, homogenous textured foods. This may not be fully adaptable to the diversity of sensory differences experienced by autistic people, including hyposensitivity and the seeking of food with more intense sensory qualities (Crane et al., 2009; MacLennan et al., 2021). Many statements meeting consensus in the current study highlighted the need to adapt treatment to the individual autistic person.

Several statements met consensus that suggested staff should adapt their communication when working with autistic women. These statements provide a variety of recommendations for how staff could change their communication, including asking specific questions and providing more written information. Previous research suggests autistic people desire adaptations to communication in healthcare settings, including the option to communicate in writing (Nicolaidis et al., 2015). Howard and Sedgewick (2021) found that autistic people's communication preferences depended on how well they knew the person they were communicating with. When accessing services, autistic people most prefer communicating by email, and preferred communicating by text to communicating face-to-face (Howard & Sedgewick, 2021). Taken together with the previous research, the current Delphi study suggests staff and services should adapt how they communicate with autistic women with AN, particularly by being more open to written communication.

Experts in the Delphi study suggested that there will be differences in communication preferences between different autistic women and they may benefit from individual communication 'passports' to detail their unique preferences. This is consistent with previous research which found some autistic people prefer written communication, whereas others

prefer face-to-face communication depending on their individual strengths (Cummins, Pellicano, & Crane, 2020). Communication and hospital passports are typically used to document the communication needs of individuals with intellectual disabilities (ID) who may or may not be autistic (Millar, 2007; Northway, Rees, Davies, & Williams, 2017; Thurman, Jones, & Tarleton, 2005). There is limited research into the impact of communication passports for adults with ID; the quality of passports vary (Northway et al., 2017) and having a passport is not associated with observed improvements in staff communication (Bradshaw, 2020). Despite this, a recent survey of inpatient psychiatric services found communication passports were used for autistic adults with and without ID (Jones, Gangadharan, Brigham, Smith, & Shankar, 2021). Overall, the results of this Delphi study suggest communication passports may be helpful for autistic women with AN, although it is important to ensure staff are adequately trained to develop and use them.

### ***Involving autistic people in treatment***

Several statements met consensus which emphasised the importance of including autistic people in the development of training, treatment, and their own care. Experts in the current study agreed that autistic women should be involved with the development and delivery of training for staff. This recommendation is in line with the wider context of autistic people's dissatisfaction with the focus of research about autism (Pellicano, Dinsmore, & Charman, 2013) and desire for more meaningful involvement in research (Fletcher-Watson et al., 2018; Milton, 2019). Despite development of guidelines on involving autistic people in research (Nicolaidis et al., 2019), there is a lack of research on involving autistic people in the coproduction of services. Stark et al. (2020) reflect on the process of coproducing a document in a team of autistic and non-autistic people, and their experiences are useful when considering the coproduction of treatment and services. The researchers reflect on aspects of the process such as the development of group rules, consideration of the meeting environment, and the use of digital communication to facilitate coproduction (Stark et al., 2020). Experts in the present study recommend autistic people are involved in the

development of services and treatment adaptations for autistic people with AN. The developing literature and guidelines on the meaningful involvement of autistic people in research are likely to be important in achieving this.

In addition, experts in the current study agreed that services should work with autistic women to ensure treatment is tailored to their individual needs. This is also reflected by consensus-reaching statements which suggest accommodations for sensory and communication differences need to be specific to the needs of the individual. Nicolaidis et al. (2015) found that autistic people felt that to improve experiences of healthcare, it was important for autistic people to be involved in providing information about their individual needs. Similarly, autistic people accessing mental health services feel support is not tailored to their individual needs, resulting in them withdrawing from services (Crane, Adams, Harper, Welch, & Pellicano, 2018). Autistic people identify individually tailored care as being important in enabling them to access mental health services (Camm-Crosbie, Bradley, Shaw, Baron-Cohen, & Cassidy, 2018; Crane et al., 2018). This Delphi study aligns with the literature in recommending that ED treatment for autistic women is tailored to their individual needs.

### ***Clinical implications***

The present Delphi study has implications for existing guidelines for adapting care for autistic women with AN and the development of training for staff working with autistic women with AN. All of the statements relating to training for staff in the present study reached consensus and could be utilised to develop a training package for staff.

Some of the recommendations endorsed in this study overlap with recommendations made by the PEACE pathway. Participants in the current study also endorsed a statement suggesting it is helpful for ED services to use the PEACE pathway. Recommendations shared between the current study and the PEACE pathway include training staff to screen for autism, and making adaptations to the physical environment (Tchanturia, 2021;

Tchanturia et al., 2020). Tchanturia et al. (2020) implemented staff training as part of the PEACE pathway, providing information for staff on how autism may present differently between males and females, and how to adapt interventions for autistic people. Experts in the current study also agreed that staff training should cover these areas. This study provides systematic support for these recommendations and suggests they may be beneficial in contexts elsewhere in the United Kingdom and globally.

The current study extends the recommendations made by the PEACE pathway further by providing additional information about the content of training for staff. Experts in the current study specified that training should be provided to all staff working with people with ED, include information on autistic strengths and theories of neurodiversity, train staff to avoid setting treatment goals which target autistic behaviour, and train staff about responding to autistic meltdowns and shutdowns.

The statements meeting consensus from the current study could be used to develop a training package for staff. It is recommended that any training package is developed and delivered in partnership with autistic women with AN as suggested by experts in the present study. The training package should aim to enable staff to distinguish between autism- and AN-related behaviours, possibly by drawing on Brede et al.'s (2020) theory of restrictive eating in autistic people. Staff should be trained to avoid attempting to change autistic behaviours. This has implications for existing ED treatments such as CBT-E, with difficulties such as perfectionism and interpersonal difficulties which are traditionally understood as maintaining factors and targeted in treatment (Cooper & Fairburn, 2011; Fairburn et al., 2003) instead being understood as precipitating factors which may not be possible to change. Staff should instead be trained to support women to cope with autism-related difficulties which indirectly affect their AN such as difficulties with attention and coping with past and present social experiences. Staff should be trained to accommodate autistic traits such as sensory sensitivities and differences in communication. Finally, staff should be trained to tailor treatment to the individual autistic person.

### ***Strengths and limitations***

This research represents a systematic investigation of how to support autistic women with AN, with equal and transparent contributions from professionals and people with lived experience. To the author's knowledge, this is the first time adaptations to treatment for autistic women with AN has been investigated in this way. Future research should investigate the effect of implementing these recommendations on outcomes for autistic women with AN.

The Delphi study included experts from across the UK as well as participants from the USA and Canada, suggesting that the recommendations are generalisable across these contexts. One limitation of the current study is the lack of detail about the backgrounds of experts. It would have been useful to collect additional details about the demographics of clinicians in the current study, such as their professional backgrounds, and details about whether EbE were currently receiving treatment or had recovered from having an ED. As the Delphi study involved storing personal data for participants across multiple rounds to be able to remind them of their previous responses, it was decided to collect minimal personal data from the participants to preserve their anonymity as much as possible. Instead of collecting more identifiable data about professional background and recovery status, number of years of experience and service development experience was collected to ensure participants were suitably qualified.

The present research aimed to investigate how to support autistic women with AN, however some participants referred to EDs in autistic people of other genders during the content analysis. As a result, two statements were generated which referred to non-binary or transgender autistic people with AN, although these did not reach consensus. It is possible these statements did not reach consensus because experts did not consider them helpful. However, as the present study specifically recruited participants with expertise about autistic women and AN it is possible that these participants did not have sufficient expertise about autistic people of other genders and with other EDs. A developing body of research suggests



a relationship between autism and the desire to be a different gender (van der Miesen, Hurley, Bal, & de Vries, 2018; van der Miesen, Hurley, & de Vries, 2016; Warriar et al., 2020), however the exploration of this in relation to the prevalence of EDs has been limited (Pham et al., 2021). Future research should investigate whether recommendations from the present study are useful for autistic people with other EDs and of other genders.

There was considerable attrition of experts between the initial recruitment phase and the first-round questionnaire. Attrition between survey rounds is a common difficulty in Delphi studies (Jorm, 2015). This can be due to both the length of questionnaires and the time commitment involved in these studies. It is worth noting that the round one questionnaire consisted of only open questions. Previous research has identified that clinicians lack confidence in working with autistic people with AN (Kinnaird et al., 2017). It is possible given this lack of confidence it would be challenging for clinicians to answer open questions about what would be helpful for autistic women with AN. This might have led to clinicians not completing the first questionnaire and contributed to attrition. Additional experts were recruited in the third round to ensure there a more equal number of participants from different expertise backgrounds. A potential weakness of this is there were fewer clinicians involved in the initial development of the statements and as a result they may not reflect the views of clinicians as well as they reflect the views of researchers and EbE.

## ***Conclusion***

The present research is a systematic investigation of the views of professionals and people with lived experience on the best ways to support autistic women with AN. The majority of statements generated from experts' suggestions met consensus, suggesting a high level of agreement. Some recommendations from this study overlap with suggestions made by the PEACE pathway (Tchanturia, 2021; Tchanturia et al., 2020) providing support for these recommendations and suggesting they may generalise to contexts other than the service where they were first developed. Overall, the Delphi study recommends that treatment for autistic women with AN aims to differentiate between behaviour relating to

autism and behaviour relating to ED. The present study recommends that staff, treatments, and services do not attempt to change autistic behaviour and instead accommodate autistic traits including sensory and communication needs during treatment. The Delphi study recommends staff support autistic women to cope with autistic traits as these may indirectly affect their AN by causing emotional distress which they use restrictive eating to cope with. Statements in the current study recommended that autistic women are supported to cope with difficulties with attention, memory and organisational skills, regulating their sensory needs, and coping with social relationships including past experiences which may have been traumatic. The present study recommends that any training package is developed together with autistic people and that staff and services work with individual autistic people to tailor treatment to their unique needs.

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## Appendix A

Submission guidelines for the Journal “Autism”, retrieved from wider author instructions available at <https://journals.sagepub.com/author-instructions/AUT>



# Autism

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DESCRIPTION

AIMS AND SCOPE

EDITORIAL BOARD

ABSTRACTING / INDEXING

SUBMISSION GUIDELINES

*Autism* is a major, peer-reviewed, international journal, published 8 times a year, publishing research of direct and practical relevance to help improve the quality of life for individuals with autism or autism-related disorders. It is interdisciplinary in nature, focusing on research in many areas, including: intervention; diagnosis; training; education; translational issues related to neuroscience, medical and genetic issues of practical import; psychological processes; evaluation of particular therapies; quality of life; family needs; and epidemiological research.

*Autism* provides a major international forum for peer-reviewed research of direct and practical relevance to improving the quality of life for individuals with autism or autism-related disorders. The journal's success and popularity reflect the recent worldwide growth in the research and understanding of autistic spectrum disorders, and the consequent impact on the provision of treatment and care.

*Autism* is interdisciplinary in nature, focusing on evaluative research in all areas, including:

- intervention
- diagnosis
- training
- education
- neuroscience
- psychological processes
- evaluation of particular therapies
- quality of life issues
- family issues and family services
- medical and genetic issues
- epidemiological research

All issues of *Autism* are available to browse [online](#).

## 1. What do we publish?

### 1.1 Aims & Scope

Before submitting your manuscript to Autism, please ensure you have read the [Aims & Scope](#).

### 1.2 Article Types

The Journal considers the following kinds of article for publication:

1. Research Reports. Full papers describing new empirical findings;
2. Review Articles

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

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

Both full Research Reports and Review Articles are generally restricted to a maximum of 6,000 words, including all elements (title page, abstract [**200 words maximum**], notes, tables, text), but excluding references. Editors may ask authors to make certain cuts before sending the article out for review.

3. Short Reports. Brief papers restricted to a maximum of 2,000 words with no more than two tables and 15 references. Short reports could include other approaches like discussions, new or controversial ideas, comments, perspectives, critiques, or preliminary findings. The title should begin with 'Short Report'.
4. Letters to the Editors. Readers' letters should address issues raised by published articles. The decision to publish is made by the Editors, in order to ensure a timely appearance in print. Letters should be no more than 800 words, with no tables and a maximum of 5 references.

### 1.3 Writing your paper

The SAGE Author Gateway has some general advice and on [how to get published](#), plus links to further resources.

## 4. Preparing your manuscript for submission

### 4.1 Formatting

When preparing your paper, think about how you can make it discoverable. The title, keywords and abstract are key to ensuring readers find your article through search engines such as Google. For 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](#).

Figures supplied in colour will appear in colour online regardless of whether or not these illustrations are reproduced in colour in the printed version. For specifically requested colour reproduction in print, you will receive information regarding the costs from SAGE after receipt of your accepted article.

### 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

#### 4.4.1 Terminology about autism and autistic people

*Autism* has researched and produced its own guidance on terminology and language used in autism research. Please consult the guide here: [autism terminology guidelines](#).

#### 4.4.2 Language used to discuss race and ethnicity

Likewise, *Autism* has also produced the following guidance to be considered when writing about race and ethnicity. Please consult the guide here: [race and ethnicity language guidelines](#).

### 4.5 Reference style

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

### 4.6 English language editing services

Authors seeking assistance with English language editing, translation, or figure and manuscript formatting to fit the journal's specifications should consider using SAGE Language Services. Visit [SAGE Language Services](#) on our Journal Author Gateway for further information.



### 5.3 Lay Abstracts

As part of your submission you will be asked to provide a lay abstract of your article. Lay abstracts are a brief (max 250 words) description of the paper that is easily understandable. These abstracts will be made widely available (to the general public, and particularly to autistic people and their families). As such, lay abstracts should avoid both technical terminology and the reporting of statistics. Examples of lay abstracts are provided in recent issues of the journal.

Authors may consider the following questions when composing their lay abstract.

- a. What is already known about the topic?
- b. What this paper adds?
- c. Implications for practice, research or policy

Authors may also find the following resources helpful on this topic:

- [How to write a summary paragraph](#)
- Self Advocacy Resource and Technical Assistance Center (SARTAC): [Plain Language](#)
- Center for Plain Language: [Five steps to Plain Language](#)

## Appendix B

*Copy of email confirming ethical approval of the research project by the university ethics committee, including amendments*

**Ethics Feedback - EC.21.03.09.6315RA3**

psychethics [REDACTED]

Mon 22/11/2021 09:58

To: Sarah Field [REDACTED]

Cc: [REDACTED]

Dear Sarah,

The Ethics Committee has considered the revised amendment to your PG project proposal: *A Delphi Study on the Most Effective Ways for Staff to Support Autistic Women with Anorexia Nervosa (EC.21.03.09.6315RA3)*.

Your amendment has received a **Favourable Opinion** based on the information described in the revised proforma and supporting documentation.

### **Conditions of the favourable opinion**

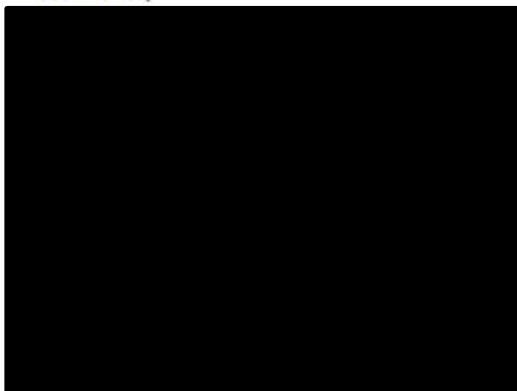
The favourable opinion is subject to the following conditions being met:

- You must retain a copy of this decision letter with your Research records.
- Please note that if any changes are made to the above project then you must notify the Ethics Committee.
- Please use the EC reference number on all future correspondence.
- The Committee must be informed of any unexpected ethical issues or unexpected adverse events that arise during the research project.
- The Committee must be informed when your research project has ended. This notification should be made to [REDACTED] within three months of research project completion.

**The Committee reminds you that it is your responsibility to conduct your research project to the highest ethical standards and to keep all ethical issues arising from your research project under regular review.**

**You are expected to comply with Cardiff University's policies, procedures and guidance at all times, including, but not limited to, its Policy on the Ethical Conduct of Research involving Human Participants, Human Material or Human Data and our Research Integrity and Governance Code of Practice.**

Best Wishes,



RE: Ethics Feedback - EC.21.03.09.6315

psychethics [REDACTED]

Tue 23/03/2021 11:01

To: Sarah Field [REDACTED]

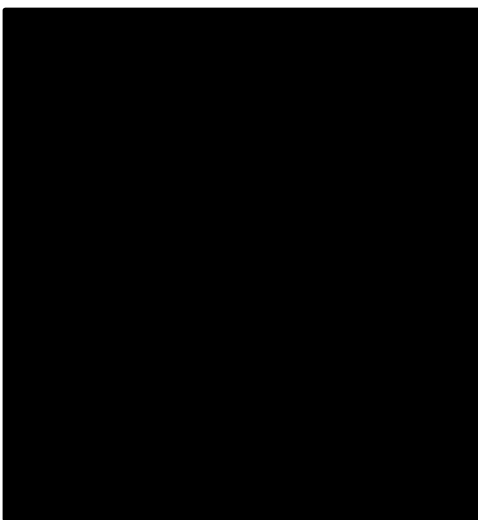
Cc: [REDACTED]

Dear Sarah,

Please note that the Committee have just approved your revised version of this proposal. Both myself and the Committee would like to say a big thank you for your incredible amounts of patience through all of this and apologies for the delay in the processing of it.

If you have any further queries, please come back to me.

Kind regards,



**School of Psychology Research Ethics Committee**

Cardiff University  
Tower Building  
70 Park Place  
Cardiff  
CF10 3AT

Prifysgol Caerdydd  
Adeilad y Tŵr  
70 Plas y Parc  
Caerdydd  
CF10 3AT



<http://psych.cf.ac.uk/aboutus/ethics.html>

Please note that I do not expect a response to this email outside of your normal working hours  
Nid wyf yn disgwyl ymateb i'r ebost hwn y tu allan i'ch oriau gwaith arferol

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**From:** Sarah Field [REDACTED]  
**Sent:** 22 March 2021 10:34  
**To:** psychethics [REDACTED]  
**Cc:** [REDACTED]  
**Subject:** Re: Ethics Feedback - EC.21.03.09.6315

[REDACTED]

Please find below my response to the ethics committee:

1. Please find attached a table showing the different points at which non-anonymised data will be collected and the point at which these bits of data will be anonymised (Personal data flowchart).
2. Participants will be made aware of and asked to consent to the anonymisation pathway. Please find attached a participant version of the document which will be given to participants as part of the consent process (Participant personal data flowchart)
3. I hope the two attached documents make the process and timescale for collecting non-anonymised data clearer.

If there are any further queries please do not hesitate to contact me.

Best wishes,  
Sarah

Sarah Field

**Trainee Clinical Psychologist**

*Doctoral Programme in Clinical Psychology, Cardiff University*  
11th Floor, Tower Building, 70 Park Place, Cardiff CF10 3AT

**Seicolegydd Clinigol dan Hyfforddiant**  
*Rhaglen Doethurol mewn Seicoleg Glinigol, Prifysgol Caerdydd*  
11fed Llawr, Adeilad y Tŵr, 70 Park Place, Caerdydd CF10 3AT

**From:** psychethics [REDACTED]

**Sent:** 12 March 2021 10:28

**To:** Sarah Field [REDACTED]

**Cc:** [REDACTED]

**Subject:** Ethics Feedback - EC.21.03.09.6315

Dear Sarah,

The Ethics Committee has considered your PG project proposal: *A Delphi Study on the Most Effective Ways for Staff to Support Autistic Women with Anorexia Nervosa* (EC.21.03.09.6315).

The following comments were made:

1. The Committee queried which stage the data will be anonymised, will it take place after stage 3 which seems to be within a year?
2. The Committee questioned whether the participants' will be consenting to this anonymisation data pathway?
3. The Committee felt that it is very important for this anonymisation to be clearly stated, and for the participants' to be crystal clear on the procedure and timeline.

Please may I have your response to these comments plus any amended paperwork (with changes highlighted) by email, as soon as possible.

Best wishes,

[REDACTED]

**School of Psychology Research Ethics Committee**

Cardiff University  
Tower Building  
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[REDACTED]

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**Please note that I do not expect a response to this email outside of your normal working hours**

**Nid wyf yn disgwyl ymateb i'r ebost hwn y tu allan i'ch oriau gwaith arferol**

## Appendix C

Statements generated in the content analysis, median agreement with each statement in round 2, and median agreement and interquartile range for each statement in round 3. Statements which reached consensus are marked with an asterisk.

Statement	Round 2 Median agreement	Round 3 Median agreement	Round 3 Interquartile range
<b>Autistic women with anorexia might...</b>			
...feel they have to stick rigidly to meal plans given to them by services, which can be distressing when the meal plan can't be kept to.	6.5	6	1*
...be more likely to have other physical or mental health conditions which need considering during treatment	7	7	1*
...be more likely to self-harm than non-autistic women with anorexia	5	4.5	2
...find weight gain distressing because of changes in their sensory experiences of their clothes or bodies	6	6	2
...need more time to complete and switch between tasks.	6.5	7	1*
...find changes in staff or unfamiliar staff more difficult to work with	7	7	0*
...not benefit from group therapy	5.5	5	2
...might be labelled as being 'resistant' due to not benefitting from traditional treatments	7	7	1*
...have a different response to mental health medication compared to non-autistic people	6	5	1.75
<b>Autistic women with anorexia might benefit from...</b>			
...being supported to explore their special interests which are separate from food.	7	7	1*
...being treated by teams which have autistic staff members and therapists.	7	7	0.75*
...being treated by staff who are experienced in working with autistic people	7	7	0*
...support and mentorship from other autistic people	7	7	1*
...receiving treatment as an inpatient instead of receiving treatment in the community	4	3	2

Statement	Round 2 Median agreement	Round 3 Median agreement	Round 3 Interquartile range
<b>Eating disorder staff might...</b>			
...have negative beliefs and reactions towards autistic behaviour e.g. believing that meltdowns are 'tantrums' or that lack of eye contact is impolite	7	6.5	2
...have concerns that non-autistic patients will think it is unfair that autistic women with anorexia receive different treatment	6	6	1*
...find it harder to relate to an autistic woman's experiences and understand her communication style compared to when they work with non-autistic women	6	6	2
...find it difficult to work with autistic women with anorexia because of pressure on services and a lack of time	6	6	1*
<b>Eating disorder staff should...</b>			
...change how they communicate with autistic women. Staff should try and ask specific questions instead of open ones. Staff should try and be clear about what they mean and check they have been understood.	7	7	1*
...develop 'communication passports' with autistic women so that all staff know the individuals' unique communication needs	7	7	1*
...be aware that some autistic women benefit from staff communicating with them in a way that puts less pressure on them. This might involve asking them to do things in a less directive or demanding way.	6.5	7	1*
...provide autistic women with more written information during treatment	7	7	1*
...be accepting of autistic women's need to stim (make repetitive actions/movement in order to get regulating sensory input)	7	7	0*
...develop trusting and empathetic therapeutic relationships with autistic women with anorexia nervosa.	7	7	0*
...be aware that it might take more time to develop therapeutic relationships with autistic women with anorexia compared to with non-autistic women with anorexia.	7	7	0.75*
...be aware that autistic women with anorexia may be more likely to feel blamed by staff and should try and communicate information in a sensitive, non-blaming way.	7	7	1*
<b>Eating disorder treatment for autistic women should...</b>			
...usually place less focus on body image than treatment for non-autistic women	5	5	1.75
...be aware that autistic people are more likely to be gender non-conforming, non-binary or transgender. This can have an impact on their body image and might need to be explored during treatment.	6	6	1.75
...involve asking autistic people with anorexia screening questions about their gender identity.	6	6	2
...involve support in a broader range of areas compared to non-autistic women with anorexia. Autistic women may benefit from support accessing education and employment, finding suitable accommodation, and finding support with daily tasks	6.5	6	1*
...support autistic women to learn how to manage difficulties they might have with their attention, memory and organisational skills	6	6	1*
...provide autistic women with information about the effects of starvation and refeeding on their bodies and minds	6.5	7	1*

Statement	Round 2 Median agreement	Round 3 Median agreement	Round 3 Interquartile range
<b>Eating disorder treatment for autistic women should...</b>			
...support autistic women to understand what parts of their experiences are related to their autism and what parts are related to their eating disorder	7	7	1*
...support autistic women with anorexia to develop new routines and rituals to replace unhelpful routines which are related to their eating disorder	7	7	1*
...support autistic women to develop social skills	5.5	5	2
...support autistic women to manage the demands of social relationships	6	6	1*
...provide some autistic women with a trauma-informed approach or therapy to manage their past social experiences i.e. experiences of living in a society that can be negative about autism and autistic behaviour	7	7	1*
...ensure that any specific psychological therapies like CBT are adapted for autistic women with anorexia.	7	7	0.75*
...involve a longer course of psychological therapy.	6	6	2
...include specific therapy aimed at identifying and regulating emotions	6	6	2
...support autistic women to explore their self-esteem and identity. This might involve exploring their identity as an autistic person.	6	6	1*
...support autistic women to identify what hunger cues feel like in their body	7	7	1*
...adapt meal plans for autistic women to avoid their sensory sensitivities.	7	7	0*
...encourage autistic women with anorexia to try new foods and new food textures	4	4	2
...support autistic women to learn the best ways to regulate their sensory needs. This might involve using aids like weighted blankets, stim toys or headphones/ear plugs and allowing these to be used during mealtimes.	7	7	1*
...support autistic women to develop coping strategies that can be used in lots of different environments	7	7	1*
...draw on the individual's strengths to help them recover	7	7	0*
...include education and support for autistic women's families where possible.	6	6	1*
<b>A training package for eating disorder staff should...</b>			
...be developed and delivered together with autistic women	7	7	0*
...be delivered to all eating disorder staff so that they have a better understanding of autism	7	7	0*
...teach staff about how autism might look different in women compared to men	7	7	0.25*
...draw attention to autistic people's strengths and theories of neurodiversity instead of just deficit-based information.	7	7	0*



Statement	Round 2 Median agreement	Round 3 Median agreement	Round 3 Interquartile range
<b>A training package for eating disorder staff should...</b>			
...ensure staff are able to screen patients for autism	6.5	7	1*
...ensure staff are able to distinguish between anorexia and ARFID (avoidant/restrictive food intake disorder, where a person finds eating particular foods very aversive due to things like texture and taste).	7	7	0.75*
...teach staff about the ways that anorexia and autism may interact and affect each other	7	7	0*
...ensure staff are able to distinguish between eating disorder behaviour and autistic behaviour, and train them to avoid setting treatment goals which aim to change autistic behaviour	7	7	0*
...teach staff about meltdowns and shutdowns that autistic women may experience when overwhelmed, and how to avoid and respond to these	7	7	0*
...teach staff how to adapt interventions so they are more suitable for autistic women	7	7	0*
<b>Eating disorder services should...</b>			
...support autistic women with anorexia to manage changes in treatment. This might involve having more warning about changes or having longer transitions between teams.	7	7	0*
...ensure that any rules (including 'unwritten' rules) are fully explained and justified, as autistic women may find it difficult to adjust to different rules in different services.	7	7	0.75*
...provide autistic women with anorexia with structured, clear treatment plans with goals which are broken into achievable steps.	7	7	0.75*
...work collaboratively with autistic women to tailor treatment to their individual needs, as what is helpful for one autistic woman may be unhelpful for another.	7	7	0*
...ensure different staff to have a consistent approach with autistic women with anorexia	6	6	1*
...ensure staff working with autistic women with anorexia need regular supervision to discuss their work.	6	7	1*
...adapt buildings to be more autism-friendly and less triggering to sensory sensitivities. This could be done by designing spaces together with autistic people.	6.5	7	1*
...be adapted to be more accessible for autistic people, i.e. communicating via text messages and emails as well as phone calls	7	7	0*
...provide more online information aimed at autistic women with anorexia i.e. educational information, blog posts, community spaces	6.5	6	1*
...use the PEACE pathway (Pathway for Eating disorders and Autism developed from Clinical Experience, developed by Kings College London and South London and Maudsley NHS Trust).	6	6	0.75*
...be aware that traditional treatment and environments which are aimed at neurotypical people can be harmful to autistic women with anorexia	7	7	1*
...be aware that some changes to treatment that would be helpful for autistic women might also be helpful for non-autistic women.	7	7	1*

