TOWARDS A BETTER UNDERSTANDING OF RESTRICTIVE EATING DISORDERS IN AUTISTIC WOMEN

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Thesis submitted for the Degree of Doctor of Philosophy

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September 2021

Declaration

I, Janina Brede, confirm that the work presented in this thesis is my own. Where information has been derived from other sources, I confirm that this has been indicated in the thesis.

Janina Brede

Signed, 24th September 2021

Acknowledgements

Supervisors: I would like to thank my brilliant primary and secondary supervisors, Professor Will Mandy and Professor Lucy Serpell, for your constant support and guidance throughout this PhD. I have learned a lot from both of you and am fortunate to have had you as my supervisors. This PhD has been such an enjoyable and rewarding experience, and I am very grateful for the opportunity.

SEDAF team: I would like to thank Professor John Fox and Dr Catherine Jones for your contributions and guidance. Charli Babb, it was incredibly reassuring to have you on my side and I truly enjoyed sharing this journey with you.

Collaborators and Colleagues: I would like thank all of the other collaborators for their contributions to different parts of this PhD. I am very grateful for your time and insights, which have shaped this research for the better. Special thanks to Mair Elliot, Dr Cathy Zanker, Anika Smith, and Lisa Palmer. Thank you to everyone in our Lab group, especially Dr Julia Cook, Dr Laura Hull, and Laura Bourne for all your advice and support. Thank you to Emily Thomas, Gianna Kohl and Dr Mike Wang for being amazing colleagues and supportive friends.

Participants: I would like to thank all of the participants for generously sharing their time and experiences. I hope that the research you contributed to will translate into meaningful change.

Friends and Family: Thank you to my friends within and outside of academia for motivating, supporting, and distracting me. Carlos, you have been a constant source of confidence and encouragement. Thank you for your patience during the more stressful times. I would like to thank my brother Julius, and, in particular, my parents, Carola and Mike Brede, for your unconditional support; I truly appreciate it.

Funders: The work conducted for this thesis was funded by a studentship provided by Autistica and UCL. Thank you for making this work possible.

Abstract

Autistic women are overrepresented among individuals with restrictive eating disorders (REDs), such as Anorexia Nervosa, and commonly available eating disorder treatments tend to lack efficacy in this client group. This PhD employed a mixed-method approach with the aim of contributing evidence that can inform the improvement of eating disorder service provision for autistic women. Specifically, this thesis sought to generate a better understanding of (1) women's experiences of REDs, (2) the mechanisms that might link autism and REDs in women, and (3) the ways in which mental health services function for their autistic clients.

Three studies were undertaken. In Study 1 we conducted semi-structured interviews with autistic women with experience of Anorexia Nervosa, parents, and healthcare professionals (N=45) to identify potential causal and maintaining factors of Anorexia Nervosa in autistic women. Based on these findings, we developed a theoretical model of restrictive eating difficulties in autistic individuals.

Study 2 further examined the clinical presentation of autistic women with REDs and tested elements of the model developed in Study 1. Study 2 compared the presentation of autistic traits, disordered eating-related symptoms and sensory sensitivities, measured using self-report questionnaires, in autistic women with and without REDs and non-autistic women with REDs (N=210). Autistic women with REDs presented with similar levels of autistic traits and sensory sensitivities to autistic women without REDs. They presented with: (i) significantly lower levels of traditional disordered eating symptoms, traditionally associated with Anorexia Nervosa, than non-autistic women with REDs, although these were still evident compared to autistic women without REDs, and (ii) significantly higher levels of autism-specific unusual eating behaviours than both other groups. These findings

suggest that while core autism characteristics and sensory sensitivities are unlikely to directly contribute to REDs in autistic women, there might be other autism-related difficulties that make some autistic women more vulnerable to developing REDs than others. Study 2 also identified a subset of women with REDs who did not have an autism diagnosis, but had very high autistic traits (n=36). These presented similarly to formally diagnosed autistic women with REDs on measures of autistic traits, autism-specific unusual eating behaviours and sensory sensitivities, suggesting a significant proportion could be undiagnosed autistic women.

Study 3 was systematic review and meta-synthesis of qualitative research on autistic adults' experience of accessing and receiving support for mental health difficulties. This study elucidated perceived barriers for autistic adults in mental health services and ways to overcome them.

The current thesis increases our understanding of the clinical presentation for autistic women with REDs and can help eating disorder services to become more autism friendly, by informing treatment adaptations to better meet their needs. In the long-term, the current thesis may contribute to the development of new autism-informed eating disorder treatments and interventions to prevent of development of restrictive eating disorders in autistic individuals.

Impact statement

The research conducted as part of this thesis directly benefits affected individuals by increasing awareness of autism-specific restrictive eating disorder (RED) presentations and helping eating disorder (ED) services to become more autism-friendly. The current thesis generated new insights, which will stimulate further research and inform clinical practice.

The systematic review and meta-synthesis highlights treatment adaptations and changes to service provision, which could increase mental health services' accessibility for autistic adults. Its finding have applicability across a range of mental health services settings, and thus, have the potential to inform policy and practice related to mental health service provision for autistic adults.

We present the first study assessing the clinical presentation of autistic women with REDs, in comparison to both autistic women without REDs and non-autistic women with REDs. The finding that autistic women's REDs presentation deviated from other women with REDs could explain why autistic women with REDs have poor treatment outcomes (Nazar et al., 2018; Stewart et al., 2017; Tchanturia et al., 2016), as commonly offered treatments do not address autism-specific mechanisms underlying their REDs.

We developed a theoretical model of potential mechanism underlying restrictive eating difficulties in autistic individuals and present empirical data providing initial evidence supporting some elements of the model. Following further testing, a revised version of the model could be used as a framework for clinical formulation and to inform treatment adaptations. In the long-term, it may contribute to the development and testing of new autism-specific ED treatments and inform

interventions to prevent the development of restricted eating behaviours in autistic individuals.

We demonstrated that a significant proportion of women with REDs have very high autistic traits and resemble formally diagnosed autistic women in their clinical presentation. This insight will improve the recognition of individuals in ED settings, who could benefit from autism-specific adaptations.

We provide initial evidence for the utility of the Ritvo Autism Asperger Diagnostic Scale –14 (RAADS-14; Eriksson et al., 2013) as an autism screening measure and of the SWedish Eating Assessment for Autism spectrum disorders (SWEAA, Karlsson et la., 2013) to identify autism-specific unusual eating behaviours in ED populations. This thesis also raises questions about the applicability of existing sensory sensitivities questionnaires to measure food-specific sensory sensitivities, and highlights opportunities for new, bespoke measures.

By informing the improvement of mental health care for autistic adults, this thesis addresses a key research priority of the autism community and policy, as established by community priority setting exercises (e.g. Cusack & Sherry, 2016) and as recognised by policy bodies, such as the World Health Organisation (WHO) and National Health Service (NHS) long-term plan (WHO, 2013; NHS, 2019). This research addresses another important issue, namely early mortality in autistic individuals, who on average die 16 years earlier than non-autistic people (Hwang et al., 2019), with suicide rates being nine times higher (Hirvikoski et al., 2016). Anorexia Nervosa has the highest mortality rate of all mental disorders, mostly due to high levels of medical complications in underweight individuals and suicide (Arcelus et al., 2011; Chesney et al., 2014). By promoting the development of better

ED treatments for autistic individuals, this research contributes towards countering a cause of early death in autism.

Research presented in this thesis has and will be disseminated in academic and clinical circles including through academic publications, conference presentation and posters. Study 1 was published in the Journal of Autism and Developmental Disorders (Brede et al., 2020), which has been accessed over 14,000 times between April 2020 and September 2021. Study 3 is currently under review at Clinical Psychology Review. The conducted research has already gained attention from the autism community, other researchers, ED services and charities. It has generated requests for invited talks, including for the NAS Harrogate Autism and eating disorder conference (2019), NELFT eating disorder conference (2019), German WGAS conference (2021), FICAPS conference (2021), and Autistica Expert Webinar (2021).

The research presented as part of this thesis was conducted by establishing new academic and non-academic collaborations, including with researchers at Cardiff University, autistic advocates, and members of the Autistica mental health study group.

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List of Abbreviations

AN = Anorexia Nervosa

ADHD = Attention Deficit Hyperactivity Disorder

ADOS-2 = Autism Diagnostic Observation Schedule, Second Edition

ANCOVA = Analysis of co-variance

ANOVA = Analysis of variance

APA = American Psychiatric Association

AQ = Adult Autism Spectrum Quotient

ARFID = Avoidant restrictive food intake disorder

ASD/C = Autism Spectrum Disorder/Condition

BFNE = Brief Fear of Negative Evaluation Scale

BSQ = Body Shape Questionnaire

CAT-Q = Camouflaging Autistic Traits Questionnaire

COVID-19 = Corona Virus

DSM-5 = Diagnostic and Statistical Manual of Mental Disorders – 5th Edition

ED = Eating Disorder

EDE-Q = Eating Disorder Examination-Questionnaire

GAD = General Anxiety Disorder

GSQ = Glasgow Sensory Questionnaire

HAADS = Hospital Anxiety and Depression Scale

HCP = Healthcare professional

HCT = heartbeat counting task

HRA = Health Research Authority

IAT = Implicit Association Test

ICD-11 = International Classification of Diseases – 11th Edition

ID = Intellectual Disability

ISQ = Interoception Sensory Questionnaire

IUS-12 = Intolerance of uncertainty -12 item version

MMAT = Mixed Methods Appraisal Tool- Version 18

Mdn = Median

NICE = National Institute for Health and Care Excellence

NHS = National Health Service

OCD = Obsessive–Compulsive Disorder

ODD = Oppositional Defiant Disorder

PDD-NOS = Pervasive Developmental Disorder-Not Otherwise Specified

PEP-S = Pride in Eating Pathology Scale

RAADS-14 = Ritvo Autism Asperger Diagnostic Scale –14

RED = Restrictive eating disorder

RRBs= Restricted and Repetitive Behaviours

SATAQ-3 = Social Attitudes Towards Appearance Scale

SARS-CoV-2 = severe acute respiratory syndrome coronavirus 2

SPIN = Social Phobia Inventory

SD = Standard deviation

SNP = Single-nucleotide polymorphism

SWEAA = SWedish Eating Assessment for Autism spectrum disorders

TAS-20 = Toronto Alexithymia Scale

ToM = Theory of Mind

ToPF = Test of Premorbid Functioning

WHO = World Health Organisation

3Di-Adult = Dimensional, Developmental and Diagnostic Interview-Adult version

Chapter 1: General Introduction

Autistic women are overrepresented in restrictive eating disorder (RED) populations (Huke et al., 2013; Westwood & Tchanturia, 2017), and commonly available eating disorder (ED) treatment approaches appear to lack efficacy in this client group (Nazar et al., 2018; Nielsen et al., 2015; Stewart et al., 2017; Tchanturia et al., 2016). This PhD thesis employs a mixed-method approach, combining qualitative and quantitative research, with the aim of contributing to an evidence base that can inform the improvement of ED service provision for autistic women. Specifically, this thesis seeks to generate a better understanding of (1) women's experiences of REDs, (2) the mechanisms that might link autism and REDs in women, and (3) the ways in which mental health services function for their autistic clients. The current chapter provides an introduction in the form of a narrative overview of relevant background literature, as well as providing the rationale for and an outline of the remainder of the thesis.

What Is Autism?

Autism, which is referred to as autism spectrum disorder (ASD) in the Diagnostic and Statistical Manual of Mental Disorders (DSM-5; American Psychiatric Association [APA], 2013) and the International Classification of Diseases (ICD-11; World Health Organisation [WHO], 2018), is a lifelong neurodevelopmental condition that affects the way people interact with and experience the world around them. Autistic individuals present with persistent differences in initiating and sustaining social communication and interaction, as well as repetitive patterns of behaviour and focused interests, including hyper- and hypo-reactivity and seeking behaviours towards to sensory stimuli. Autism is considered to exist along a spectrum, which gives rise to two overlapping understandings of the condition. First, the presentation

of autistic characteristics, and its associated strengths and difficulties, vary widely across autistic people (Duvall et al., 2021; Lai et al., 2013). Second, autism is a dimensional, rather than a categorical condition. Those who meet the diagnostic criteria represent the extreme of a trait continuum that extends throughout the general population, and there is no natural cut point between autistic and non-autistic individuals (Abu-Akel et al., 2019; De Groot & Van Strien, 2017). To obtain a clinical diagnosis of autism, an individual must experience characteristics that cause significant difficulty to everyday functioning, and those characteristics must be present from early childhood, although they may not fully manifest until social demands exceed the individual's capacity, or they may be masked by learned strategies in later life (APA, 2013; WHO, 2018).

Language Use Around Autism

This thesis will use identity-first language when talking about autistic people, as this tends to be preferred by members of the autistic community and those who support them (Bury et al., 2020; Kenny et al., 2016). However, it should be noted that different individuals use different ways of identifying and/or referring to autistic people (Kenny et al., 2016).

Similarly, the current thesis will avoid 'deficit,' 'impairment,' and 'disorder' focused language, which often dominates discourse around autism, particularly in the medical field (Kapp et al., 2013). Many members of the autistic community reject these labels, because they tend to pathologise autistic people's differences, overemphasise the difficulties they experience, and minimise their strengths and capacities (Farahar, 2021). However, this approach is not intended to undermine or ignore the challenges and support needs many autistic people experience (Griffiths

et al., 2019), including the high prevalence of co-occurring mental health difficulties (Lai et al., 2019), which is the focus of this thesis.

Prevalence and Causes

In the UK, around 1% of the population is thought to meet the diagnostic criteria for autism, which is in line with global prevalence estimates (Baird et al., 2006; Elsabbagh et al., 2012). At least 15%–29% of autistic individuals present with co-occurring intellectual disability (ID) and/or do not use functional language to communicate (Kinnear et al., 2020; Rose et al., 2016), although estimates vary, with some as high as 50%–70% (Matson & Shoemaker, 2009).

The aetiology of autism is not yet fully understood (Mandy & Lai, 2016). However, it is clear that autism has a strong genetic component (Amaral, 2017). The concordance rate for autism has been consistently found to be higher for monozygotic twins than dizygotic twins (e.g., Colvert et al., 2015; Ronald & Hoekstra, 2011), and heritability rates are estimated at up to 80% (Lichtenstein et al., 2010; Mandy & Lai, 2016). The search for specific genetic contributors to autism is complex, partly due to its significant heterogeneity (Freitag et al., 2010). Single Nucleotide Polymorphisms (SNP) research, which focuses on common types of genetic variation among people, shows that in a majority of cases, autism is caused by the additive effect of multiple common variants of genes acting in combination (Gaugler et al., 2014). In contrast, approximately 10%–20% of autism cases are caused by a specific identifiable genetic syndrome or de novo genetic mutation (Abrahams & Geschwind, 2008). Numerous combinations of genetic variants and specific genetic mutations thought to be implicated in autism aetiology have been identified thus far, and more likely exist (Betancur, 2011). However, each genetic

contributor only explains a small fraction cases, and their presence does not always mean that an individual will meet autism diagnostic criteria (Gerdts & Bernier, 2011).

In addition to genetic components, there are also a number of environmental factors that are thought to increase the likelihood of autism and influence its presentation and developmental pathway, either alone or in combination with genetic predispositions. Most of these factors act prenatally (Amaral, 2017; Mandy & Lai, 2016). They include greater parental age, maternal infections, and use of certain drugs during pregnancy (Amaral, 2017; Kim et al., 2019). Finally, how autism characteristics affect an individual's life will depend in part on the environment the individual is in and the support they receive (Mandy & Lai, 2016). Given the variety of genetic and environmental pathways, autism, as it is currently conceptualised, is not assumed to be a single entity, but rather a behavioural manifestation of various combinations of causes (Betancur, 2011).

Autism in Females

Autism is more commonly diagnosed in males than in females[1] (Loomes et al., 2017). However, there is growing evidence that autism is underdiagnosed in females. Loomes and colleagues (2017) conducted a meta-analysis, which pooled 54 studies, to assess gender ratios in autism. Across studies, the gender ratio was around 4:1 (Loomes et al., 2017). Interestingly, studies that only included participants with a pre-existing autism diagnosis (for example, recruited from clinical settings) reported an average ratio of 4.6:1, whereas studies that screened the general population to identify participants regardless of diagnostic status showed a lower ratio, closer to 3:1. While autism is likely to be less common in females due to a

[1] Note that we use the term females to describe both women and girls, and males to describe both boys and men.

general protective effect of biological sex differences against genetic conditions (Baron-Cohen, 2002; Kreiser & White, 2014; Robinson et al., 2013), the discrepancy in gender ratios observed by Loomes et al. (2017) also suggests there are females in the general population who, if assessed, would meet the criteria for autism, but who do not receive a clinical diagnosis.

Diagnostic biases are thought to contribute to an exaggeration of the true male-to-female ratio in autism. Autistic girls are referred and receive an autism diagnosis significantly later than boys, meaning it takes longer for their autism to be recognised (Begeer et al., 2013; Rutherford et al., 2016; Shattuck et al., 2009). Further, girls with equivalent levels of autism characteristics are less likely than boys to receive an autism diagnosis, unless they present with co-occurring intellectual disability or substantially more emotional and behavioural problems (Duvekot et al., 2017; Dworzynski et al., 2012; Russell et al., 2011). Autism diagnostic assessments are based on observation and description of core characteristics and related behaviours against established diagnostic criteria (APA, 2013; WHO, 2018; National Collaborating Centre for Mental Health, 2013). These criteria, and the standardised diagnostic assessment tools used to identify them, were informed by research that used predominantly male participants (Thompson et al., 2003). This is not surprising, given the gender difference in diagnosis (Loomes et al., 2017). However, there is evidence that autism can present differently in females (Hull et al., 2020), particularly those without intellectual disability (Russell et al., 2011). The lack of inclusion of autistic females in research informing autism diagnostic criteria is thought to have resulted in a biased understanding of the expression of core autism characteristics, as well as decreased sensitivity of diagnostic tools when identifying autistic traits in girls and women (Kirkovski et al., 2013; Kopp & Gillberg, 2011; Kreiser & White,

2014). This gap in the research continues to perpetuate the under-recognition of autistic girls and women.

There are several ways in which the presentation of autism in females might deviate from more traditional expectations of what autism looks like, which is why it might be missed in autistic girls and women (Lai et al., 2015; Loomes et al., 2017; Whitlock et al., 2020). First, differences in social communication and interaction might be less apparent in autistic females. Often, these differences become evident in the social relationships of autistic individuals. However, the friendships and social motivation of males and females on the autism spectrum differ (Head et al., 2014; Sedgewick et al., 2018). Autistic boys tend to have different friendship patterns than non-autistic boys, and tend to be less motivated to form social relationships (Sedgewick et al., 2016). In contrast, autistic girls and women tend to have similar motivation to form social relationships as non-autistic girls/women (Lai et al., 2015; Sedgewick et al., 2016), and are more likely to be able to initiate friendships (Hiller et al., 2014). Nevertheless, autistic females still commonly experience difficulties in their social relationships. Autistic girls tend to experience more conflict and find it harder to maintain relationships than their non-autistic peers, particularly in adolescence, when greater social skills are required to navigate peer relationships (Hiller et al., 2014; Picci & Scherf, 2014; Sedgewick et al., 2018). This means autistic boys' social and interaction differences might stand out more, whereas difficulties experienced by autistic girls might not become apparent until they are older, resulting in greater rates of late or misdiagnosis in autistic girls (Bargiela et al., 2016; Fusar-Poli et al., 2020; Lai et al., 2015).

Secondly, the presentation of restricted, repetitive behaviour and interests can be different in autistic girls and women, compared to boys and men. Special interests

are often seen as indicators of this criterion during diagnostic assessments. Special interests are activities and topics that autistic people pursue with high intensity and focus and that are often a source of joy and excitement for them (Grove et al., 2018). There is some evidence that autistic males are more likely to have special interests than autistic females (Grove et al., 2018). In addition, there are gender differences in the topics of special interest, with the interests of autistic girls and women often being less obvious, less stereotypical, and more in line with the interests of their peers (Grove et al., 2018; Nowell et al., 2019). Further, autistic girls and women tend to more often describe autism, relational objects, or the social world as one of their special interests (Grove et al., 2018; Mandy, Chilvers, et al., 2012), and they might use the knowledge they gain from engaging with these interests to navigate their own relational difficulties. This might be another reason why autistic girls are not as commonly recognised.

Finally, on average, autistic girls and women are more likely to engage in camouflaging and masking behaviours (Cook, Hull, et al., 2021; Hull et al., 2020). These are conscious and unconscious strategies used to mask or compensate for autistic traits in social interactions (Hull et al., 2017). Examples of camouflaging and masking behaviours include looking at a social partner's forehead to maintain the appearance of eye contact, altering facial expressions and gestures to appear less autistic, and supressing unusual behaviours, such as stimming (e.g. hand flapping), which might be perceived as odd and unfavourable (Cook, Crane, et al., 2021). Engaging in camouflaging and masking behaviours can help autistic individuals to cope with the stigma of being autistic and fit in in social situations, such as the workplace (Hull et al., 2017). However, these behaviours have also been linked to burnout and mental health difficulties (Beck et al., 2020; Cage et al., 2018; Cage &

Troxell-Whitman, 2019; Hull et al., 2021), potentially due to the effort required to keep up camouflaging behaviours and the impact on the person's sense of self (Bargiela et al., 2016; Hull et al., 2017; Tierney et al., 2016). Autistic people who engage in camouflaging and masking behaviours present as less 'traditionally' autistic, and thus might be less likely to be picked up for a diagnostic assessment or receive a diagnosis. Consequently, they might not receive support they could benefit from.

Autism and Co-Occurring Mental Health Difficulties

In addition to the strengths and difficulties directly associated with being autistic, autistic individuals also experience elevated rates of co-occurring mental health conditions compared to the general population (Croen et al., 2015; Joshi et al., 2013; Lai et al., 2019), and this is often a source of additional support needs (Russell et al., 2016). Seventy percent of autistic children present with at least one co-occurring mental health condition, and 41% have multiple co-occurring conditions (Simonoff et al., 2008). Similarly, prevalence rates of mental health conditions for autistic adults range from 54%–80% (Croen et al., 2015; Lever & Geurts, 2016), with up to 57% meeting criteria for multiple co-occurring conditions (Lever & Geurts, 2016). Anxiety and mood disorders are the most common mental health difficulties experienced by autistic individuals. A recent meta-analysis reported pooled estimates of 27% for current and 42% for lifetime prevalence for any anxiety disorder and estimates of 23% and 37%, respectively, for depressive disorder (Hollocks et al., 2019). However, almost all mental health conditions are elevated in autistic people compared to the general population (Hofvander et al., 2009; Joshi et al., 2013; Lai et al., 2019).

There are gender differences in the presentation of co-occurring mental health conditions between autistic men and women. There is some evidence that autistic women experience mental health difficulties at higher rates than autistic men (Sedgewick et al., 2020). Further, as in the general population (Leadbeater et al., 1999), there are gender differences in the types of mental health difficulties that autistic people experience, particularly in adult samples (Sedgewick et al., 2020; Tsakanikos et al., 2011). Females tend to present with more internalising difficulties, where emotions are expressed inward, such as anxiety, depression, self-harm, and EDs (Gotham, Brunwasser, et al., 2015; Maddox et al., 2017; Margari et al., 2019; Oswald et al., 2016; Sedgewick et al., 2020). Males tend to present with more externalising difficulties, where difficulties are turned outward, resulting in aggression and problems relating with others, such as oppositional defiant behaviour and substance abuse (Hofvander et al., 2009; Mandy, Chilvers, et al., 2012; May et al., 2016). In the general population, these gender differences become more pronounced after adolescence (Leadbeater et al., 1999), and there is some evidence that this might also be the case in the autistic population (Margari et al., 2019).

Co-occurring mental health difficulties in autistic adults have been associated with lower social and adaptive functioning (Moss et al., 2015), employment and educational difficulties (Keen et al., 2015; Taylor & Gotham, 2016), reduced quality of life (Mason, Mackintosh, et al., 2019; Mason et al., 2018), and premature mortality (Hirvikoski et al., 2016). Further, there is evidence that autistic individuals with co-occurring mental health conditions experience greater burden, in terms of trajectory and impact on functioning, than non-autistic individuals with comparable levels of mental health difficulties (Joshi et al., 2013). Autistic adolescents and adults who are referred to mental health services present with lower levels of global functioning and

require more intense forms of care (e.g., higher rates of hospitalisation) than their non-autistic counterparts (Joshi et al., 2010; Joshi et al., 2013).

Despite this, service provision for autistic individuals with co-occurring mental health difficulties is insufficient, particularly for autistic adults (Murphy et al., 2016; Wise, 2020). While support tends to be more accessible for autistic individuals when they are younger, they often struggle to obtain appropriate support once they transition to adult services (Crane, Adams, et al., 2019). Autistic adults report higher levels of unmet mental health needs compared to non-autistic adults (Nicolaidis et al., 2013) and children on the spectrum (Turcotte et al., 2016). In addition, autistic adults with mental health difficulties report being less satisfied with services than those seeking support for physical health difficulties (Vogan et al., 2017).

There are two potential reasons why current mental health service provision is less effective in supporting autistic adults. Firstly, there is the possibility of autism-specific causal and maintaining factors for co-occurring mental health difficulties in autistic individuals, as has been proposed for anxiety (Magiati et al., 2017; Rodgers & Ofield, 2018). These are often poorly understood, and are unlikely to be addressed by standard mental health treatments, which were developed for and evaluated with non-autistic people (Malik-Soni et al., 2021). Secondly, service environments, and the way treatments are structured and delivered, might be less accessible to autistic people without adaptations that take into account their skills and abilities (Camm-Crosbie et al., 2019; Spain et al., 2015). A better understanding of co-occurring mental health difficulties in autistic individuals and autism-informed treatment adaptations are therefore vital for improving service provision for autistic adults and enabling them to live happier and healthier lives. In particular, it will be important to

consider the mental health difficulties of autistic women, as they constitute an already under-supported group (Bargiela et al., 2016; Tint & Weiss, 2018).

Feeding and Eating Disorders

One mental health condition that commonly co-occurs with autism and has received increasing attention in recent years is EDs (Huke et al., 2013; Westwood & Tchanturia, 2017). The DSM-5 defines feeding and eating disorders as 'characterised by a persistent disturbance of eating or eating-related behaviour that results in the altered consumption or absorption of food and that significantly impairs physical health or psychosocial functioning' (APA, 2013, p. 329). The DSM-5 specifies several ED diagnoses, including anorexia nervosa (AN), bulimia nervosa, binge eating disorder, pica, rumination disorder, and avoidant/restricted food intake disorder (ARFID) (APA, 2013). In addition, the category of 'otherwise specified feeding and eating disorders' (OSFED) is an umbrella term for ED presentations involving eating disturbances that cause significant impairment in functioning or distress, but do not meet the full criteria for the other ED diagnoses. OSFED includes atypical AN, binge eating disorder of low frequency and/or limited duration, bulimia nervosa of low frequency and/or limited duration, purging disorder, and night eating syndrome.

Figure 1 provides an overview of the criteria for each ED diagnosis. Research on the co-occurrence between autism and EDs has been primarily conducted in samples with AN (Huke et al., 2013; Westwood & Tchanturia, 2017). There are other ED diagnostic categories, namely atypical AN and ARFID, that resemble AN in terms of their restrictive nature, but differ from AN in terms of presentation, in that restriction does not result in low body weight and/or is not driven by weight and

shape concerns. Collectively, the current thesis will refer to individuals with these diagnoses as presenting with REDs.

Figure 1

DSM-5 diagnostic criteria for feeding and eating disorders

Feeding and Eating Disorders						
Anorexia Nervosa (AN)	**Bulimia Nervosa**	**Binge Eating Disorder**	**Otherwise Specified Feeding and Eating Disorders (OSFED)**	**Pica**	**Rumination Disorder**	**Avoidant/Restricted Food Intake Disorder (ARFID)**
• Restriction of energy intake relative to requirements, leading to a significant low body weight in the context of the age, sex, developmental trajectory, and physical health (less than minimally normal/expected). • Intense fear of gaining weight or becoming fat or persistent behaviour that interferes with weight gain. • Disturbed by one's body weight or shape, self-worth influenced by body weight or shape, or persistent lack of recognition of seriousness of low bodyweight.	• Recurrent episodes of binge eating. An episode of binge eating is characterized by both of the following: o Eating, in a discrete period of time (e.g., within any 2-hour period), an amount of food that is definitely larger than most people would eat during a similar period of time and under similar circumstances. o A sense of lack of control over eating during the episode (e.g., a feeling that one cannot stop eating or control what or how much one is eating). • Recurrent inappropriate compensatory behaviour in order to prevent weight gain, such as self-induced vomiting, misuse of laxatives, diuretics, or other medications, fasting, or excessive exercise. • The binge eating and inappropriate compensatory behaviours both occur, on average, at least once a week for three months. • Self-evaluation is unduly influenced by body shape and weight. • The disturbance does not occur exclusively during episodes of anorexia nervosa.	• Recurrent episodes of binge eating. An episode of binge eating is characterized by both of the following: o Eating, in a discrete period of time (e.g., within any 2-hour period), an amount of food that is definitely larger than what most people would eat in a similar period of time under similar circumstances. o A sense of lack of control over eating during the episode (e.g., a feeling that one cannot stop eating or control what one is eating). • The binge-eating episodes are associated with three (or more) of the following: o Eating much more rapidly than normal. o Eating until feeling uncomfortably full. o Eating large amounts of food when not feeling physically hungry. o Eating alone because of feeling embarrassed by how much one is eating. o Feeling disgusted with oneself, depressed, or very guilty afterward. • Marked distress regarding binge eating is present. • The binge eating occurs, on average, at least once a week for 3 months. • The binge eating is not associated with the recurrent use of inappropriate compensatory behaviour as in bulimia nervosa and does not occur exclusively during the course of bulimia nervosa or anorexia nervosa.	• Feeding or eating behaviours that cause clinically significant distress and impairment, but do not meet the full criteria for any of the other disorders. **Atypical AN** • All criteria are met, except despite significant weight loss, the individual's weight is within or above the normal range. **Bulimia Nervosa (of low frequency and/or limited duration)** • All of the criteria for bulimia nervosa are met, except that the binge eating and inappropriate compensatory behaviour occurs at a lower frequency and/or for less than three months. **Binge Eating Disorder (of low frequency and/or limited duration)** • All of the criteria for binge eating disorder are met, except at a lower frequency and/or for less than three months. **Purging Disorder** • Recurrent purging behaviour to influence weight or shape in the absence of binge eating. **Night Eating Syndrome** • Recurrent episodes of night eating. Eating after awakening from sleep, or by excessive food consumption after the evening meal. The behaviour is not better explained by environmental influences or social norms. The behaviour causes significant distress/impairment. The behaviour is not better explained by another mental health disorder.	• Persistent eating of non-nutritive, non-food substances over a period of at least 1 month. • The eating of non-nutritive, non-food substances is inappropriate to the developmental level of the individual. • The eating behaviour is not part of a culturally supported or socially normative practice. • If the eating behaviour occurs in the context of another mental disorder (e.g., intellectual disability [intellectual developmental disorder], autism spectrum disorder, schizophrenia) or medical condition (including pregnancy), it is sufficiently severe to warrant additional clinical attention.	• Repeated regurgitation of food over a period of at least 1 month. Regurgitated food may be re-chewed, re-swallowed, or spit out. The repeated regurgitation is not attributable to an associated gastrointestinal or other medical condition (e.g., gastroesophageal reflux, pyloric stenosis). • The eating disturbance does not occur exclusively during the course of anorexia nervosa, bulimia nervosa, binge-eating disorder, or avoidant/restrictive food intake disorder. • If the symptoms occur in the context of another mental disorder (e.g., intellectual disability [intellectual developmental disorder] or another neurodevelopmental disorder), they are sufficiently severe to warrant additional clinical attention.	• An eating or feeding disturbance (e.g., apparent lack of interest in eating or food; avoidance based on the sensory characteristics of food; concern about aversive consequences of eating) as manifested by persistent failure to meet appropriate nutritional and/or energy needs associated with one (or more) of the following: o Significant weight loss (or failure to achieve expected weight gain or faltering growth in children). o Significant nutritional deficiency. o Dependence on enteral feeding or oral nutritional supplements. o Marked interference with psychosocial functioning. • The disturbance is not better explained by lack of available food or by an associated culturally sanctioned practice. • The eating disturbance does not occur exclusively during the course of anorexia nervosa or bulimia nervosa, and there is no evidence of a disturbance in the way in which one's body weight or shape is experienced. • The eating disturbance is not attributable to a concurrent medical condition or not better explained by another mental disorder. When the eating disturbance occurs in the context of another condition or disorder, the severity of the eating disturbance exceeds that routinely associated with the condition or disorder and warrants additional clinical attention.

Note. (APA, 2013). Restrictive eating disorders (REDs) highlighted in grey.

Anorexia Nervosa

For an individual to be diagnosed with AN, their RED needs to have resulted in significantly low body weight (APA, 2013). Significantly low body weight is defined as a body mass index (BMI) of 18.5 kg/m^2 or below for adults and on corresponding percentiles for children and adolescents, i.e., less than 85% of expected body weight (WHO, 2018). Weight and shape concerns are thought to be a central driver of AN (Fairburn et al., 1999), although AN can be diagnosed as long as the individual engages in behaviours that interfere with weight gain and shows persistent lack of recognition of the seriousness of their low body weight (APA, 2013).

There are two recognised subtypes of AN, which are based on behaviours over the past three months prior to diagnosis (APA, 2013). Individuals with the restricting AN subtype present with weight loss stemming from dieting, fasting, and/or excessive exercise, with no recurrent episodes of binge eating or purging symptoms. Individuals with the binge-eating/purging AN subtype also experience recurrent episodes of binge eating or purging, such as through self-induced vomiting or laxative abuse. However, the predictive validity and utility of these subtypes has been questioned (Peat et al., 2009; Peterson et al., 2016). These groups exhibit few differences in terms of other psychiatric symptoms (Peterson et al., 2016), and both groups have similar outcomes in terms of recovery, relapse, and mortality (Eddy et al., 2002). Further, individuals often fluctuate between the two subtypes; more than half of individuals with an AN diagnosis move between restricting and binge-eating/purging AN subtypes over time (Eddy et al., 2008; Peat et al., 2009). For the purpose of this thesis, individuals with either subtype will be considered to be presenting with an RED, and the thesis will not distinguish between AN subtypes.

In a systematic review of prevalence rates for different ED diagnoses, the lifetime AN prevalence rate in females ranged from 1.7% to 3.6%, and the point prevalence ranged from 0.67% to 1.2%, whereas both point and lifetime prevalence in males were estimated at 0.1% (Dahlgren et al., 2017). Reported prevalence rates varied widely depending on age groups and sampling techniques (Dahlgren et al., 2017).

AN most commonly develops in adolescence or early adulthood (Volpe et al., 2016), with the typical age of onset for AN ranging from 14–18 years (Abbate-Daga et al., 2007). A variety of biological, psychological, and social risk factors for AN have been proposed. Some, including genes, personality traits, and cognition, are thought to increase vulnerability; others, including stress, life events, and media, might trigger the onset of AN—and yet another set of physical, psychological, and social responses might contribute to the maintenance of the illness (Treasure & Schmidt, 2013; Woerwag-Mehta & Treasure, 2008).

AN is considered to be one of the most debilitating and dangerous EDs and mental health conditions overall. It has significant impacts on health and social and occupational functioning (Chapelon et al., 2021; Tchanturia, Hambrook, et al., 2013). Once manifested, it is difficult to overcome (Steinhausen, 2009). A systematic review found relapse rates of up to 52% (Khalsa et al., 2017). In a 30-year follow-up study of adolescents with AN, only 64% had fully recovered, with an average length of illness of 10 years, whilst 38% had other mental health diagnoses, and 19% continued to meet criteria for an ED (Dobrescu et al., 2019). Further, AN has the highest mortality rate of all mental disorders, including other EDs, mostly due to high levels of medical complications in underweight individuals and suicide (Arcelus et al., 2011; Chesney et al., 2014). Those who survive tend to present with poorer physical

health and report more frequent somatic and psychological problems than matched controls (Chapelon et al., 2021), although those who fully recover have a good chance of overcoming other psychiatric disorders and adapting to social requirements (Herpertz-Dahlmann et al., 2001).

Atypical AN

Atypical AN falls under the umbrella of OSFED. Individuals with atypical AN meet all criteria for AN, except their weight remains within or above normal range despite significant weight loss (APA, 2013). This is often the case when individuals have previously been overweight, and their restriction has led to weight loss, but they are not (yet) in the underweight range (Forney et al., 2017). Nonetheless, atypical AN can also result in severe medical and psychiatric complications (Moskowitz & Weiselberg, 2017).

ARFID

ARFID is characterised by avoidant and restrictive eating, but without the weight and shape concerns that are inherent to AN (APA, 2013; Nicely et al., 2014; Thomas et al., 2017). Instead, individuals with ARFID engage in avoidant or restrictive eating behaviours for reasons such as avoidance of sensory aspects of food, lack of interest in food, or feared negative consequences unrelated to weight and shape, such as fear of vomiting and/or choking (Norris et al., 2018; Reilly et al., 2019). ARFID often results in significant weight loss, or failure to gain expected weight in children, but being underweight is not a diagnostic requirement (APA, 2013). Affected individuals may restrict the range of foods they eat, resulting in nutritional deficiency or significantly interfering with psychosocial functioning, but still have a high enough calorie intake to maintain their weight or meet weight targets. A retrospective chart review of 133 patients with ARFID in a paediatric eating disorders

treatment programme found that around 50% of individuals with ARFID classify as having significantly low body weight (Reilly et al., 2019). ARFID was introduced as a formal diagnostic category in DSM-5 (APA, 2013) and, more recently, in ICD-11 (WHO, 2018). Prior to this, such behaviours were predominantly considered in young people and would have been captured under feeding and eating difficulties in childhood (Bryant-Waugh et al., 2010; Sharp & Stubbs, 2015). However, there is growing recognition that ARFID can occur and persist across the lifespan, which has resulted in changes to its categorisation (Claudino et al., 2019).

RED Categorisation and Diagnostic Overlap

Although ED diagnostic categories are exclusive, with AN trumping other potential diagnoses in the diagnostic rubric (APA, 2013), there can be considerable overlap in presentation. In reality, the presentation of an individual's EDs often fluctuates, or might cross over to a different ED presentation as it evolves (Eddy et al., 2010). For example, case reports suggest that individuals with ARFID are at heighted risk of subsequently developing more traditional (i.e., weight- and shape-driven) RED psychopathology (Becker et al., 2020). In addition, there is a chance of misdiagnosis because of similarities in presentation. For example, because ARFID is a relatively new diagnostic category, it might not be recognised in adult women with low body weight and might be mislabelled as AN (Becker et al., 2019). Thus, although the current thesis initially focused on the co-occurrence between autism and AN, it later broadened its focus to include individuals with other REDs.

We acknowledge that using diagnoses alone to determine whether an individual presents with an RED has its limitations. For example, the REDs umbrella includes individuals with the binge-eating/purging AN subtype, even though they may not restrict as much as those with the restricting subtype, whereas it excludes

individuals with bulimia nervosa, even though some individuals with this diagnosis might frequently engage in severe restriction (alternating with binges). However, it can often be difficult to establish the exact presentation and frequency of individual symptoms in relation to one another. Thus, for the purpose of this thesis, diagnostic categories were considered a reasonably good indicator of RED.

ED Gender Differences

Women are more likely to present with EDs than men (see above for AN prevalence rates by gender) and EDs have long been viewed as a primarily female illness (Till, 2011). Fewer than 10% of patients in ED settings are males (Button et al., 2008). However, EDs are often underdiagnosed in men (Stanford & Lemberg, 2012; Strother et al., 2012) and there is evidence for differences in the causes, presentations and needs of males and females with EDs (Murray et al., 2017; Thapliyal et al., 2018). Because of these gender differences in ED prevalence and presentation, the focus on autistic women (see above), and practical limitations of recruiting sufficient numbers of participants from each gender with either or both conditions (more detail in Chapter 2 and Chapter 3), the current thesis focuses on females with EDs. However, we acknowledge that in ED research, there is a similar problematic regarding gender bias as the field of autism, with much research (including ours) excluding men, which perpetuates a poor understanding and under-recognition of EDs in men (Murray et al., 2017).

The Co-Occurrence Between Autism and REDs

The potential overlap between autism and REDs was first proposed in the clinical literature by Gillberg (1983), who anecdotally observed in his clinical work that a disproportionate number of women with AN had autistic family members (Gillberg, 1983). Since then, there has been an increased interest in the co-

occurrence between autism and EDs, particularly AN. Research is being conducted mainly in Western Europe, specifically in Sweden, the UK, and Italy (e.g., Nielsen et al., 2015; Vagni et al., 2016; Westwood et al., 2018) .

Autistic women are overrepresented in ED settings. Studies have consistently found that 20%–35% of women with AN meet criteria for autism (for reviews, see Huke et al., 2013 and Westwood & Tchanturia, 2017). This is somewhat surprising, given that both conditions are conceptualised very differently. Autism is a lifelong, neurodevelopmental condition that is more common in males and has predominantly genetic cause (Amaral, 2017; Loomes et al., 2017). In contrast, AN is an illness that can be overcome and which typically has its onset in teenage years (Abbate-Daga et al., 2007), AN predominantly affects females (Dahlgren et al., 2017), and is caused by a combination of biological, psychological, and social factors (Woerwag-Mehta & Treasure, 2008). However, there are several parallels in the presentation of autism and AN (Kinnaird & Tchanturia, 2020). These include, but are not limited to, difficulties in social relationships and socioemotional functioning (Kerr-Gaffney, Harrison, et al., 2020a; Zucker et al., 2007), rigid behaviours and cognition (Westwood, Stahl, et al., 2016), detail focus (Fonville et al., 2013; Oldershaw et al., 2011) and obsessive interests (e.g., intense focus on food, calories or exercise in the case of women with AN; Serpell et al., 2002). Further, restrictive eating behaviours, in the form of picky/fussy eating, are common among autistic individuals (Kinnaird, Norton, Pimblett, et al., 2019; Mayes & Zickgraf, 2019), albeit their severity and quality in most cases will be different to disordered eating behaviours in AN populations (Karjalainen et al., 2019).

Pseudo-Autism or True Autism?

Some have questioned the high rates of autism in AN samples, arguing that the effect of starvation in AN may mimic or exacerbate autistic traits, resulting in a pseudo-autistic presentation, including poor mentalising ability and temporary cognitive rigidity, which may no longer be present once affected individuals have recovered (Hiller & Pellicano, 2013; Treasure, 2013). Indeed, the so-called Minnesota starvation experiment has demonstrated that the effect of starvation can have profound temporary effects on cognition and behaviour (Keys et al., 1950). In this historically unique experiment, 36 healthy male volunteers were food deprived to study the impact of starvation and the effectiveness of rehabilitation strategies in the context of famine at the end of World War II (Kalm & Semba, 2005). For 6 months, the volunteers' calorie intake was reduced from 3,200 to 1,570 calories a day, resulting in at least 25% weight loss. This had profound physical and psychological impacts, some of which mimic autism characteristics and related difficulties, including social withdrawal and isolation, decline in cognitive functioning, obsessions with food and recipes, ritualistic behaviours around eating, and greater irritability, depression, and apathy (Keys et al., 1950).

While the effect of starvation might exaggerate the presentation of autistic traits for some individuals with AN, there is evidence that the high levels of difficulty with social functioning and flexibility observed amongst women with AN cannot simply be understood as a starvation-induced pseudo-autism.

First, high prevalence rates hold even when rigorous, gold-standard autism assessment instruments are used (Westwood et al., 2017b). Initial studies, which suggested elevated autism prevalence rates among AN samples, have been criticised for applying inconsistent and unconventional methods of assessment to identify individuals who meet autism criteria. This resulted in great variability in

estimates, ranging from 8%–37% (Huke et al., 2013). More recently, studies have used more thorough, in-depth assessment tools to identify autistic individuals (Westwood et al., 2017b). For example, Westwood et al. (2017b) used the Autism Diagnostic Observation Schedule-2 (ADOS-2; Lord et al., 2012), a standardised observational schedule recommended for diagnostic assessments (National Institute for Health and Care Excellence (NICE), 2013), with a group of 60 women with AN who were recruited from specialist ED services. Twenty-three percent of their sample scored above the cut-off for autism on the ADOS-2 (Westwood et al., 2017b).

Secondly, studies using retrospective reports of autistic traits during early development and longitudinal cohort studies suggest that, for many women with AN, high autistic traits were already present in childhood, prior to the onset of their ED and associated starvation (Vagni et al., 2016; Westwood et al., 2018). Vagni et al. (2016) used the Ritvo Autism Asperger Diagnostic Scale Revised (RAADS-R; Ritvo et al., 2011), which includes retrospective self-report on the presence of autistic behaviours during childhood, to assess autistic traits in ED outpatients aged 15 or over (n = 71). Thirty-three percent of their participants were classified as having elevated autistic traits which had been present since childhood, thus pre-dating the onset of their ED. Another study, which included 40 adolescent females with AN, used the ADOS-2 in combination with structured parent interviews on the developmental presentation of autism characteristics (Westwood et al., 2018). The study found that 10% of individuals scored above the cut-off on both measures, suggesting that autism characteristics in these individuals likely predated their ED. This is supported by a longitudinal cohort study, which found that young people who presented with disordered eating behaviours at age 14 were more likely to have had higher autism-related social traits throughout childhood and up to mid-adolescence

than those without (Solmi et al., 2021). These differences in autism-related social traits were already present (i.e., trajectories were already divergent) at 7 years of age, when disordered eating behaviours are rare. This suggests that high autistic traits in childhood might constitute a risk factor for disordered eating in later life, rather than disordered eating leading to greater autistic social traits over time (Solmi et al., 2021).

Finally, autism prevalence rates remain high in samples of women who have restored a healthy body weight after recovering from AN (Anckarsäter et al., 2012; Bentz, Jepsen, et al., 2017). Bentz, Jepsen, et al. (2017) compared autism characteristics in participants with first-episode, recent-onset AN to those in recovered participants using the ADOS-2 (Lord et al., 2012). Sixteen percent and 21% of individuals, respectively, scored above the ADOS-2 cut-off for autism. Further, social function was not associated with BMI, and both groups presented with similar levels of functional impairment, suggesting that autistic traits represent a stable trait for a subgroup of AN patients, independent of their ED status (Bentz, Jepsen, et al., 2017). A longitudinal cohort study in Sweden followed 51 adolescents with teenage-onset AN for a time period of 18 years, assessing the presence of autistic traits at four time points (Anckarsäter et al., 2012). The majority of individuals had restored their weight 6 years after the initial assessment, and all but two had restored their weight 18 years after the initial assessment. The estimated autism prevalence at each follow-up point varied depending on the diagnostic measures used and changes in diagnostic criteria over time. Thirty-two percent of the sample was categorised as meeting autism criteria in at least one of the follow-up time points, and 12% met diagnostic criteria at all four time points (Anckarsäter et al., 2012).

Together, these studies suggest that a subgroup of women with AN are likely to present with ‘true autism,’ as high autistic traits in these individuals hold even when gold-standard diagnostic assessment tools are used, precede the development of an eating disorder, and persist after weight recovery.

Prevalence of EDs in Autism

Equivalent evidence from studies in the autism field suggest that prevalence rates of EDs, particularly of AN, are elevated in autistic individuals. Lever and Geurts (2016) used standardised neuropsychiatric interviews to examine the presence of co-occurring mental health conditions in 138 autistic adults and a comparison group of 170 people from the general population. Lifetime rates for any ED were significantly higher in the autism sample, with 5.8% meeting ED criteria compared to 1.7% in the general population group. This is despite the fact that the autism group included significantly fewer women (33% vs. 44%), who are more commonly affected by EDs (Smink et al., 2014). Karjalainen et al. (2016) assessed the prevalence of different ED diagnoses (AN, bulimia nervosa, and binge eating disorder) in 228 young adults without co-occurring ID (55.7% males), who had been referred for a diagnostic assessment of autism and/or attention-deficit hyperactivity disorder (ADHD). Of these, 119 received an autism only or autism and ADHD diagnosis, and 109 received an ADHD diagnosis only. Across participants, 7.9% reported a past or current ED diagnosis, most commonly AN or binge eating disorder. Interestingly, AN was more common in those who received an autism diagnosis compared to an ADHD-only diagnosis (5% vs. 1.8%, respectively), whereas binge eating was more common in those with an ADHD-only diagnosis (0.8% vs. 6.4%).

Further, there is evidence that the prevalence of EDs, and AN specifically, are particularly high among autistic girls and women compared to boys and men. In a

large-scale online survey, significantly more autistic than non-autistic participants reported having a past or current ED diagnosis (36% vs. 20%), and gender was found to have a significant effect on current ED symptoms, with females in both groups reporting significantly higher ED symptomatology (Sedgewick et al., 2020). It should be noted that this was a self-selected sample, which likely increased the prevalence of mental health difficulties in both groups. Hofvander et al. (2009) assessed the lifetime prevalence rates of co-occurring mental health conditions in 79 autistic men and 40 autistic women without co-occurring ID who had been referred to an adult autism diagnostic service. In their sample, lifetime rates for EDs were significantly higher in autistic females than in males, with 10% of women but only 2% of men meeting ED criteria. This suggests higher rates of eating disorders in both autistic females and males, with a similar gender ratio to that found in the general population. For reference, an ED prevalence study in a community cohort of young adults estimated a lifetime prevalence rate for any ED of 5.7% in females and 1.2% in males (Smink et al., 2014). Another study reviewed the case records of 100 autistic boys (mean age = 9.91 years) and 59 autistic girls (mean age = 10.97 years) who had been referred to a neuropsychiatry unit for an autism diagnostic assessment, to explore gender differences in the prevalence of co-occurring mental health difficulties (Margari et al., 2019). AN was the only ED among the co-occurring mental health difficulties identified, and the only one where there was a significant difference between males and females. In their sample, 1% of boys and 6.8% of girls presented with AN. The relatively high prevalence rate in such a young sample suggests that AN in particular might be overrepresented in autistic females.

Together, these studies suggest high rates of EDs, especially AN, among autistic individuals. As in the general population (Smink et al., 2014), autistic females appear to be affected more than males.

Outcomes and Treatment Experience of Autistic Women with AN

There is evidence to suggest that autistic women and those with high autistic traits benefit less from current interventions and care pathways, and have worse outcomes, than women with low autistic traits, experiencing especially low recovery rates and levels of functioning (Nazar et al., 2018; Nielsen et al., 2015; Tchanturia et al., 2016). Further, autism characteristics are associated with longer illness duration (Saure et al., 2020), and those with high autistic traits tend to require more intense treatment (Stewart et al., 2017).

Despite this, current treatment guidelines do not acknowledge, let alone address, the needs of autistic individuals in their recommendations for ED service provision (Kinnaird, Norton, Stewart, et al., 2019; Kinnaird et al., 2017). In England, NICE guidelines (2017) provide evidence-based recommendations for health and mental health care**.** Autism is not mentioned in the latest NICE treatment guidelines for EDs (NICE, 2017), as the evidence base was not considered sufficient to make informed recommendations at the time the guidelines were developed (L. Serpell, personal communication, September 13, 2021). Several qualitative studies with autistic women and those with high autistic traits, as well as the parents of such women and professionals working in ED settings, have highlighted a need for greater consideration of autism in ED settings (Adamson et al., 2020; Babb et al., 2021; Kinnaird, Norton, Stewart, et al., 2019; Kinnaird et al., 2017). A qualitative study with ED clinicians found that adaptations to treatment tended to be idiosyncratic and based on the previous experience of individual clinicians, rather than representing a

systematic approach (Kinnaird et al., 2017). Whilst most participants recognised the importance of considering autism in AN treatment, many did not feel they had enough knowledge to provide adequate treatment for this client group (Kinnaird et al., 2017). In line with this, autistic women in treatment for AN reported that they experience unique needs associated with their autism, which they feel are not met by currently offered treatments (Kinnaird, Norton, Stewart, et al., 2019). Specifically, in a study done by our group, autistic women, their parents, and ED clinicians described how being autistic affected both autistic women's experience of their eating disorder and their ability to engage with and access treatment (Babb et al., 2021). They felt that many barriers experienced by autistic women in AN treatment related to a lack of understanding of their autism (Babb et al., 2021).

Rationale and Thesis Outline

Thus far, there is a limited evidence base to guide service improvements for autistic women seeking support for AN (Kinnaird & Tchanturia, 2020; Westwood & Tchanturia, 2017). Specifically, there is a need to better understand how AN develops and persists in autistic women, and the role autism-specific factors might play. A first step toward this is to develop and test a theoretical model of autism processes that might give rise to and maintain the restrictive eating behaviours underlying AN in autistic individuals. Further, there is a need to better understand autistic adults' experience of treatment for their REDs. Thereby, it would be of value to consider the wider literature on autistic adults experience in mental health services more generally, rather than just focusing on ED settings, as issues experienced by autistic women in treatment for AN are likely to also apply to other autistic individuals receiving mental health care, and there is a wealth of existing research on autistic adults experience in mental health services to draw on.

This has the potential to help ED, as well as other mental health services to improve the way they engage with autistic individuals, and may inform treatment adaptations and the development of new autism-specific ED treatments and interventions to prevent REDs in autistic individuals. By contributing towards an evidence base regarding the presentation of autistic women with REDs the research conducted as part of this thesis also has the potential to inform the next issue of the NICE guidelines. Therefore, the current thesis aims to:

1) Generate hypotheses about causal and maintaining factors of AN in autistic women;
2) Derive a theoretical model of restrictive eating difficulties in autism;
3) Test elements of this model using quantitative methods;
4) Review existing literature to elucidate perceived barriers and ways to overcome them for autistic adults in accessing and receiving support for mental health difficulties, so that these findings can be applied to improving ED services for autistic people.

This thesis employs a mixed-method approach across three distinct but related studies. Study 1 takes an inductive, data-driven approach to generate new ideas. We conducted in-depth qualitative interviews with autistic women who have experience of AN, as well as those who support them, to identify potential causal and maintaining factors, and developed a theoretical model of restrictive eating difficulties in autism based on those findings (Aims 1 and 2). This is presented in Chapter 2 of this thesis.

Study 2 uses a deductive, theory-driven approach to make a start with testing some elements of the model developed in Study 1 via in a group comparison design (Aim 3). The methodology employed in Study 2 is outlined in Chapter 3. The

demographics and clinical characteristics of the Study 2 participants are described in Chapter 4, with a specific focus on autistic traits and disordered eating-related presentations. A group comparison of general and food-specific sensory sensitivities in autistic and non-autistic women with and without REDs is presented in Chapter 5.

Study 3 involves a systematic review and meta-synthesis of qualitative research on autistic adults' experiences of accessing mental health services (Aim 4). This is presented in Chapter 6.

The final chapter (Chapter 7) presents an overarching discussion, including implications for clinical practice and future research.

Throughout the thesis, a participatory approach was employed, engaging autistic women with relevant lived experience in various stages of the research process. They were actively involved in deciding the focus of this project, how it was conducted, and how the findings were interpreted. Collaborative research is encouraged in both the autism (Chown et al., 2017; Fletcher-Watson et al., 2019) and eating disorder fields (van Rensburg, 2021). It is thought to improve the quality of research and enhance the translation of findings into practice, by ensuring that research is ethically informed by the values of its community and that findings are contextualised within real-world settings (Cornwall & Jewkes, 1995; Fletcher-Watson et al., 2019).

Chapter 2: "*For me, the Anorexia is Just a Symptom, and the Cause is the Autism*" – Investigating REDs in Autistic Women

This chapter is a version of a previously published paper, Brede et al. (2020). The full reference for this publication is:

Brede, J., Babb, C., Jones, C., Elliott, M., Zanker, C., Tchanturia, K., Serpell, L., Fox, J., Mandy, M. (2020). "For Me, the Anorexia is Just a Symptom, and the Cause is the Autism": Investigating Restrictive Eating Disorders in Autistic Women. *Journal of Autism and Developmental Disorders* (50), 4280–4296. https://doi.org/10.1007/s10803-020-04479-3

Introduction

The current chapter presents Study 1 of this thesis, for which we conducted in-depth qualitative interviews with autistic women who have experience of AN, as well as those who support them, to identify potential causal and maintaining factors, and developed a theoretical model of restrictive eating difficulties in autistic individuals.

The link between autism and AN was first suggested in the clinical literature by Gillberg (1983), who anecdotally observed in his clinical work that the two conditions co-occurred within the same families (Gillberg, 1983). Since then, there has been an increasing interest in the co-occurrence between autism and REDs, particularly AN. Autistic women have an elevated risk of developing AN, as indicated by the fact that they are substantially overrepresented among people in treatment for AN. Studies have consistently shown that 20-35% of women with AN meet criteria for autism (Westwood & Tchanturia, 2017). In contrast, less than 1% of the general population of women meet criteria for autism (Loomes et al., 2017).

Despite a significant proportion of autistic women in ED services, current service provision does not acknowledge or address their needs (Kinnaird, Norton, Stewart, et al., 2019; Kinnaird et al., 2017). This is problematic, since women with high autistic traits benefit less from current interventions and care pathways and have worse outcomes than other women with AN (Nazar et al., 2018; Nielsen et al., 2015; Tchanturia et al., 2017). Overall, there is a limited evidence base to guide service improvements for autistic women seeking support for AN (Huke et al., 2013; Westwood & Tchanturia, 2017). A first step towards better guidance for services would be to develop a testable theoretical model of the specific autism-related processes that might give rise to and maintain restrictive eating behaviours, underlying AN, in autistic individuals.

Within the ED literature, a considerable body of research has established the presence of certain characteristics in AN populations, which are also recognised in autism, and thus are of potential relevance to building models of AN in autistic individuals. These include, but are not limited to, atypical social cognition (e.g. Zucker et al., 2007), difficulties processing emotions (e.g. Lang et al., 2016), weak central coherence (e.g. Oldershaw et al., 2011), and cognitive rigidity (e.g. Westwood et al., 2017). Several of these characteristics have been associated with autism and/or autistic traits within ED populations. For example, Tchanturia, Smith, et al. (2013) explored associations between self-reported autistic traits and clinical ED symptoms in 66 individuals with AN and 66 healthy controls. The AN group reported more autistic traits than controls. Autistic traits discriminated between groups related to global thinking, inflexibility of thinking and problems with social interactions, but were not associated with ED symptoms. This suggests that autistic traits may exacerbate factors that maintain the eating disorder rather than cause the eating

disorder directly. Lang et al. (2016) found that reduced positive emotion expression was associated with autistic traits and several other clinical variables in 66 individuals with AN. Westwood et al. (2017a) investigated the relationship between autistic traits and neuropsychological performance in 99 females with AN. Their results suggest that the presence of autistic traits is related to increased cognitive rigidity in females with AN.

Within the autism literature, evidence suggests that sensory sensitivities may play a role in the development of picky eating and food selectivity, both of which are common in autistic individuals (Cermak et al., 2010; Kuschner et al., 2015). However, it is unclear whether sensory sensitivities have a specific impact on the development of REDs, such as AN, in autism (Kinnaird, Norton, Pimblett, et al., 2019).

Qualitative interviews with autistic people with AN are important for a better understanding of the autistic features that may contribute to the development and maintenance of their eating difficulties, as this ensures that emerging knowledge is grounded in the lived experience of affected individuals. At the time the current study was planned, there had only been one relevant qualitative study (Kinnaird, Norton, Stewart, et al., 2019), although the study's main focus was on autistic women's experience of ED treatment and potential adaptations. Kinnaird, Norton, Stewart, et al. (2019) interviewed nine diagnosed autistic women and four women with high autistic traits about their experience of AN and the treatment they received. Participants reported experiencing their autism and their ED as fundamentally interlinked, with their autistic traits motivating apparent ED behaviours in ways that are not accounted for by traditional models of AN. Participants described how rigidity and inflexibility associated with their autism had contributed towards the

development of fixed routines and rituals around food. Participants also felt that commonly assumed motivations, such as a desire to lose weight, low self-esteem, and body image issues, were less relevant in the development of their illness compared to other less typical motivations, such as need for control, sensory difficulties, social confusion, organisational problems surrounding cooking and food shopping, exercise as a method of stimulation, and the ED acting as a special interest (Kinnaird, Norton, Stewart, et al., 2019).

Kinnaird, Norton, Stewart, et al.'s findings (2019) therefore suggest that there may be autism-specific mechanisms underlying AN in autistic women and that restrictive eating behaviours in autistic women, although being labelled AN, may deviate from traditional AN presentations. However, there is a need to gain further understanding of potential autism-specific mechanisms that underpin these restrictive eating difficulties. Specifically, not only are more targeted, in-depth interviews required to extend understanding of the experiences of autistic women with AN, but an approach that integrates the perspectives of autistic women with the views of those who support them will provide more comprehensive insight. There might be aspects of their presentation autistic women with AN might be less aware off, due to their illness presentation. While autistic women's accounts of their own experiences should be central to the development of knowledge about them, triangulation with the views of other groups, specifically those involved in their care, can further enrich the emerging understanding and give insight into the wider recognition of their autistic perspective (Carter et al., 2014). Developing a model that proposes mechanisms underlying restrictive eating difficulties in autistic individuals more generally, rather than just mapping autistic women's experience of restrictive eating onto our current understanding of AN, will facilitate a discussion of other

potentially autism-specific motivations for restrictive eating beyond those that are commonly associated with AN. In addition, such model has the potential to provide a foundation to guide clinical adaptations and will stimulate future research by generating new hypotheses.

The current study brought together the perspectives of autistic women, parents of autistic women, and healthcare professionals to: (1) better understand how AN develops and persists in autistic individuals and (2) derive the first theoretical model of restrictive eating difficulties in autism.

Methods

Design

This study employed a qualitative research design, as this allowed us to deepen our understanding of the phenomenon in question and to generate new hypotheses, rather than testing pre-established hypotheses or predictions (Pistrang & Barker, 2012). We generated data using semi-structured interviews with individual participants to give participants the freedom to describe their experience in their own words. Thematic Analysis (Braun & Clarke, 2006, 2019) was used to identify patterns of meaning across the data. This approach was chosen because of its flexibility, which suited both the aim of capturing the phenomenon of interest, i.e. AN in autistic women, as well as the more theory-generating aim of developing a model (Fereday & Muir-Cochrane, 2006). Data were interpreted within an essentialist framework, assuming that language directly reflects meaning and experience of participants and that these largely map onto a singular reality in the world. An inductive approach was used for theme development, with themes being driven by the data and grounded in participant's experiences.

Participants

We recruited participants from the following groups: (1) autistic women; (2) parents of autistic women; and (3) healthcare professionals with relevant experience. This was done via social media, the Autistica research network (Autistica, 2019), and existing contacts. Based on the teams previous experience of conducting qualitative research with autistic women and individuals with eating disorders and on other guidance (Guest et al., 2016), we aimed to recruit 15 participants for each group. We reflected on our progress throughout data collection and stopped recruiting once we estimated that data saturation had been reached. The final sample included 15 autistic women, 12 parents, and 16 healthcare professionals. Participants were distributed across England, Scotland and Wales.

Autistic women: Autistic women were eligible to participate if they met the following inclusion criteria: (1) above the age of 18 years; (2) clinical diagnosis of an autism spectrum disorder (self-report); (3) score above the cut-off of a screening measure for autistic traits; (4) past or current experience of AN; and (5) living in the UK. Since all autistic women were required to have received an independent autism diagnosis, we used a brief screening questionnaire instead of an in-person ADOS-2 assessment to confirm participant's autism diagnostic status. This was to reduce burden on participants (i.e. time) and to allow for participation via Skype or phone, if autistic women preferred this or this was more feasible because of their location. We used the 10-item Autism-Spectrum Quotient (AQ-10; Allison et al., 2012) to confirm their autism status. Initially we recruited 17 women, but two scored below the cut-off, and their interviews were not included in the analysis.

The demographics of the autistic women are provided in Table 1. All autistic women had been in contact with services for their ED and other mental health conditions first, often for years before their autism was recognised. Their ED status

was varied at the time of study. Some considered themselves to be currently living with AN, some considered themselves to be recovered, and some considered their condition to be improved, but still struggled with aspects of their ED. Women's Body Mass Index (BMI) was based on self-reported height and weight. Eight women declined to share this information. At the time of the study, most autistic women were not in full-time employment, several were studying at university level, but some had interrupted their education due to their ED, and some held part-time jobs or voluntary positions.

Table 1

Demographics for autistic women and autistic daughters of parents who participated in the study.

		Age in years	**Age AN diagnosis (years)**	**Age autism diagnosis (years)**	**AQ-10**	**EDE-QS**	**BMI†**
Autistic women (N=15)	Range	23-58	10-34	14-34	7-10	0-26	15-23
	M (SD)	32.6 (10.32)	17.40 (6.07)	29.40 (11.34)	8.73 (1.1)	11.53 (6.49)	18.28 (3.19)
Daughters of parents (N=12)*	Range	15-31	10-25	9-30			
	M(SD)	24.75 (6.36)	15.50 (4.17)	21.17 (7.15)			

Note. AN: Anorexia Nervosa; AQ-10: Autism-Spectrum Quotient (Allison, Auyeung, & Baron-Cohen, 2012); EDE-Qs (Eating Disorders Examination Questionnaire Short (Gideon et al., 2016); BMI: Body Mass Index, calculated on self-reported weight and height.
*Five parent participants were parents of autistic women in this study.
†Eight women declined to provide details on their weight and height for their BMI to be calculated.

Parents: The parent sample included five parents of autistic women who also participated in this study, and eight whose daughters did not participate. Parents were eligible to participate if their daughters met the same inclusion criteria as those applied to autistic women, with the exception that their daughters could be below the age of 18 years. One set of parents (father and mother) were interviewed together, meaning a total of 12 parent interviews with 13 individuals were included; all other parents were mothers and were interviewed individually. One additional mother's interview was conducted, but not included in the final analysis because her daughter was one of the participating autistic women who scored below the autism screening cut-off. The demographics for parents' daughters (Table 1) were similar to those of the autistic women, although they were a slightly younger sample.

Healthcare professionals: Healthcare professionals were identified through contacts of the research team and via snowball sampling, asking professionals who had participated if they were aware of any colleagues who might be suitable. Healthcare professionals had relevant experience of working with autistic individuals with eating difficulties. We invited professionals from different services across the country, with different professional backgrounds and at different stages of their career, to ensure variation in training and work context. On average, they had worked in autism and/or ED services for 10 years (range 2 – 23 years). They belonged to a variety of professions, including child and adolescent psychiatry (N=2), adult psychiatry (N=3), clinical psychology (N=6), counselling psychology (N=1), nursing (N=1), speech and language therapy (N=1), dietetics (N=1), and social work (N=1).

Procedure

We consulted two autistic women with experience of AN to advise on the interview schedule and to ensure that participation was comfortable and accessible for autistic women. Both women advised on an early draft of the design and one gave detailed feedback on the interview schedule. Both also provided feedback at different stages of the analytic process.

Participant interviews were conducted face-to-face, via Skype, or over the phone and lasted on average for 1h 23min (range: 43min – 2h 26min) with autistic women, 1h 27 min (range: 43min – 1h 54min) with parents, and 52 min (range: 20 min-1h 15min) with healthcare professionals. Basic demographic information (all three groups) and questionnaires (autistic women only) were collected immediately prior to the interview. Interviews were conducted by one of two non-autistic female PhD students. Participants participated in a one-off interview only and were offered £10 to thank them for taking part. Informed consent was obtained from all individual participants included in the study.

Materials

Semi-structured interview schedules (Appendix 1) were developed by the research team and via consultation with the autistic advisors. The interview schedule development was guided by the research question of how AN develops and persists in autistic individuals. We intended for the generated data to also aid a separate investigation concerning autistic women's ED service experience, which is not included as part of the current thesis. We initially developed the interview schedule for autistic women, and then adapted it as appropriate for the other two groups. Interviews with autistic women covered their experience of autism, AN, factors that might be underlying the development of their AN, as well as their journey towards an autism diagnosis and their ED service experience. After giving them the opportunity

to share their experiences more generally, we asked specific questions about the relevance of potential influencing factors in the development of their AN. These were identified from the existing literature and anecdotal accounts e.g., the role of weight and shape concerns and food-related sensory experiences. Parent interviews included questions about their daughters' autism and AN, how their daughters' AN had developed, the relevance of the potential influencing factors, and their daughters' experience in services. We asked professionals how AN and/or autism tends to present in female clients they are working with, their thoughts on the relationship between both conditions, treatment provision for these women, and their experience of working with autistic women with AN. Participants within each group were asked the same key questions, but further prompts were used flexibly to follow up on points as they emerged.

The 10-item Autism-Spectrum Quotient (AQ-10; Allison et al., 2012) was used to confirm autism status and indicate symptom severity. Scores on the AQ-10 range from 0 to 10, with higher scores indicative of the presence of greater autism symptom severity. Using a cut-off score of six, the 10-item version yielded a sensitivity of 0.88, specificity of 0.9 (Allison et al., 2012). The AQ-10 has excellent predictive validity (>90%), comparable to the full 50-item AQ (Booth et al., 2013), and is recommended as screening tool by the NICE guidelines (2012). Internal consistency for the autistic women in our sample was low (α=.29).

The Eating Disorders Examination Questionnaire Short (EDE-QS; Gideon et al., 2016) was used to measure current ED psychopathology. The EDE-QS is a 12-item, single-factor self-report questionnaire, asking participants to indicate how many days during the last week they have experienced various ED symptoms using a 4-point response scale ranging from "0 days" to "6–7 days". These response options

correspond to scores of 0 through 3, with higher scores indicating more severe ED symptoms (max=36). In addition, the EDE-QS asks participants for their height and weight for BMI to be calculated. The EDE-QS demonstrates sound psychometric properties and is able to distinguish between individuals with and without clinical EDs (Mdn = 17.5 vs. Mdn=5.0) (Gideon et al. 2016). Internal consistency for our participants was acceptable (α=0.77).

Analysis

All interviews were audio-recorded. Interviews were transcribed verbatim and entered into NVivo (version 12; NVivo, 2018) for analysis. The full transcripts were used in this study.

We used Thematic Analysis (Braun & Clarke, 2006, 2019; Clarke & Braun, 2013) to identify patterns of meaning across the data guided by the overarching research questions of how AN may develop and be maintained in autistic women. This involved familiarisation with the data by reading all transcripts, followed by line-by-line coding of the data to capture interesting features of the data of potential relevance to the research question. These codes were then used as building blocks for candidate themes, which captured larger patterns of meaning, underpinned by a central organising concept (Braun & Clarke, 2013). The researchers moved back and forwards between these steps, reviewed candidate themes against codes and the full data set and adapted them until the final set of themes was thought to represent a comprehensive framework that allowed the researchers to sufficiently organise and report their interpretation of the data in relation to the research question.

We adhered to guidelines for good practice in qualitative research (Mays & Pope, 2000; Pope et al., 2000) to ensure that interpretations of the data were

thorough and consistent. We employed a consensus approach to coding. After familiarisation with the interview transcripts, two researchers (JB and CB) jointly analysed the data to avoid relying on a single analyst driving theme development (Hill et al., 1997). Both researchers analysed all transcripts for each group in the opposite order to each other. At least twice during each group's analysis, JB and CB reviewed and merged each other's coding to ensure consistency across transcripts. By analysing the transcripts in reverse order, both researchers brought different insights when discussing theme development at various stages of the analysis. It also balanced the weight of each participant's perspective, ensuring that all voices contributed to the shaping of themes. The transcripts from the three participant groups were analysed separately, starting with the autistic women's data, before merging themes across the data set. Codes and candidate themes were developed for each group separately, before combining data sets. This allowed us to develop a comprehensive understanding of the nuanced variations in the different groups' perspectives, while keeping the autistic women's direct experiences central to theme development. The researchers also regularly discussed their progress with the wider research team to generate alternative ways of viewing the data and expand their understanding of the data (Barbour, 2001), until a consensus on the best way to represent the data was reached. At two points during the analytic process, we consulted with the autistic advisors, who commented on the interpretations made by the researchers. Codes and/or themes were adapted if the research team agreed with their interpretation. This ensured that the findings made sense in the context of the advisors' lived experience and their understanding of the experiences of others within their community.

Once the themes had been identified, further analysis and discussion within the research team led to the development of a model of restricted eating difficulties in autism, which highlights the relationships between themes and underlying processes. The model was developed separately from the themes and adds another layer of interpretation, which was conducted for a more theory-generating purpose. This process included a wider range of approaches of engaging with the data, such as representing relationships spatially by arranging printed codes and themes on the floor, and visually capturing potential processes in diagrams, which then served as the foundation for the model developed. The model is directly informed by, but goes beyond, the qualitative data and themes, generated by the thematic analysis. The themes partly map onto the model, but are more closely link to the data, whereas the model goes beyond the data in that it generates hypotheses about processes and underlying mechanisms. It also highlights links and parallels between the themes.

Findings

Thematic Analysis

We structured our codes around six themes, some of which include further subthemes (see Table 2): “sensory sensitivities”, “social interaction and relationships”, “self and identity”, “difficulties with emotions”, “thinking styles”, and “need for control and predictability”. Overall, these themes were endorsed by all participant groups, although some were more clearly expressed by some, as will be outlined below. These themes overlap and influence one another, as highlighted in the subsequent theme presentation.

Table 2

Overview of themes from thematic analysis.

Main themes	Subthemes

Sensory sensitivities	Sensory overload
	Food-specific sensory sensitivities
	Internal and bodily sensations
Social interaction and relationships	
Self and identity	
Difficulties with emotions	
Thinking styles	Literal thinking
	Intense interests
	Rigid thinking
Need for control and predictability	

Sensory sensitivities. Sensory sensitivities contributed to autistic women's REDs through general sensory overload, food-specific sensory sensitivities, and discomfort and confusion related to internal and bodily sensations.

Sensory overload. Some women reported having aversive sensory sensitivities related to noise, touch and certain lighting. Parents also noted sensory issues as one of the key ways in which their daughters' autism affected their day-to-day life and related this to 'meltdowns' their daughters experienced. Healthcare professionals observed that many of their autistic clients struggled with the sensory experience of the treatment environment. These experiences of sensory overload appeared to affect autistic women's eating behaviour, with some women seemingly using the effect of starvation on their body to numb these sensations.

Food-specific sensory sensitivities. Almost all of the women experienced food-specific sensitivities related to food texture, taste, smell, temperature, or the mixing of different foods, which limited the range of foods they would eat.

"I've never eaten a tomato in my life because it's just hard and it's squidgy in the middle, it just disgusts me. There's absolutely no way I could eat it. […] And I'm

not keen on lettuces either. The fact it's all mixed up, which in my head it shouldn't all be mixed up, so for me a salad is actually a terrifying food!" AW08

This quote illustrates how repulsive certain textures and mixing of foods are for this participant. Several healthcare professionals emphasised that autistic women's motivation for food restriction often related to sensory properties of food, rather than primarily being based on calorie or fat content, which they saw as different from other women with AN.

Some women took extreme measures to avoid anticipated negative sensory experiences, refusing to touch certain types of food or even cutting out whole food groups in response to one negative experience, which parents and healthcare professionals related to their rigid thinking style. These food-specific sensory sensitivities were reported to have been present since early childhood, predating the women's REDs, and continued to interfere with their eating, even for those who had recovered. Most parents recalled their daughters having difficulties during mealtime or when others around them were eating. This mother's quotes emphasises the impact this had on her daughters behaviour and on how she was seen by others:

"If somebody else had a packed lunch that had a strong smell, she wouldn't just say 'I don't like the smell of that'. She would just overreact, and the teacher would think she was just badly behaved and stuff. But for her the smell was just unbearable." P05

Several parents said they had only realised in hindsight that some of their daughters challenging behaviours during mealtimes might have been due to their sensory sensitivities. In line with this, autistic women reported that, particularly when they were younger, others often misunderstood their responses to these sensory

experiences or refused to accommodate their sensory sensitivities, which further exacerbated their difficulties.

Some participants felt that autistic women's sensory-related restrictive eating had increased the chances of them developing an ED, because their relationship to food had always been difficult. Several participants, particularly healthcare professionals, drew parallels with the presentation of Avoidant/Restrictive Food Intake Disorder (ARFID), an ED that is not driven by weight and shape concerns (American Psychological Association 2013).

"I think also there is the crossover with ARFID. Being quite restrictive about the kind of foods they will eat, quite fussy about textures, tastes, how it's prepared. And that can sometimes tip over into more rigid patterns of eating." HCP 2

A few of the women and parents, who had come across this label, even wondered whether this would have been a more appropriate diagnosis than AN, or whether one had morphed into the other.

Internal and bodily sensations. Hypersensitivity to sensory stimuli also applied to internal sensations. For some women the internal sensations associated with eating, such as feeling bloated or the sensations of digesting food, were very distressing and they reported restricting their eating to avoid these sensations. Although some parents speculated that this might be the case, this was mainly described by autistic women themselves.

"That feeling of putting on weight… that's what kind of sends me back into restricting food, because it's not about 'oh god my stomach looks really big', it's more about 'I don't like the sensation of how my stomach feels'." AW11

In contrast, several other women talked about hyposensitivity to internal sensations, which led to difficulties with interoception, i.e. the ability to sense the

internal state of the body. This resulted in difficulty recognising and understanding emotions, as well as a difficulty interpreting eating-related sensations, such as hunger and satiety. Some reported consistently missing meals because they failed to notice they were hungry. Others would overeat without realising and then feel so uncomfortable they would subsequently restrict food. This woman described how her difficulties with interoception could result in both:

"I'm not very good at judging my own emotions or physical sensations. I don't really fully understand my thirst and hunger responses, or my fullness responses, so that really influences my eating because I can binge or miss meals very, very easily." AW09

Interoceptive difficulties were viewed as a pathway towards establishing ED behaviours, such as restricting food intake for long periods or entering a cycle of bingeing and restriction. For some women this also meant that they had never been able to regulate their eating routine without relying on external cues, such time of the day or size of a dish, even before their ED started. This was described as an additional challenge in overcoming their ED and developing a healthy eating routine.

Several healthcare professionals pointed out that this seemed to be unique to the presentation of autistic women with AN.

"Girls without autism do feel hunger, but they are actively working against those feelings of hunger. Some of the girls with autism I've spoken to don't seem to recognise it […] there's something about their sensory profile that possibly means that they don't experience hunger in quite the same way." HCP02

Social interaction and relationships. All participants talked about autistic women having longstanding difficulties with social interaction and communication,

including difficulties in friendships and experience of loneliness, bullying and abuse, which affected their eating.

Difficulties with social interaction made them vulnerable to adverse experiences and left them in a constant state of confusion and exhaustion. Restricting their eating was described as a way to cope with social difficulties and distract from or numb consequent emotions. The following quote exemplifies how the emotional burden of losing a friend lead to this woman immersing herself in ED behaviours:

"I think I was lonely a lot after [my only friend changed school] and that affected it, and I could just get engrossed in food and exercise and just forget about everything else." AW07

In many cases, autistic women's social difficulties got worse or their awareness of them increased as they reached adolescence, which coincided with the onset of their ED.

Another way, in which social difficulties might affect restrictive eating, seems to be avoidance of social settings that happen to involve food. For example, several women described how they initially started restricting their food intake when they skipped lunch in school canteens because they felt overwhelmed by the social or sensory environment, did not have anyone to sit with, or wanted to avoid bullies.

"The moment when I stopped eating at school, was because there was a big canteen, lots of people, lots of social stuff going on, lots of noise." AW03

Self and Identity. Almost all participants talked about autistic women lacking a sense of self, feeling different, and not fitting in as central to the development of their ED. These feelings caused emotional upset, which they reportedly tried to cope with by immersing themselves in ED behaviours. In addition, for some women dieting

or focusing on their appearance was used as a way to fit in with peers, or the ED provided a sense of identity.

Autistic women mainly attributed their feelings of difference and lack of sense of self to not having been able to make sense of their autistic experiences. The following quote illustrates how this woman's lacking understanding of her autism-related differences affected her self-esteem:

"You constantly feel like you're failing, you constantly feel different, you think it's all your fault because you don't know that there is something different about you." AW08

None of the women had an autism diagnosis when their eating difficulties emerged, and many participants wondered whether the women would have found it easier to cope if they had known they were autistic. Several parents blamed themselves for not recognising their daughter's difficulties or for not fighting enough to get the right diagnosis in childhood.

"I wonder, if I'd have picked up on the autism earlier, I might've been able to prevent the eating disorder. Or at least stop it getting to that severe point." P10

For some women, struggles with their sense of self led to them focusing on their weight and shape. In an attempt to make sense of their experience of not fitting in, a few women concluded that the reason must relate to their body and appearance.

For others, being exposed to societal messages about the importance of women being thin resulted in them wanting to change their body weight and shape in order to fit in and connect with peers.

"All her life [my daughter] had been surrounded by women who would talk about dieting, you know, I wished my legs weren't so fat, all those things. And [my

daughter] knew that that's important, even though she didn't care what she looks like, but she knew that it's a thing for normal women, for other women, and she wants to be the same." P12

In a few cases, anorexia and its values, including the desire to be thin, provided a sense of identity that autistic women had been lacking.

"I have never had much of a sense of self, and I think possibly [AN] then became a little bit like an identity. Going into hospital and being aware that everybody has the same condition, you then do become a lot more aware of some of the anorexia traits and you do sort of take them on" AW08

These women reported copying others and adopting their anorexic values as a way of camouflaging and passing in the neurotypical world.

Yet, although all of the women reported issues around their sense of self, for only a few of them this resulted in over evaluation of their weight and shape, as outlined in the examples above. Most autistic women stressed that weight loss was not the initial aim of their ED behaviour, but rather a secondary and unintentional consequence.

"What I wanted was to be able to restrict food and over-exercise without losing weight. So that's why it was so atypical. It was more like behaviours that I engaged with to feel calm, but would lead to catastrophic weight loss". AW13

Assumptions by others that body image issues drove their ED behaviours made these women feel even more misunderstood and alienated, further contributing to their feelings of being different.

The role of weight and shape concerns was an area where some parents' perceptions differed from those of autistic women. Several parents assumed that weight and shape concerns must be directly related to their daughters' poor sense of

self and ED. However, a few also reported that body image issues did not play a role for their daughters ED, or recognised the more nuanced reasons behind apparent body image issues and their relationship to the underlying autism, as described by the autistic women.

In line with the account that most autistic women's ED is not primarily driven by the influence of weight and shape on self-evaluation, healthcare professionals noted that many autistic women seemed less drawn to comparing their appearance to others or taking pride in their weight loss. They also reported that autistic women tend to show less competitive behaviours in inpatient settings than other women with AN.

"When you unpick it, it's not driven the same way, it's not about body image, they couldn't care less what other people think about their body." HCP10

Emotional difficulties. Many women reported that they had longstanding difficulties identifying, regulating, and communicating their emotions, resulting in emotional confusion and feelings of being overwhelmed. They also reported regularly having difficult and emotionally upsetting experiences, and some healthcare professionals suggested that autistic individuals might be particularly vulnerable to having traumatic and difficult experiences. Participant's accounts suggest that autistic women with AN may use restriction and other ED behaviours, such as exercise, in order to numb or distract themselves from overwhelming and confusing emotions.

This is something some reported to have discovered accidentally but then learnt to use purposefully. This woman's quote illustrates how restriction offered a solution to her previously uncontrollable 'meltdowns':

"When I was restricting my eating, I would get this feeling of just calmness, and I know that I am safer, I know that I am not going to experience these meltdowns, that made me feel embarrassed and frightened. […] So I was no longer just losing it." AW03

Healthcare professionals recognised how REDs in autistic women often relate to other mental health difficulties, particularly anxiety.

"[Their ED] is a way of channelling anxiety. They can just worry about food and nothing else and that feels more manageable than everything in their life that feels horrendous." HCP09

During the interviews, almost all of the women described additional mental health difficulties, which they saw as being closely intertwined with their autism and their ED.

"My OCD [obsessive compulsive disorder] started to get worse as I started to fight my eating disorder. I just seem to have kind of variations on the same theme, with the OCD and with the eating disorder. The problem seemed to be not what the content of my thoughts was, but how I thought." AW05

Similarly, this woman's quote illustrates the complex interplay between autism, difficulties with emotions, interoceptive difficulties and ED behaviours:

"I misinterpret [emotions] as physical symptoms and I get very anxious about it: Am I unwell? Am I going to vomit? And that's when I stop eating because I know that will dampen things down and calm them, so my emotions are feeding into my eating disorder behaviours, whereas I think my difficulties in perhaps coping with emotions stem perhaps more from the autism." AW08

Giving up on their ED behaviours, but lacking alternative ways of coping was one of the greatest challenges in recovery.

"When she had a BMI of 12, she had that control because she had no hormones, no emotions, no nothing. Apart from the fact it might kill you, it was quite good for her. But once she was getting better, all those thoughts flooded back into her brain, and her mind was feeling an awful lot worse." P03

*"I sometimes imagine life without [AN], and then think, well actually, I would still have a lot of problems, but I wouldn't have my coping mechanism."*AW05

Thinking styles. Participants talked about several autistic thinking styles contributing to AN in autistic women, including literal thinking, obsessive and intense interests and rigid thinking, because they made them more vulnerable to develop rules around eating and food, and/or made it more difficult to shift their focus away from these rules once they were established. This was mentioned by all participants across groups, although the autism-related thinking styles that they suggested give rise to eating difficulties varied between individual participants. Many participants mentioned several thinking styles as being relevant.

*"The autism and the routine and rigid thinking maintained the eating disorder. I think that's why my recovery has taken so long for me to get to what I would call true recovery. For me, the anorexia is just a symptom, and the cause is the autism."*AW03

While participants acknowledged that these patterns of thinking became more entrenched with the persistence of the ED, they reported that they had pre-dated their ED and were closely linked to their autism.

Literal thinking. In some cases, processing information in a literal way was thought to have led to distorted thinking around healthy eating and body image, which then gave rise to ED cognitions and behaviours. Parents in particular noticed

that their daughters tended to make sense of the world in a very 'black-and-white' way.

"She takes things as absolutely true and cannot cope with nuances, untruths, or lack of clarity. This shades over into 'all or nothing thinking' too –"If I'm not thin then I'm fat and horrible", with nothing in between." P13

In many cases, overheard comments, public health advice, and lessons at school about healthy eating, such as "fat is bad for you", were described as initially giving rise to rigid rules about eating and exercise and thus leading to the development of the eating disorder.

Intense interests. Obsessive thinking and intense 'special' interests related to ED behaviours also contributed to autistic women's AN.

"She has always had obsessions with things, and once she had got on to healthy eating and food, that became extreme and made her very ill very quickly." P11

For women in this study, such interests included exercise, nutrition, veganism or environmental concerns. A passion for counting and monitoring numbers, such as counting calories or looking for patterns in the numbers on weighing scales, was also common. For many autistic women these interests were described as an important source of enjoyment and a way to alleviate anxiety and bring calmness, which contributed to their persistence.

Rigid thinking. Another autism-related thinking style that was thought to give rise to and maintain ED in autistic women was rigid and inflexible thinking. Participants described how autistic women's rigid thinking resulted in difficulty with planning daily tasks and adapting to changing demands in day-to-day life, which in turn caused stress and emotional upset. Many participants felt that this rigid thinking

style also made it harder to overcome anorexic thinking patterns and to not fall back into behaviours out of habit.

"Sometimes it's just habit that I will [engage in ED behaviours], because that's what I have done for the last 15 years, rather than a driven behaviour, if that makes sense." AW04

However, some participants acknowledged that rigidity could also be an important tool for recovery, potentially driving the determination to get better.

"I think the ASD is making it so difficult to shift her thoughts.[…] I know that once she's made up her mind about something, it's very difficult to change it. So I live in hope that one day she'll decide she's going to get better, because if she does, because she's so determined, she will do it. But until she makes that decision, it's a battle." P04

Need for control and predictability. Participants described how autistic women's rigid thinking and difficulty coping with change, which they saw as linked to their autism, elicits a need for control and predictability. Women seemed to address this need through controlling their food intake, sometimes in a ritualised fashion.

While most autistic women recalled that they could cope in early childhood when their life was more structured, they often started to struggle around the onset of puberty. Parents and healthcare professionals in particular felt that hormonal changes and resulting emotional extremes during this time further exaggerated feelings of confusion and perceived loss of control.

Stressful life events with unpredictable outcomes, such as illness or conflict in the family, or transitions to a new school or university, were also described as leading to worsening of eating behaviours. Although several women noticed these patterns, this was particularly clear to parents and healthcare professionals.

Being able to take control of something, having clear rules to follow and creating predictability were understood as powerful functions of AN in the autistic women. Autistic women's inherent need for control, difficulty with change, and tendency to follow routines also made recovery difficult, and in some cases even made them doubt whether they could overcome their ED.

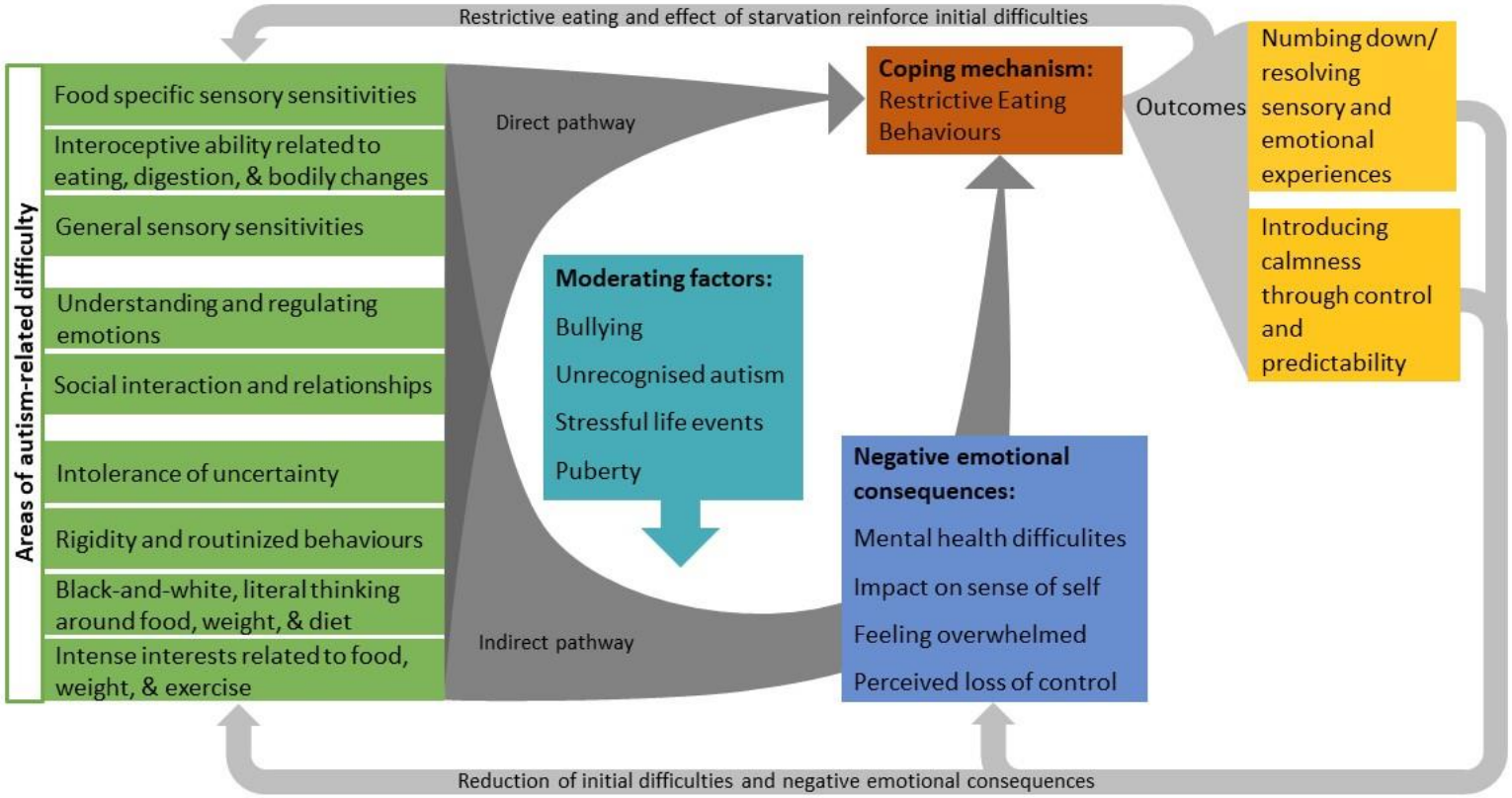
"I seem to have a strong need for control; I will always try and fill it with something. And if I could get rid of that, if I could learn to think differently… that would probably be the only way I could really recover." AW03

Autism-Specific Model of Restrictive Eating Difficulties

Based on these findings, we developed a theoretical model based on hypothesised autism-specific mechanisms for restrictive eating difficulties (Figure 2).

Figure 2

Proposed model of autism-specific mechanism underlying restrictive eating difficulties



We propose that autism may give rise to restricted eating behaviours via a direct pathway and an indirect pathway. It seems that there are a range of autism-related difficulties that autistic individuals who develop restrictive eating difficulties might experience in their life. These difficulties seem to relate to core autistic traits, such as sensitivities, social and emotional difficulties, and their cognitive profiles. In the direct pathway, autism-related difficulties, which revolve around food and ED related behaviours, are suggested to increase risk of severe restrictive eating. For example, food-related sensory aversions or special interests focused on eating or exercise may contribute directly to restrictive eating and related behaviours. In the indirect pathway, autism-related difficulties are thought to give rise to negative emotional consequences, and we suggest that restrictive eating is used as an attempt to cope with this, although it risks causing further harm in the long-term. For example, particularly for an undiagnosed and unsupported autistic individual, a longstanding history of social ostracism and peer victimisation can give rise to emotional distress; and they may discover that restricting food intake serves to numb these feelings, whilst the experience of gaining control over their calorie intake helps assuage anxiety. It is important to note that external factors, such as being bullied, being misunderstood because the individual's autism is not recognised or diagnosed, stressful life events, or puberty, are likely to play an important role in the indirect pathway. These may moderate the relationship between autism-specific difficulties and emotional consequences. The nature of the initial difficulties and the combination of different factors experienced by an individual may result in a variety of restrictive eating presentations. For example, strong aversion to food characteristics might result in a more ARFID type presentation, whereas issues in social relationships or experiences, which affect the individuals sense of identity and

direct their focus towards weight and shape, may result in a more traditional AN presentation. It is hypothesised that restrictive eating behaviours are maintained because their outcomes directly reduce the individual's autism-related difficulties and their negative emotional consequences by: (1) numbing down or resolving some of the sensory and emotional experiences; (2) introducing calmness through giving a sense of control and providing predictability. At the same time, the ED and effect of starvation may work against this ameliorating effect to exacerbate some of the initial difficulties.

Discussion

This qualitative study specifically investigates how AN develops and is maintained in autistic women from the combined perspectives of autistic women with AN, parents and healthcare professionals. Our interviews suggest that autistic women with AN experience their autism and AN as closely intertwined. AN in autistic individuals seems to relate to sensory sensitivities, difficulties with social interaction and relationships, autistic women's sense of self and identity, difficulties with emotions, autistic thinking styles and a need for control and predictability. Further, we draw on these findings to propose a theoretical model of the hypothesised processes by which autism-related difficulties may give rise to and maintain restrictive eating difficulties in autistic individuals.

Although identifying differences and similarities between participant group's perspectives was not the primary focus of the current study, it is noteworthy that the perspectives of the different participant groups tended to be aligned, rather than contradict each other. However, some themes were more strongly endorsed by particular participant groups. For example, 'internal and bodily sensations' were more frequently discussed by autistic women, whereas stressful life events preceding the

onset of worsening of disordered eating behaviours was more often mentioned by parents and healthcare professionals.

The triangulation of different groups perspectives enriches the emerging understanding of autistic women's experience of AN. Parents were able to contribute a developmental perspective and insights into areas of personal history that the autistic women had more difficulty reflecting upon, such as triggering factors that preceded episodes of disordered eating. Healthcare professionals were able to identify common patterns of behaviour from having worked with multiple autistic women, while also comparing them to their non-autistic clients. Although some clinicians might lack the confidence to treat these individuals (Kinnaird et al., 2017), it is notable that the healthcare professionals in our study demonstrated relevant clinical insight and discussed similar themes to the autistic women. Given parents and practitioners role in facilitating access to and providing support, greater awareness of different potential presentations of restrictive eating difficulties in autism and a shared understanding of a women's difficulties seems to be vital for improving outcomes for affected girls and women.

The findings of the current study accord with those of Kinnaird, Norton, Stewart, et al. (2019), even though they were conducted in separate samples. Both studies suggest that autistic women experienced their AN and autism to be deeply interlinked, with autism-related difficulties both contributing towards AN development and making recovery more challenging (Kinnaird, Norton, Stewart, et al., 2019). This study added to Kinnaird, Norton, Stewart, et al.'s findings (2019) by illuminating some of the underlying processes through which autism-related traits might introduce the individual to restrictive eating behaviours or maintain an ED once it has developed. Kinnaird, Norton, Stewart, et al. (2019) suggested that many of the

factors that were identified as contributing to the development and maintenance of AN, such as sensory sensitivity and social communication difficulties, also cause autistic women difficulty engaging in treatment.

Kinnaird, Norton, Stewart, et al. (2019) reported that participants described how a desire to lose weight, low self-esteem, and body image issues were less relevant in the development of their illness compared to other motivations that are less commonly associated with AN. In line with this, many women in our study emphasised that weight and shape concerns were not driving their restrictive eating behaviours. Further, when weight and shape concerns did play a role, this study was able to add insights into autism-related motivations that seem to underpin such preoccupations. In contrast to Kinnaird, Norton, Stewart, et al.'s findings (2019), low self-esteem did emerge as highly relevant for women in the current sample, who felt different and struggled with their sense of self because of their autism not being recognised. However, this deviated from traditional understanding of low self-esteem in REDs, as it was closely linked to these women being autistic.

Based on the findings from our interviews, we developed a theoretical model of autism-specific mechanisms for restrictive eating difficulties, hypothesising how autism-related difficulties may contribute to the development and maintenance of restrictive eating behaviours in autistic individuals (Figure 2). Our model proposes that restrictive eating behaviours and consequent difficulties in autistic individuals can stem directly from their autism, for example reflecting sensory aversions to foods. Eating difficulties may also arise as an attempt to cope with the indirect challenges of being autistic, such as consequent mental health difficulties or issues around identity. Engaging in restrictive eating behaviours and the effect of starvation seem to numb or resolve emotional and sensory overload, and controlling food

intake can counter anxiety arising from being in an unpredictable environment. Each of the themes, which were captured by thematic analysis (see Table 2), spans multiple elements of this model (Figure 1). The model illustrates how the different themes may relate to and interact with each other, and thus emphasises potential processes and underlying mechanisms through which autism might give rise to and maintain restrictive eating behaviours, which in their extreme take on the form of an ED. The additional theoretical discussion of the themes and data, which was part of the model development, added another layer of interpretation, such as the conceptualisation that underlying factors might have different types of influence (i.e. direct and indirect) on restrictive eating difficulties or that causal and maintaining factors could be categorised as either autism-related difficulties, negative emotional consequences, or external influences.

Many elements of the proposed model have been established in both AN and autistic populations, which supports their relevance for AN in autism. For example, both autistic individuals and those with AN present with social difficulties (Zucker et al., 2007), emotional dysregulation (Mazefsky, 2015; Oldershaw et al., 2015), high rates of intolerance of uncertainty (Brown et al., 2017; South & Rodgers, 2017), rigid thinking (Coniglio et al., 2017; Westwood, Stahl, et al., 2016), and even general and food-specific sensory sensitivities (Crane et al., 2009; Kinnaird et al., 2018; Tonacci et al., 2019; Zucker et al., 2013). However, few studies have looked at these factors in relation to autism and AN within the same sample, and studies tend to use different forms of measurement, which makes direct comparison between populations difficult.

Elements of the proposed model relate to other established models of AN, such as the cognitive-interpersonal maintenance model maintenance model

(Schmidt & Treasure, 2006), which further supports the models validity. Such models provide helpful additional factors to consider when attempting to understand autistic people's REDs experience and supporting them. The cognitive-interpersonal maintenance model proposes that cognitive, socio-emotional and interpersonal elements act together to both cause and maintain the ED (Treasure & Schmidt, 2013). It includes certain cognitive factors, e.g. set shifting ability and weak central coherence (Treasure & Schmidt, 2013), which align with cognitive styles associated with autism described by participants in our study. The cognitive-interpersonal maintenance model also highlights socio-emotional processing difficulties, including with emotional regulation and social cognition that are thought to be in part consequence of starvation, but may also be an inherent vulnerability factor (Treasure & Schmidt, 2013). Autistic individuals might be particularly likely to experience these prior to the onset of their RED. Finally, the cognitive-interpersonal maintenance model highlights interpersonal elements and the maintaining role of systems interacting with the individual (Treasure & Schmidt, 2013), which were less pronounced in the current study, but might well play out in autism specific ways, for example with regard to misunderstandings of autistic traits and lack of autism-informed support for (undiagnosed) individuals, and how this affects autistic individual's sense of self and their relating to others, but also the challenges carers and healthcare professionals might face in supporting them (Kinnaird, Oakley, Lawrence, et al.; 2021; Kinnard et al., 2017). A recent evaluation of the model also discussed perpetuating aspects of the AN as an illness, such as consequent isolation, secondary mental health problems, and chronic stress that accumulate in the severe and enduring stage of the illness (Treasure et al., 2020). These will be important to consider when supporting autistic adults.

Our focus on autistic women with AN and the use of qualitative methodology means that we do not know to what extent the proposed themes are distinct to this group, rather than applying more generally to women with AN who are not autistic, although health care professionals provided some insight by comparing their experience with both groups. Given the overlap between the two conditions (Westwood & Tchanturia, 2017), it may be that some of the factors proposed by the current study are autism-specific, and that (unrecognised) autistic individuals are driving observations made in AN samples. It will be important for future research to assess whether there are indeed differences in these factors between women with AN with high levels of autistic traits and those without autism. Another possibility is that some proposed factors are relevant to both autistic and non-autistic women with AN. If this is the case, there might still be subtle yet clinically meaningful differences in terms of how these factors present. For example, other models of AN suggest that emotional difficulties in AN tend to relate to intolerance of negative emotions in the self and others, resulting in emotional avoidance (Mansour et al., 2016; Treasure, 2013), whereas the autistic women in the current study seemed to have an underlying inability to identify and regulate emotions and struggled with consequent emotional confusion. Finally, some factors might be general risk factors for AN, but given their close association with autistic behaviours, they are likely to affect autistic women disproportionately, both in terms of severity and number.

Similarly, while some elements of the model, such as food-related sensory sensitivities, seem particularly relevant to restriction and disordered eating in autism, other components might also be relevant to other mental health conditions. This could explain the co-occurring mental health difficulties experienced by autistic women with AN in our sample, which is in line with high rates of additional mental

health conditions reported in similar samples (e.g. Westwood et al., 2017b). Some elements of the model, such as intolerance of uncertainty or difficulties regulating emotions, have been associated with other mental health difficulties and maladaptive behaviours, such as addiction and substance abuse, in autistic individuals (Mazefsky, 2015; South & Rodgers, 2017; van Wijngaarden-Cremers & van der Gaag, 2015). Thus, they may be shared vulnerability factors for poor mental health outcomes in autism.

The current study focused exclusively on females. Both AN and autism are considered to have somewhat gender-specific presentations (Hiller et al., 2014; Hull et al., 2020; Lai et al., 2015; Stanford & Lemberg, 2012), which raises the possibility that interactions between autism and AN may be different in females and males. With the prevalence rates of AN being much higher in females than males (Bulik et al., 2006; Nagl et al., 2016), recruiting sufficient numbers of autistic males with AN to adequately capture their experience would have been beyond the scope of this project. The applicability of the proposed model to autistic males, non-binary and transgender people with restrictive eating difficulties warrants further investigation.

Even though this research focused on autistic women with AN, the findings highlight potential overlap with other REDs and seem to have relevance for restrictive eating difficulties in autistic individuals more generally. For most women in our sample, weight and shape concerns did not seem to be driving their ED, even though this is commonly assumed to be the case for individuals with AN (APA, 2013; Fairburn et al., 1999). Instead, their restrictive eating seemed to be driven by other factors, such as food-specific sensitivities, a desire to avoid certain bodily sensations, or an absence of hunger signals. For some women there seemed to be behavioural parallels to individuals with ARFID, who present with avoidant and

restrictive eating behaviours, but without the body shape issues that typify AN (APA, 2013; Nicely et al., 2014; Thomas et al., 2017). Autism commonly co-occurs with ARFID (Nicely et al. 2014). Even though ARFID can present across the lifespan, it is more commonly considered in children, and thus may be overlooked or misdiagnosed as AN in adult women with low weight (Becker et al., 2019). The model we developed purposefully refers to restrictive eating difficulties in general, rather than just AN, as our findings do not necessarily suggest that the proposed autism-specific mechanisms are limited to a specific diagnostic category and/or severity level. The subsequent chapters will further investigate the apparent lack of weight and shape concerns in autistic women with restrictive eating difficulties, and include women with a variety of REDs to establish whether elements of the proposed model also apply to autistic individuals with REDs other than AN.

All women in our sample received their autism diagnosis in adulthood (mean age= 29.4 years), often years after first receiving treatment for AN (mean age=17.4 years). Both being female and having other co-occurring mental health conditions are risk factors for delayed or missed autism diagnosis, and living with undiagnosed autism is associated with the development of mental health difficulties (Bargiela et al., 2016; Brown et al., 2019; Leedham et al., 2019). It is unclear whether some of the factors identified in this study would have affected autistic women differently if their autism had been recognised and supported earlier in life. Being recognised as autistic, and receiving appropriate support for associated difficulties might act as a protective factor. The role of diagnosis and other protective factors for the development of REDs should be explored further by future research. Early autism diagnosis and specialist intervention for autistic girls and women at risk of restrictive eating difficulties may help to prevent the development or worsening of ED

symptoms. However, ED clinicians self-report lack of confidence in identifying autistic individuals in their care (Kinnaird et al., 2017), and existing screening and diagnostic tools, including the AQ-10 (Allison et al., 2012) used in this study, are poorly equipped to reliably detect autistic traits in ED samples (Westwood & Tchanturia, 2017). It should be noted that the AQ-10 has been criticised for its poor ecological validity in clinical settings (Wigham et al., 2018). Ashwood et al. (2016) used the AQ-10 with participants, who were consecutively referred to an autism assessment clinic and had high rates of comorbid mental health conditions. In this setting the AQ-10, with a cut-off of six, did not predict autism diagnosis (established through gold standard assessments including the ADOS) better than chance. Relying on the AQ-10 to confirm presence of high levels of autistic traits should therefore be noted as a limitation of the current study. Future research should work towards better identification of autistic traits in AN, which will benefit both clinical practice and research.

Future Directions and Implications

This research suggest a variety of avenues for future research. For example, further qualitative work in other samples and using different approaches, such as Grounded Theory (Bryant, 2017; Glaser & Strauss, 1967), could explore the applicability and refine the model proposed in this paper. Similarly, systematic clinical case studies could be used to confirm the relevance of the factors identified in this study and determine the role of other potential factors, including how women's support networks (parents and professionals) might influence their RED experience. Longitudinal and group comparison studies could further establish the causal role of different factors and their relevance for individuals with different presentations. The subsequent chapters will make a start with exploring the relevance of some of the

factors proposed in the current study by comparing their presentation in autistic women with REDs, autistic women without REDs and non-autistic women with REDs.

This findings of the current study have important implications for the treatment of autistic individuals in ED services and for preventing the development or worsening of restrictive eating difficulties in autistic individuals. The finding that autistic women with AN report causal and maintaining factors that are not traditionally associated with AN raises the possibility that autistic women with AN may have more enduring presentation and poorer outcomes (Nazar et al., 2018; Tchanturia et al., 2017) because standard treatments do not address autism-specific mechanisms underlying their REDs. There is a need for ED services to identify autistic individuals in their care and to adapt treatment accordingly. In the long-term, this research may also contribute to the development and testing of new autism-specific AN treatments. Preventative approaches should aim to support individuals at risk with their difficulties, particularly during mealtimes, and help them to develop alternative copying mechanisms. The theoretical model presented in this study was based on the thematic analysis of the insights of autistic women with AN, their parents and relevant HCPs. It therefore provides a useful initial framework for considering relevant issues affecting restricted eating in women with AN and autism or high levels of autistic traits. However, further work is needed to empirically test and refine the model proposed in this study to maximise its impact.

Conclusion

In this study, we propose a theoretical model of the autism-specific mechanisms underlying restrictive eating difficulties based on the experiences of affected individuals and those involved in their care. Autistic women with AN

experience their autism and RED as closely intertwined. Our findings suggest that AN in autistic women may be distinct from AN in non-autistic women in terms of its presentation and underlying mechanisms. Further research is required to test these novel insights about the nature of AN in autism. The findings of this study may directly benefit affected individuals by increasing awareness of autism-specific restrictive eating presentations, and helping ED services to improve the way they treat autistic individuals with AN.

Chapter 3: Methods for Study 2

In this chapter, the methods for Study 2 will be described in detail. The rationale and results of this study will be presented and discussed in the subsequent chapters. Specifically, Chapter 4 will describe the sample in terms of their demographics and background characteristics and will compare participant groups on autistic traits and disordered eating-related presentations. Chapter 5 will compare participant groups with regard to food-specific and general sensory sensitivities.

Impact of COVID-19

We initially designed the study to be a between-participant comparison of three participants groups, namely (1) autistic women without REDs, (2) autistic women with REDs, and (3) non-autistic women with REDs. We intended to conduct data collection in-person, which would have included in-depth autism diagnostic assessments, combining observational and self-report measures, physiological and experimental tasks, and multiple self-report questionnaires. The autism assessment would have allowed us to confirm autism diagnostic status of participants with a formal autism diagnosis, identify undiagnosed autistic women with REDs, and rule out the presence of autism among participants recruited to the group of non-autistic women with REDs. Including physiological and experimental tasks would have allowed us to compare subjective self-reported experiences and attitudes to objective measures of participants' behaviour.

However, after a couple of months of data collection the Corona Virus (COVID-19) pandemic arrived in the UK, and lockdown restrictions meant we were no longer able to see participants in-person. COVID-19 is an infectious disease caused by severe acute respiratory syndrome coronavirus 2 (SARS-CoV-2), which was first discovered in late 2019 and rapidly spread across the world. In March 2020

the WHO declared the COVID-19 outbreak a pandemic in March 2020, and national lockdowns measures were imposed in many countries including the UK. This included travel restrictions and shop, school and workplace closures, which had widespread implications on public activity (Han et al., 2020). COVID-19 affected the project in a number of ways. Firstly, it affected the timeline. After pausing recruitment for a number of months due to uncertainty about how the pandemic would develop, data collection was moved online, which required changes to the design and ethical amendments before data collection could resume. Secondly, it affected the nature of data available for collection. We were no longer able to conduct in-person autism assessments and physiological and experimental tasks. Thus, for some measures, data is only available for a subset of participants (see missing data below). For self-report measures, we had to review how the COVID-19 pandemic might affect the applicability of questionnaire items and participants experience of the constructs being measured. For example, social distancing measures were likely to have affected participant's ability and experience of socialising, which could affect responses to certain items on autism-related measures. Thirdly, it affected our recruitment strategy. We initially intended to include undiagnosed autistic women with REDs and to recruit the majority of our REDs participants with and without (suspected) autism from NHS ED services. The rationale for this was that previous research and clinical experience suggests that the autistic women in ED settings are often undiagnosed (Babb et al; 2021; Fusar-Poli et al., 2020; Westwood et al; 2018). Identifying and including such women would have allowed us to make the sample more representative and conclusions from the research more clinically meaningful. We had trained ED clinicians to recognise high autistic traits in women on their caseload, and would have asked them to refer potential participants with REDs who

they believed were not autistic, as well as women who they suspected to be autistic or who had a formal autism diagnosis. We would have then used the in-depth autism assessment to confirm eligibility and group allocation. However, all non-COVID-19-related research activity in NHS settings was paused at the start of the COVID-19 pandemic, and even when it resumed, NHS services were facing additional pressures as a consequence of the COVID-19 pandemic, which meant some were no longer able to support recruitment. Thus, we were required to rely on online recruitment to a greater extent. The lack of clinicians' judgement of autistic traits and the inability to conduct thorough in-person autism assessments, combined with the wider reach of online recruitment, meant we had put additional steps in place to ensure participants were eligible for inclusion. In particular, we felt it was no longer viable to include women with suspected autism in the group of autistic women with REDs, because we were unable to verify suspected autism status. At the same time, we anticipated a recruitment bias, in that more women with REDs, who might suspect they are autistic but do not have a formal autism diagnosis, would express interest in the study. As a consequence, we regrouped recruited participants into four groups before conducting analyses:

1) Autistic women without REDs ('Autism only'),

2) Autistic women with REDs, who have an independent formal autism diagnosis ('Autism+REDs'),

3) Women with REDs with normal or low levels of autistic traits, without a formal autism diagnosis ('REDs only').

4) Women with REDs with high autistic traits, without a formal autism diagnosis ('REDs high autistic traits')

Participants

A total of 222 participants were recruited, 210 of whom were included in the final sample. Of these, 47 participants were included in the 'Autism only' group, 51 in the 'Autism+REDs' group, 76 in the 'REDs only' group, and 36 in the 'REDs high autistic traits' group.

Recruitment

Participants were recruited via NHS services, social media, and charities. Eight NHS ED and two NHS adult autism services agreed to support recruitment. The study's blog, Twitter and Facebook page as well as the research team members' personal twitter accounts were used to disseminate the study advert via social media. An example of the recruitment advert is presented in Appendix 2. Further, we advertised the study via the UK autism research charity Autistica, who shared the research advert via their email network and Twitter, and the UK eating disorder charity BEAT, who shared the research advert on their website, Twitter and Facebook.

As outlined above, we started recruiting participants to take part in-person (prior to the COVID-19 pandemic) and later to complete to the study online (during the pandemic). All participants who took part in-person had been recruited via social media or charities. Participants who took part online had been recruited via all recruitment pathways, including NHS services. The number of participants recruited via each pathway and who participated in-person vs online is presented in Table 1, Appendix 3. We compared participants in each group, who participated in-person vs online, on key variables varied to check whether they varied with regard to their clinical characteristics. Mean scores on key variables and group comparisons are presented in Table 2, Appendix 3. In-person and online participants in each group did not differ significantly on any of the key variables (see Table 2, Appendix 3).

Target Sample Size

This is a novel research topic, so there was insufficient existing literature from which to estimate anticipated group difference effect sizes to inform sample size / power calculations. Therefore, we chose to power this study to be sensitive to detect difference of an effect size which we estimated to be of clinical importance (medium-large), while having an achievable recruitment target in terms of sample size. We calculated a priori that we needed to recruit a minimum of 45 individuals in each group to have acceptable power (≥80%; Field, 2013) to detect group differences of medium-large effect size (Cohen's $d \geq .6$) with two-tailed alpha at .05 (Cohen, 1988). While greater sensitivity would have been desirable, when intending to conduct this study in-person, we judged it to be unrealistic to recruit a larger sample, within the time restraints of the project, particularly for the group of autistic women with REDs. We did not set an upper limit for recruitment, as more participants would increase statistical power as well as utility of the data for secondary analysis.

Following the re-grouping of our participants after recruitment (see above), the 'REDs high autistic traits' group did not reach the desired sample size. Further, Chapter 5 presented some preliminary analysis of in-person measures for a subset of the 'Autism only' (n=25) and 'Autism+REDs' (n=12) groups. Table 3 presents a sensitivity analyses, i.e. the minimum effect size each group comparison was powered to detect based on the final acquired sample sizes with power level of 80% and two-tailed alpha at .05, conducted using G*Power version 3.1.9.2 (Faul et al., 2007). The sensitivity analysis indicates that group comparisons in the final sample were powered to detect differences of a medium-large effect size, with exception of the comparison of the subset of 'Autism only' and 'Autism+REDs' participants, who

completed in-person measures, which was only powered to detect very large effect sizes.

Table 3

Effect size needed for each group comparison to be sufficiently powered based on the final acquired sample size

Group comparison	Minimum effect size required (*d*)
Autism only vs Autism+REDs	.57 / 1.01*
Autism only vs REDs only	.52
Autism only vs REDs high autistic traits	.63
Autism+REDs vs REDs only	.51
Autism+REDs vs REDs high autistic traits	.62
REDs only vs REDs high autistic traits	.57

Note. Autism only (n=47), Autism+REDs (n=51), REDs only (n=76), REDs high autistic traits (n=36),
* Subset included in analysis of in-person data: Autism only (n=25), Autism+REDs (n=12)

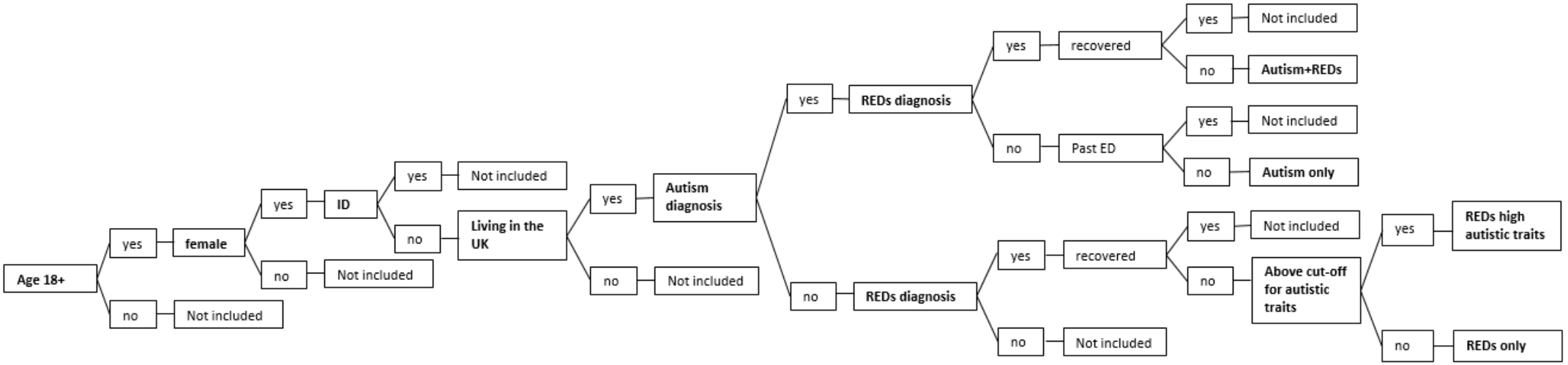
Inclusion Criteria

The decision process for including participants is outlined in Figure 3. Inclusion criteria related to age, sex, intellectual ability, geographic location, autism and REDs diagnostic status, current levels of autistic traits, and disordered eating. Individual criteria are detailed below. Some criteria were applied to all participants, whereas others were specific to their respective group. Inclusion criteria were confirmed in three stages. First, a potential participant's eligibility was established through self-report responses to screening questions (Appendix 4). For participants recruited via NHS services, inclusion criteria were also confirmed by screening their medical records. Second, their responses to relevant questions on the background questionnaire (Appendix 5), which they completed as part of the study, were checked for consistency with the information provided at the screening stage. Third,

participant’s scores on selected measures of autistic traits and disordered eating were used to confirm inclusion and determine group allocation.

Figure 3

Participant inclusion decision process



Note. ID=intellectual disability; REDs=restrictive eating disorder

Inclusion criteria for all participants.

Age. All participants were required to be aged 18 years or above.

Sex. All participants were required to be female, including non-binary and trans-female gender identities. A combination of practical and theoretical considerations have led us to focus our investigation on females, excluding males. Autistic girls and women can present differently to males on the autism spectrum (Hull et al., 2020; Lai et al., 2015), which extends to presentation of co-occurring conditions (Sedgewick et al., 2020). Similarly, there are sex/gender differences in the causes, manifestations and needs of people with REDs (Stanford & Lemberg, 2012). If we included males in our study, we would have required sufficient numbers of autistic and non-autistic males and females with and without REDs to investigate sex/gender effects. Males are rare in ED services, constituting fewer than 10% of AN patients (Button et al., 2008). Recruiting enough male participants to allow for adequately powered analyses of sex/gender effects was not considered feasible within the scope of the project.

Intellectual ability. All participants were required to have no ID, also referred to as general learning disability, to ensure they had capacity to consent, to process the information provided, and to independently complete the measures included in the study battery.

Location. All participants were required to be living in the UK. This was specified for in-person data collection, which required participants to live within travelling distance of the research sites in London and Cardiff. When the study moved online due to COVID-19, this inclusion criterion was maintained for consistency. Geographic locations for participants in each group are listed in Table 1, Appendix 3. The largest proportion of participants in each group was based in the

South East of the UK, including London, (36.1-53.9%), followed by Wales (9.8-22.2%) and the Midlands (5.3-13.9%).

Group-specific inclusion criteria.

Autism diagnostic status. Participants in the 'Autism only' and 'Autism+REDs' groups were required to have a formal autism diagnosis, including autism spectrum disorder/condition (ASD/C), autism, Asperger's syndrome, high functioning autism, and pervasive developmental disorder. Formal diagnosis was defined as having received an independent autism diagnosis by a qualified healthcare professional or multi-disciplinary team in line with latest ICD or DSM criteria at the time of their assessment. Participants in 'REDs high autistic traits' and 'REDs only' group were required to not have a formal autism diagnosis. The screening questions asked participants whether they are formally diagnosed and asked for details about their diagnostic assessment, including the specific autism diagnosis received, age at diagnosis, and the service at which they were diagnosed. Where information provided was not deemed sufficient or raised doubts, potential participants were asked to participate in a screening phone call to obtain further information, until the research team were satisfied that their reported autism diagnostic status was accurate. Autism diagnostic categories reported by autistic participants are listed in Table 1, Appendix 3. Most autistic participants had received a diagnosis of ASD/C ('Autism only': n=28/47, 59.5%; 'Autism+REDs'; n=32/51; 62.8%). There was no statistically significant difference in the types of autism diagnoses reported in both groups, $\chi^2(1)=.508$, $p=0.523$, $\phi_c=.072$.

Current levels of autistic traits. After data collection, participants scores on the Ritvo Autism Asperger Diagnostic Scale –14 (RADS-14; Eriksson et al., 2013) were used to confirm the presence of autistic traits in those with a formal autism diagnosis

('Autism only' and 'Autism+REDs' group), and to identify a subgroup of women with REDs who had very high autistic traits, but no formal autism diagnosis. Only those who scored above the recommended general population cut-off of 14 on the RAADS-14 (Eriksson et al., 2013) in the 'Autism only' and 'Autism+REDs' group were included in subsequent analysis. Participants with REDs who did not have a formal autism diagnosis, were split into two groups ('REDs high autistic traits'; 'REDs only') depending whether they scored above or below a cut-off of 23. This more conservative cut-off was used as it has been demonstrated to have greater specificity (i.e. ability to accurately identify negative cases) in psychiatric samples (Eriksson, 2016; Eriksson et al., 2013) and has been used by others to rule out a pre-existing undiagnosed autism spectrum condition in psychiatric samples (Solaris, 2016).

REDs diagnostic status. Participants in 'Autism+REDs', 'REDs high autistic traits' and 'REDs only' groups were required to have been formally diagnosed with a RED. To ensure an inclusive capturing of RED presentations that are not primarily and/or overtly driven by weight and shape concerns, the current study included participants with a variety of RED diagnoses, including AN, Atypical Anorexia, OSFED, and ARFID. Participants in the 'Autism only' group were required to have no past or current formally diagnosed ED. This was in order to reduce confounding effects of potential biological and cognitive changes and persisting ED symptoms in recovered individuals (Cowdrey et al., 2011; Tomba et al., 2019; Wagner et al., 2006). The screening questions asked potential participants whether they were formally diagnosed with a RED, and asked for details about their specific RED diagnosis, age at diagnosis, and the service at which they were diagnosed. Where information provided was not sufficient or raised doubts, potential participants were

asked to participate in a screening phone call, and/or the ED clinicians of the research team were consulted to review the available information and advice on inclusion. Current and lowest ever BMI information was collected as part of the background questionnaire and was used to confirm REDs diagnostic category. Participants reporting an AN diagnosis were expected to be either currently underweight, i.e. BMI below 18.5, or to have been underweight at their lowest ever weight, in line with DSM-5 criteria (APA, 2013). We did not exclude individuals with AN who were no longer underweight, if they described their diagnosis as current, as ED related behaviours and/or cognitions can still affect weight-restored individuals (Bamford et al., 2014). For participants reporting a different RED diagnoses (e.g. ARFID and atypical AN), an underweight BMI was not required for inclusion as these disorders do not necessarily result in individuals being underweight, despite significant restriction of food intake (APA, 2013). Details on REDs diagnoses reported by participants included in the final sample are listed in Table 1, Appendix 3. Most REDs participants reported having an AN diagnosis ('Autism+REDs': n=42/51, 82.4%; 'REDs high autistic traits': n=32/36, 88.9%; 'REDs only': n=66/76, 86.8%). Other ED diagnoses reported were Atypical AN ('Autism+REDs': n=5/51, 9.8%; 'REDs high autistic traits': n=4/36, 11%; 'REDs only': n=8/76, 10.5%), ARFID ('Autism+REDs': n=4/51, 7.8%), and OSFED ('REDs only': n=2/76, 2.6%). Both OSFED participants had been recruited via NHS services, and communications with the referring service confirmed that these were of restrictive nature (i.e. atypical AN). There was no statistically significant difference in the rates of different ED diagnoses (AN vs any other) included in each group, χ^2 (2)=1.255, p=0.534, ϕ_c=.088.

Current level of disordered eating. Participants in the REDs groups were required to be currently living with their RED. They could not be recovered at the

time of participation. The screening questions asked potential participants whether they were currently living with a RED or considered themselves to be recovered; those who described themselves as recovered were not invited to participate. In addition, participants from the REDs groups were only included if they scored above a pre-defined clinically meaningful cut-off on at least one of three disordered eating measures, which were collected as part of the study. We considered scores on a combination of measures, which focus on different mechanisms underlying disordered eating behaviours and/or cognitions, to prevent exclusion of participants with less traditional RED presentations, i.e., those with less weight and shape concerns. Scores on the Eating Disorder Examination-Questionnaire global scale (EDE-Q; Fairburn & Beglin, 1994), the SWedish Eating Assessment for Autism spectrum disorders (SWEAA; Karlsson et al., 2013) eating behaviour subscale and SWEAA other behaviour associated with disturbed eating subscale were considered.

The Eating Disorder Examination-Questionnaire (EDE-Q; Fairburn & Beglin, 1994) is a widely used measure of 'traditional' ED psychopathology in relation to weight and shape concerns (more details on measures provided below). The current study utilised a cut-off score of 2.5, which has been recommended for screening purposes on the basis of optimally distinguishing non-cases from cases (sensitivity = 0.86; specificity = 0.86) in a large-scale study of Norwegian women (Rø et al., 2015). This cut-off score is less conservative than the cut-off score of 4.0, which was proposed in the initial validating study (Fairburn & Beglin, 1994). The original cut-off score has been criticised as overly strict, given that nearly half of ED patients in clinical settings obtain an EDE-Q global score of less than 4.0 (Aardoom et al., 2012).

The SWEAA (Karlsson et al., 2013) is a questionnaire developed to measure eating disturbances and eating and mealtime problems in autistic adults. It has been used in previous research to retrospectively identify ARFID-type ED presentations in a sample with REDs regardless of autism diagnostic status (Lange et al., 2019). The SWEAA comprises ten subscales, two of which were considered to be most relevant for identifying disordered eating-related behaviours as displayed by individuals with ARFID or other REDs. An overview of all SWEAA subscales is presented in Appendix 6. The SWEAA eating behaviour subscale consists of six items enquiring about eating behaviours that might be indicative of ARFID, for example, “I only eat a limited selection of foods, maximum of 10 dishes”. The SWEAA other behaviour associated with disturbed eating subscale consists of eight items enquiring about other disordered-eating behaviours, but without linking these to underlying cognitions (e.g. a desire to control weight or shape). Example items include “I induce vomiting after meals” and “I refuse to eat”. There are no specified cut-off scores for the SWEAA, but normative data for an autism sample and a neurotypical control sample has been provided in the original validation study (Karlsson et al., 2013). The autism group scored higher than the neurotypical control sample on all subscales (Karlsson et al., 2013). We considered participants who scored one standard deviation (SD) above the mean scores of the autism sample in the validation study to present with clinically meaningful disordered eating behaviours that would justify inclusion in one of the REDs groups (in combination with a self-report formal REDs diagnosis). On this basis, cut-off scores of 38.30 for SWEAA eating behaviour subscale and of 14.24 for the SWEAA other behaviour associated with disturbed eating subscale were used.

Participants in the ‘Autism only’ group were not excluded if they reported unusual eating behaviours in the absence of an ED diagnosis, as indicated by scores above cut-off on at least one of the three disordered eating measures used for screening purposes. Unusual eating behaviours are common among autistic individuals (Mayes & Zickgraf, 2019), and thus, were expected to be present for some autistic participants.

Exclusions. Altogether 222 participants met inclusion criteria based on their initial responses to the screening questions. Their responses to the background questionnaire, and their scores on measures of autistic traits and disordered eating were reviewed to confirm inclusion. One participant initially recruited to the ‘Autism only’ group reported to be formally diagnosed, but scored below the cut-off of 14 on the RAADS-14. This person was excluded from subsequent analysis. Ten participants (four from the ‘Autism+REDs’ group, six from the ‘REDs only’ group) indicated that they were formally diagnosed with a RED and considered themselves to be currently living with their RED, but scored below the cut-off on all three disordered eating measures. These participants were excluded, due to concern about their state of recovery or the accuracy of their ED diagnosis. Three participants (all recruited to the ‘Autism+REDs’ group) responded to the screening questions that they were currently living with a formally diagnosed ED, but indicated on their background questionnaire that they considered themselves to be recovered. After reviewing details of their screening and background questionnaire responses and their scores on the disordered eating measures, they were retained, as there was evidence that their RED still affected them to a clinically significant degree. All three scored above the predefined cut-off for at least two of the three disordered eating measures. One participant (from the ‘REDs only’ group) reported to be diagnosed

and currently living with AN, but reported both their current and lowest ever BMI to be above 18.5 in the (lower) normal range. Although this raised concerns about the accuracy of their reported REDs diagnosis, we decided to retain this person in the sample, as they scored above the cut-off on all three disordered eating measures. Three participants from the 'Autism only' group indicated in the background questionnaire that they were recovered from an ED, although they had not specified this in their screening response. Upon review of their screening and background questionnaire responses one of them was excluded, as she specified that she had experienced AN in her teens. The other two participants were retained in the 'Autism only' group as the description of their eating difficulty did not suggest that this was a formal ED. In total, twelve participants were excluded prior to analysis. The final sample included 210 participants.

Measures

This study collected data for two PhD projects and one DClinPsy project. Thus, not all measures included in the testing battery were used in the current thesis. The testing battery initially included a combination of observational, physiological, or computer-based experimental tasks and self-report questionnaires. When the study moved online in response to COVID-19, any in-person measures were removed or substituted by alternative online measures. As the online version of this study was conducted during the COVID-19 pandemic, specific guidelines were added at the beginning of questionnaires or next to specific items, for answers which were likely to be affected by COVID-19, lockdown or social distancing. This was to minimise biased responses. The full testing battery of measures included during in-person and/or online data collection is presented in Table 4, with COVID-19-related

amendments being specified. The table also specifies which measures were included in the current thesis. These are described in more detail below.

Table 4

Testing battery of measures included in Study 2

Measure	In-person or online	Included in this thesis	COVID-19 related adaptations:
Background questionnaire	Both	Yes	Question added about hardships experienced as consequence of COVID-19 and their impact on participants eating behaviours and mental wellbeing
The Autism Diagnostic Observation Schedule, Second Edition (ADOS-2; Lord et al., 2014)	In-person	Yes	NA
'Taste strips' (Burghart, Messtechnik, Germany; Landis et al., 2009)	In-person	Yes	NA
The heartbeat counting task (HCT; Schandry, 1981)	In-person	No	NA
The Implicit Association Test (IAT; Greenwald et al., 1998) –picture version	Both	No	None
The questionnaire-based IAT (qIAT; Yovel & Friedman, 2013)	In-person	No	NA
Test of Premorbid Functioning (ToPF; Wechsler, 2011)	In-person	No	NA
The Dimensional, Developmental and Diagnostic Interview-Adult version (3Di-Adult; Mandy et al., 2018) – conducted with informant	Both	No	None

Ritvo Autism Asperger Diagnostic Scale –14 (RADS-14; Eriksson et al., 2013)	Both	Yes	General guidance at the beginning of the questionnaire: The following questionnaire asks about life experiences and personality characteristics now (adulthood) and when you were young (16 years or younger). When thinking about your experiences now, please base your answers on your experiences as an adult, prior to the current COVID-19 situation.
Adult Autism Spectrum Quotient (AQ; Baron-Cohen et al., 2001)	Online	Yes	General guidance at the beginning of the questionnaire: COVID-19 will have affected the way we socialise and interact with others for many of us. For the next 50 items, please respond based on your experiences prior to the current COVID-19 situation.
The Eating Disorder Examination-Questionnaire (EDE-Q; Fairburn & Beglin, 1994)	Both	Yes	Additional instructions for one individual item: * [Please answer this question based on your experiences prior to the current COVID-19 situation]
Hospital Anxiety and Depression Scale (HADS; Zigmond & Snaith, 1983)	Both	Yes	
SWedish Eating Assessment for Autism spectrum disorders (SWEAA; Karlsson et al., 2013)	Both	Yes	Additional instructions for ten individual items: * [Please answer this question based on your experiences prior to the current COVID-19 situation]
Glasgow Sensory Questionnaire (GSQ; Robertson & Simmons, 2013)	Both	Yes	Additional instructions for one individual item: * [Please answer this question based on your experiences prior to the current COVID-19 situation]
Interoception Sensory Questionnaire (ISQ; Fine et al., 2018)	Both	No	None

Toronto Alexithymia Scale (TAS-20; Bagby et al., 1994)	Both	No	None
Intolerance of uncertainty -12 item version (IUS-12; Carleton et al., 2007)	Both	No	General guidance at the beginning of the questionnaire: COVID-19 will have increased the level of uncertainty in our day-to-day lives for many of us. For the next 12 items please respond based on your experience prior to the current COVID-19 situation.
The Adult Repetitive Behaviours Questionnaire (RBQ-2A; Barrett et al., 2015)	Both	No	None
The Camouflaging Autistic Traits Questionnaire (CAT-Q; Hull et al., 2019)	Both	Yes	General guidance at the beginning of the questionnaire: COVID-19 will have affected the way we socialise and interact with others for many of us. For the next 25 items please respond based on your experience of social situations prior to the current COVID-19 situation.
The Social Comparison Scale (SCS; Allan & Gilbert, 1995)	Both	No	None
Submissive Behaviour Scale (SBS; Allan & Gilbert, 1997)	Both	No	General guidance at the beginning of the questionnaire: COVID-19 will have affected how we act and feel about social situations for many of us. For the next 16 items please respond based on your experience prior to the current COVID-19 situation.
Social Phobia Inventory (SPIN; Connor et al., 2000)	Both	Yes	General guidance at the beginning of the questionnaire: COVID-19 will have affected how we feel about social situations for many of us. For the next 16 items please respond based on your

			experience in the recent past prior to the current COVID-19 situation.
Brief Fear of Negative Evaluation Scale (BFNE; Leary, 1983)	Both	No	No changes, as we would be second-guessing the impact COVID-19 might have on impression management.
The Social Attitudes Towards Appearance Scale (SATAQ-3; Thompson et al., 2004)	Both	No	None
The Pride in Eating Pathology Scale (PEP-S; Faija et al., 2017)	Both	No	None
Body Shape Questionnaire (BSQ; Cooper et al., 1987)	Both	No	Additional instructions for four individual item: * [Please answer this question based on your experiences prior to the current COVID-19 situation]

Demographic Information

A background questionnaire (Appendix 5) was developed for the purposes of this study with input from our autistic advisors to collect demographics, as well as clinical background information about the participant's autism and REDs diagnostic status. It also asked about experience of ED treatment and family history of autism and/or eating disorders (these questions are not included in the current thesis), unusual eating behaviours in childhood and whether participants had ever received any other mental health diagnoses.

When moving the study online, we added questions about hardships experienced as consequence of COVID-19 and/or related measures and on whether these had affected on participants eating behaviours and mental wellbeing to the background questionnaire (Appendix 5). This was to explain potential differences in responses of participants who completed the measures in-person (prior to the

COVID-19 pandemic) and online (during the pandemic). The questions were adapted from an existing study on autistic adults experience of COVID-19 (Bundy et al., 2021). An overview of responses to the COVID-19 questions is presented in Table 3, Appendix 3. As stated in the recruitment section above, participants who were recruited in-person and online did not differ significantly on any of the key variables (Table 2, Appendix 3).

BMI

BMI was calculated based on participant's measured (in-person) or self-reported (online) current height and weight. As part of the background questionnaire, we also asked participants in the REDs groups for their lowest ever weight, together with their height at the time if their lowest ever weight was under the age of 18 years. Individuals with a BMI below 18.5 were considered underweight, BMIs between 18.5 and 24.9 were considered healthy, and BMIs over 25 were considered overweight, and over 30 obese. BMI was included to support self-reported REDs diagnostic status (see above) and to characterise the sample and as a proxy for state of starvation to assess correlations with autistic traits and sensory sensitivities.

Participants who were seen in-person were measured by the researcher using grade 3 medical scales and a standardised height measure. This was optional, as we were mindful that being weighed might upset or trigger participants with REDs. In line with suggestions from the literature to increase chance of participants agreeing to be weighed (Tiggemann, 2006), participants could step on the scales backwards, so they did not have to see their weight. Participants who were not comfortable to be weighed could self-report their height and weight.

When we moved data collection online, participants were asked to self-report their height and weight as part of the background questionnaire. Participants had the

option to skip this if they were uncomfortable or did not know their weight and height. However, it was emphasised that this information was important for the research and they were encouraged to provide this information if possible for them. We asked participants to weigh themselves and measure their height at the time of their participation or to report a recent measurement by a healthcare professional. They could report this in their preferred unit of measurement to minimise reporting error, and we converted this for BMI calculation.

Autism-Related Measures

Autism Diagnostic Observation Schedule, Second Edition (ADOS-2; Lord et al., 2012). This is a standardised, semi-structured assessment for autism and is the most widely-used and best validated direct observational measure (NICE, 2012). The ADOS-2 has four modules, one of which is selected dependent upon the participant's expressive language abilities. Module 4, which is designed for use with verbally fluent adolescents and adults, was used for in the current study. The assessment is scored according to a standardised system and diagnostic algorithm. This has been recently revised to map on to DSM-5 diagnostic criteria and improve psychometric properties (Hus & Lord, 2014), resulting in two sub-scores, Social Affect and Restricted and Repetitive Behaviours (RRBs), and a total score. The Module 4 algorithm demonstrated high sensitivity (90.5%) and specificity (82.2%) (Hus & Lord, 2014), particularly to symptoms displayed by females and adults (Pugliese et al., 2015). The ADOS-2 was administered by a trained researcher as part of the in-person data collection. ADOS-2 assessments were filmed, with participants consent, and a subset of assessments was double coded within the research team to improve reliability of scores.

Ritvo Autism Asperger Diagnostic Scale –14 (RAADS-14; Eriksson et al., 2013). This is a 14-item NICE-recommended screening questionnaire for autism. The RAADS-14 was specifically designed to measure the adult phenotype of autism mapping onto DSM-5 symptoms (Eriksson et al., 2013). It enquires about past as well as current behaviours, thus, considering developmental presentation of autistic traits. Specifically, participants are asked to indicate whether each item is 'true or now and when I was young', 'true only now', 'true only when I was younger (16 years or younger)', or 'never true'. Responses are scored on a four-point Likert scale ranging from 3 to 0 indicative of the duration in which the individual reported having the symptoms (3 ='true now and when I was young', 2 ='true only now', 1='true only when I was younger than 16' , 0 ='never true"), which are summed to a total score, ranging between 0-42. At a cut-off score of ≥ 14 on the total score is recommended to identify autistic individuals, with a sensitivity of 97% and a specificity of 95% when including a general population comparison group (Eriksson et al., 2013). The specificity of this cut-off is reduced to 64% in psychiatric populations (Eriksson et al., 2013). Therefore, a more conservative cut-off score ≥ 23 is recommended to be used in psychiatric populations, yielding a sensitivity of 81% and a specificity of 81% in groups with mental health conditions (Eriksson, 2016). The RAADS-14 has good psychometric properties (Baghdadli et al., 2017; Wigham et al., 2018) and the original validation study (Eriksson et al., 2013) included more women (58%) than validations of other commonly used autism screening measures (Wigham et al., 2018). The RAADS-14 has one of the highest sensitivity and specificity rates for correctly identifying and ruling out the presence of co-occurring autism in psychiatric populations (Wigham et al., 2018). Internal consistency in the current sample was high (α = .91).

Adult Autism Spectrum Quotient (AQ; Baron-Cohen et al., 2001). This is a 50-item measure of autistic-like traits and behaviours in the general population and has been widely used, including with individuals with EDs (Westwood, Eisler, et al., 2016). Participants are asked to state how strongly they agree with each item on a four-point Likert scale, ranging from 'definitely agree' to 'definitely disagree'. The original scoring instructions are to convert responses into dichotomous scores, with responses endorsing the autism phenotype receiving one point, regardless of their strength. Scores are then added up, resulting in possible total scores ranging from 0-50, with higher scores indicating higher levels of autistic traits. Some studies have since used different scoring methods to make use of the full range of scores (English et al., 2020). However, in line with other studies in the ED field (e.g. Kinnaird, Stewart et al., 2020a; Stewart et al., 2017; Westwood, Eisler, et al., 2016) the original scoring instructions were followed. The AQ has been validated in the general population and in autistic individuals (Baron-Cohen et al., 2001) and the scale has robust psychometric properties, with internal consistency ranging between α =.67-.82 across different independent validation studies (see English at al., 2020 for overview). A cut-off score of ≥ 32 has been proposed for distinguishing individuals who have clinically significant levels of autistic traits, with 92.3% of women with Asperger's Syndrome in the original validation study scoring above this cut-off compared to 1% of the female control group (Baron-Cohen et al., 2001). However, the AQ has been found to be less effective in predicting autism diagnosis in clinical populations with high levels of suspected traits (Ashwood et al., 2016; Conner et al., 2019; Sizoo et al., 2015). Thus, in the current study the AQ was used to describe autistic traits dimensionally, rather than to confirm autism diagnosis or to identify

potentially undiagnosed autistic individuals in the REDs groups. Internal consistency in the current sample was high (α =.91).

Camouflaging Autistic Traits Questionnaire (CAT-Q; Hull et al., 2018). This is a 25-item self-report questionnaire measuring social camouflaging behaviours (i.e. conscious and unconscious strategies used to mask or compensate for autistic traits in social interactions). Participants are asked to rate how much they agree with statements about experiences during social interaction on a 7-point Likert scale ranging from “strongly disagree” to “strongly agree”. Items are summed up to produce a total score ranging from 25 to 175, with higher scores representing greater levels of camouflaging. The CAT-Q has been validated in autistic and non-autistic adult samples, which included females, and has good psychometric properties, including excellent internal consistency (α = 0.94) and acceptable reliability (0.77; Hull et al., 2018). Internal consistency in the current sample was high (α = .93).

Disordered Eating-Related Measures

The Eating Disorder Examination-Questionnaire (EDE-Q, 6.0; Fairburn & Beglin, 1994; 2008). This is a 28-item self-report questionnaire assessing ED symptoms, with the assumption that these are primarily driven by weight and shape concerns (Fairburn & Cooper, 1993). Participants are asked to rate how often they have engaged in certain ED behaviours or held ED-related concerns over the past 28 days on a 7-point rating scale, ranging from ‘no days’ to ‘every day’. The EDE-Q yields a global score and four subscale scores, consisting of 5–8 items each: Dietary Restraint, Eating Concern, Weight Concern, and Shape Concerns. There are five additional items, which do not count towards the global or any of the subscale scores, but can be considered individually in a clinical setting to ascertain frequently of binging and purging behaviours. The current study only used the global and

subscale scores. Mean scores for the global scale and individual subscales can range from 0-6, with higher scores reflecting greater severity and/or frequency. The EDE-Q is well validated in ED and general population samples and widely used in research and clinical practice (Berg et al., 2012; Fairburn & Beglin, 1994; Rø et al., 2015). Internal consistency has been established for the global score (α = .90) and all four subscales; Restraint (α = .70), Eating Concern (α = 0.73), Shape Concern (α = 0.83) and Weight Concern (α = 0.72; Peterson et al., 2007). While the original validation study proposed a cut-off score of 4.0 on the EDE-Q global scale, subsequent studies have found that a score of 2.5 is more appropriate to optimally distinguish non-cases from cases for screening purposes (sensitivity = 0.86; specificity = 0.86; Rø et al., 2015). Internal consistency for the global scale in the current sample was high (α = .96). Internal consistencies for all EDE-Q subscales were in the acceptable range (α ≥ .80).

The SWedish Eating Assessment for Autism Spectrum Disorders (SWEAA; Karlsson et al., 2013). This is a 60-item self-report questionnaire measuring unusual eating behaviours, eating disturbances and mealtime problems in autistic adults without intellectual disability. It includes ten subscales: perception, motor control, purchase of food, eating behaviour, mealtime surroundings, social situation at mealtime, other behaviour associated with disturbed eating, hunger/ satiety, simultaneous capacity, Pica. It also contains five additional autism-specific items and demographic and medical background items. For the purpose of the current study the five autism-specific items were removed, as they do not contribute to any of the subscale scores and autistic traits were already captured by other measures. The English translation of the SWEEA was used, with minor modifications to improve its intelligibility in line with other research conducted in English speaking

countries (Bitsika & Sharpley, 2018; Folta et al., 2020). Appendix 6 presents the SWEAA version used in the current study, including an overview of the items included in each subscale. Participants were asked to rate how much each item applies to them on a 5-point Likert scale ranging from ‘never correct’ to ‘always correct’. To score the SWEAA the mean for each subscale is transformed into a scale from 0 to 100, where 0 is equivalent to the lowest and 100 the highest possible answer on all items. The average of all transformed subscale scores can be used as total score (Karjalainen et al., 2019). The SWEAA has good psychometric properties, with high levels of reliability, convergent and discriminant validity and scaling properties in autistic individuals (n=57) and a matched, non-autistic comparison group (n=31, Karlsson et al., 2013). Internal consistency of the full scale in the current sample was high (α = .94). Internal consistency of the SWEAA subscales in the current sample were also acceptable (α ≥ .68), according to Nunnally (1978), apart from for the SWEAA Hunger/satiety subscale (α=.31). However, this could be due to the small number of items in this subscale (Cortina, 1993).

Depression and Anxiety, Social Anxiety

The Hospital Anxiety and Depression Scale (HADS; Zigmond & Snaith, 1983). This is a 14-item brief self-report questionnaire for anxiety (HADS-A) and depression (HADS-D), comprising seven questions for each. The HADS was selected for the current study due to its focus on non-physical symptoms, thus minimising potential false positives due to the presence of REDs or autism. The maximum possible score on each subscale (anxiety/depression) is 21, with higher scores indicating higher symptom levels. Scores between 0-7 are considered to be indicative of normal (non-clinical) levels of anxiety and depression, scores between 8-10 are considered borderline, and scores of 11 or above are considered to be

indicative of high levels of anxiety or depressive symptoms. It has been found that the HADS has excellent psychometric properties; Cronbach's *α* for HADS-A varies from .68 to.93 (mean α= .83) and for HADS-D from .67 to .90 (mean α=.82; Bjelland et al., 2002). The HADS performs well in assessing the symptom severity and caseness of anxiety disorders and depression in somatic, psychiatric and primary care patients and in the general population (Bjelland et al., 2002). Internal consistency in the current sample for HADS-A (α = .82) and HADS-D (α = .84) were acceptable.

The Social Phobia Inventory (SPIN; Connor et al., 2000). This is a 17-item measure of social anxiety disorder. Symptom domains of fear, avoidance and physiological arousal are assessed via a 5-point rating scale of how "bothered" respondents have felt, rating from 0 (not at all) to 4 (extremely). Good psychometric properties of test-retest reliability, internal consistency (α = 0.94) and validity have been demonstrated for this measure (Connor, 2000). Internal consistency in the current sample was high (α = .91).

Sensory Sensitivities Measures

Glasgow Sensory Questionnaire (GSQ; Robertson & Simmons, 2013). This is a 42-item self-report questionnaire about sensory signs and symptoms associated with autism. Participants are asked to rate how often they perform a particular behaviour on a 5-point Likert scale ranging from 'never' to 'always'. The items cover seven modalities (i.e. visual, auditory, gustatory, olfactory, tactile, vestibular, and proprioception). Each modality is represented by six items, three reflecting hyper-, and three reflecting hyposensitivity in the respective modality. The GSQ provides a total score, as well as subscale scores for general hyper- and hyposensitivity, and for each sensory modality. Scores for each item range from 0 to

4 and are summed up with possible total scores ranging from 0–168, hyper- and hyposensitivity subscale scores ranging from 0-84, and individual sensory modality subscale scores ranging from 0-24. Studies that have examined some psychometric properties of the GSQ have shown that it is a reliable and valid questionnaire. The GSQ has high internal consistency (α = 0.94; Robertson & Simmons, 2013). Further, it has good convergent and divergent validity, as indicated by strong correlations with other sensory questionnaires, such as the AASP Adult/Adolescent Sensory Profile (AASP; Brown & Dunn, 2002; r = 0.72; Horder et al., 2014), and much weaker correlations with questionnaires measuring other constructs such as anxiety (Spielberger Trait Anxiety Inventory (STAI); r = 0.42; Horder et al., 2014). Internal consistency for the full scale in the current sample was high (α = .94). Internal consistency for subscales combining items measuring hyper- and hyposensitivity (α ≥ .88) and sensitivities affecting individual sensory modalities (α ≥ .63) was acceptable.

'Taste strips' (Burghart, Messtechnik, Germany; Landis et al., 2009). This is a validated, commercially available examination procedure to investigate taste identification ability. It consists of a chemical taste test using taste strips that are placed on the participants' tongue to measure overall taste identification, as well as sweet, sour, salty and bitter tastes. It includes 16 strips of filter paper impregnated with four ascending concentrations of the four basic tastes: sweet, salty, sour and bitter. Specifically, these are: sweet: 0.4, 0.2, 0.1, 0.05 g/ml sucrose; sour: 0.3, 0.165, 0.09, 0.05 g/ml citric acid; salty: 0.25, 0.1, 0.04, 0.016 g/ml sodium chloride; and bitter: 0.006, 0.0024, 0.0009, 0.0004 g/ml quinine hydrochloride. In addition, each test includes two neutral taste strips with no taste. The taste test was conducted towards the end of the in-person assessment, so that participants had not

been eating or drinking anything other than water one hour before the test was conducted. Before the start of the taste test participants were given one neutral taste strip for them to get used to the sensation of the paper. The remaining taste strips were given to participants in a standardised order of increasing taste intensity with the four basic tastes being randomised for each intensity level, as specified in the test instructions. The order was the same for all participants. For each taste strip, participants are asked to place the strip in the middle of their tongue, and to identify whether the strip was sweet, salty, sour, bitter or had no taste. Participants were provided with a written response card and response options were verbally repeated for each trial to remind them of their options. After each strip, participants rinsed their mouth with water. Each correct answer yielded one point, giving a maximum score of 16, and 4 for each individual taste quality, with higher scores indicate greater taste sensitivity. The two neutral strips were not scored. Accuracy scores were calculated, reflecting the percentage of correctly identified tastes. Participants were also asked to rate the pleasantness of taste after each taste strip on a 5-point rating scales, ranging from ‘very unpleasant’ to ‘very pleasant’. Taste strips are a widely used measure in taste research and have been used in both autistic samples, and those with AN (Kinnaird, Stewart, et al., 2020b; Tavassoli & Baron-Cohen, 2012). In the current study, the taste test was only administered to participants who were seen in-person.

Procedure

Data collection was initially conducted in-person, but moved then online during the COVID-19 pandemic. Two autistic women with experience of AN reviewed the study protocol and materials, including any adaptations when the study was moved online, and advised on how to make the study as accessible as possible for

potential participants. All potential participants who expressed interest in the study were screened for eligibility either via email or via the phone (see Appendix 4 for screening questions). Those who met the inclusion criteria were sent a participant information sheet via email or post and were invited to ask any questions before deciding whether they would like to participate. An example of the participant information sheet is presented in Appendix 7. It was emphasised that participation was voluntary and that participants could change their mind at any time.

In-person procedure

For in-person data collection participants met with one of three researchers, based in London and Cardiff, either at the University or their home to complete a combination of observational, physiological, or computer-based experimental tasks and self-report questionnaires. A protocol with standardised instructions was used to ensure researcher's engagement with participants was the same across sites. Participants in all groups completed the same measures, which altogether took around 2.5-3 hours including breaks. Participants were offered regular breaks and had the option to complete part of the questionnaire measures in their own time after the in-person meeting. Participants were also offered the option to split the testing into two sessions, but no participant opted for this. During the meeting with the researcher, first, written consent was obtained (see Appendix 8 for an example of the consent form), participants completed the background questionnaire and their weight and height were measured. Following this, participants completed the in-person measures and questionnaires. Tasks were completed in a semi-randomised order, as certain measures had to be completed at the start, before other measures, or towards the end of the meeting. The online survey software Qualtrics (Qualtrics, 2018), accessed via the researcher's laptop, was used to establish the order in

which tasks were administered and to record participant's responses. The order in which measures were completed in-person is outlined in Table 5.

Table 5

Order of activities during in-person data collection

1	Consent
2	Background questionnaire
3	Height, weight measure
4	ADOS-2
5	Experimental tasks - Block 1 (randomised): Q-IAT, HCT task
6	Break
7	Self-report questionnaires (randomised)
8	Experimental tasks - Block 2 (randomised): Picture IAT, Taste test, ToPF
9	Remaining self-report questionnaires (randomised)

Participants always started with the ADOS-2 (Lord et al., 2012) to ensure they were not yet too familiar with the researcher, which could have affected their interaction during the assessment, and thus their performance on this measure. The remaining in-person measures were completed in two blocks. The measures in each block were the same for all participants, but the order within each block was randomised. After the first block, participants were offered a longer break and had the option to start completing the questionnaire measures via a separate Qualtrics survey using the researcher's computer. This was to allow participants a break from in-person interaction and prevented possible effects of fatigue when attempting to complete all questionnaires in one sitting. The survey presented the questionnaires in a randomised order and indicated how many questionnaires participants had completed via a progress bar. After completing around half of the questionnaires, participants continued with the second block of in-person tasks. At the end, they had the option to complete the remaining questionnaires in the presence of the researcher or in their own time after the meeting, in which case, participants were emailed a link to their survey with the questionnaire measures. Finally, participants

were debriefed (see Appendix 9) and travel expenses were paid, if applicable. Participants were offered a £30 e-voucher to thank them for their time, which was emailed to them after they completed the questionnaire measures.

Online procedure

The online version of the study consisted of a Qualtrics survey, which participants could access via a secure link emailed to them. The survey started with the online version of the consent form and the background questionnaire, followed by the questionnaire measures in a randomised order. At the end participants were debriefed. Participants were also asked to complete an online version of the picture IAT task, which could be accessed via a separate link. Altogether this took around an hour to complete, but participants were told they had two weeks to complete the survey after being sent the link and could take as many breaks as they liked. They were offered a £15 e-voucher to thank them for their time.

Ethical approval

Full ethical approval was gained by the UCL Research Ethics Committee to recruit participants via non-NHS pathways (Appendix 10). Additional ethical approval was obtained from the Health Research Authority (HRA) to recruit participants via NHS services (Appendix 11). Amendments were sought from each approving body to move this study online in the context of COVID-19, and for subsequent changes to the measures included, participant instructions, information sheets, consent form and debrief (Appendix 7-9).

Missing data

The raw data were inspected for missing responses and reasons for missing data were considered to inform subsequent approaches of dealing with missing data.

Missing Body Mass Index (BMI) scores. Nineteen participants did not report their height and/or weight or their entries were invalid, preventing us from calculating BMI scores. For a subset of these participants (n=5), who had been recruited from NHS service, BMI was retrieved from medical record entries around the time of individual's participation. This resulted in a total of 14 missing BMI scores ('Autism only' (n=1), 'Autism+REDs' (n=5), 'REDs high autistic traits' (n=5), 'REDs only' (n=3)). According to Fischer-Freeman-Halton Exact Test the level of missing BMI data was not statistically significantly different between groups, *p*=.141. Nonetheless, there are likely specific reasons related to their ED why these participants did not report their height or weight. Previous research has shown that greater weight and shape concerns are associated with non-reporting of weight and /or height (Tiggemann, 2006). Further, some participants provided feedback explaining that they were not allowed to know their weight and were prohibited from weighing themselves as part of their treatment plan, suggesting they were likely to be at a stage of their ED where they got easily fixated or distressed about their weight. Therefore, this information is likely to not be missing at random, and, it was not considered sensible to estimate participants missing BMIs (Tabachnick & Fidell, 2013). Non-available BMI data was treated as missing data and pairwise deletion was employed where required.

We compared EDE-Q global scores of participants with and without BMI data to understand whether there were any systematic differences in their ED presentation. Across REDs participants, mean EDE-Q global scores of participants for whom BMI data was not available (*M*=4.34, *SD*=1.21) were similar to those whose BMI was available (*M*=3.97, *SD*=1.32). The mean difference in ED-Q global scores of REDs participants with and without BMI data available, 0.36, 95%CI [-.38-

1.11], was not statistically significant $t(161)=.969$, $p=.334$, $h=.279$, suggesting that REDs participants with missing BMI did not significantly differ in terms of their ED presentation.

Missing data for methodological reasons. ADOS-2 scores are only available for in-person participants. The taste strips were also only administered with in-person participants, but there was a delay in the delivery of the testing equipment, which meant that only 25 participants in the 'Autism only' and 12 participants in the 'Autism+REDs' group completed the measure. AQ scores are only available for online participants (n=161), since this measure was added to the online version after removing the ADOS-2 from the testing battery. Only participants for whom data on these measures are available were included in respective analyses.

Missing questionnaire responses. The raw data for all questionnaires were inspected for missing responses on scale-level (i.e. whether whole questionnaires were competed or not) and item-level (i.e. whether responses to individual items were missing). To inform subsequent steps to minimise resulting bias, missing data was assessed for whether any of these responses were missing at random (Newman, 2014).

Levels of missing data were generally low. Across all questionnaire data 0.68% of responses were missing. With regard to scale-level missing data, five out of 222 participants had only completed part of the survey, thus they were missing total scores for some questionnaires. All five participants completed more than 50% of the survey, with the number of questionnaires they missed ranging from one to eight out 18. The survey presented questionnaires in a random order, which means that the measures missed are likely missing at random.

To determine item-level missing data, we considered whether participants who completed the respective questionnaire missed any individual items. No participant missed more than 6% of responses to any one questionnaire. Little's Missing Complete at Random (MCAR) test (Little, 1988) was carried out on the original, non-recorded items for each questionnaire to assess whether items were missing at random. The results are presented in Table 6. The tests were non-significant for all measures, indicating no pattern to missing data (Tabachnick & Fidell, 2013).

Table 6

Missing data on participant and item level

Measure	Number of participants missing the whole scale due to partial completion of the survey	Number of individual items missing across all participants (excluding those missing the whole scale)	Little's MCAR	Included in current thesis
RAADS	none	1	X^2 (13, 222)=7.99, p=.844	Yes
AQ	1	3	X^2 (47, 222)=53.55, p=.238	Yes
EDE-Q	2	3	X^2 (63, 222)=31.27, p=1.000	Yes
HADS	1	1	X^2 (13, 222)= 3.08, p=.998	Yes
SWEAA	1	7	X^2 (353, 222)= 375.04, p=.201	Yes
SATAQ	2	3	X^2 (36, 222)= 53.34, p=.649	No
ISQ	1	2	X^2 (38, 222)= 39.99, p=.382	No
IUS	2	None	NA	No
TAS	2	1	X^2 (19, 222)= 6.58, p=.996	No
RBQ	4	2	X^2 (38, 222)= 49.80, p=.095	No
BFNE	1	None	NA	No

PEP-S	4	31	X^2 (329, 222)=3222.70, p=.588	No
SBS	1	5	X^2 (59, 222)= 47.90, p=.849	No
BSQ	1	2	X^2 (66, 222)=43.37, p=.986	No
GSQ	1	2	X^2 (, 222)= 92.75, p=.196	Yes
SCS	1	None	NA	No
SPIN	1	None	NA	Yes
CAT-Q	1	None	NA	Yes

Given that data are likely to be missing completely at random and only a small portion of data are missing (Tabachnick & Fidell, 2013), it is recommended to estimate missing responses to retain statistical power (Enders, 2001). Multiple imputation was chosen to deal with missing data, as it is considered the most comprehensive and robust method (Newman, 2014; Tabachnick & Fidell, 2013). Multiple Imputation was conducted using R (R Core Team, 2020). Missing data were handled at an item-level where possible, as this is considered to increase power relative to scale-level missing data handling (Mazza et al., 2015). This means missing items were imputed individually and used in combination with participant's available responses to calculate respective total and subscale scores where possible. Only for participants who were missing responses for all items of the respective questionnaire, were missing data imputed at scale level, i.e. as total or subscale scores.

Normality

To determine whether parametric statistics could be used in subsequent analysis, assumptions of normality were tested by visual inspection of histograms, assessment of skewness and kurtosis z-scores and Kolmogorov-Smirnov tests. Normality was considered for each group separately rather than for the whole data set, as groups were considered to represent distinct populations (Field, 2013).

Assumption of normality was deemed to be satisfied when each group's data visually depicted a normal distribution, skewness and kurtosis z-scores were between -1.96 and +1.96 and/or Kolmogorov-Smirnov tests were not significant (Field, 2013). Skewness and kurtosis scores z-scores and Kolmogorov-Smirnov tests for each variable are provided in Table 1 and 2, Appendix 12. Data distributions were tested for normality before and after addressing any outliers (see below). According to their histograms and z-scores and/or Kolmogorov-Smirnov tests the following variables met assumption of normality for all groups: HADS-D, CAT-Q, SWEAA perception, SWEAA mealtime surroundings, SWEAA total score, GSQ tactile sensitivity, GSQ hypersensitivity, GSQ hyposensitivity, GSQ total, and SPIN total. For all other variables apart from EDE-Q weight concern subscale, EDE-Q shape concern subscale, and SWEAA pica subscale at least two of the four group's data was normally distributed (see Table 1 and 2, Appendix 12).

We considered addressing non-normal distributions by transforming the data following guidelines from Tabachnick and Fidell (2013). However, this was largely unsuccessful, because different groups' data tended to be skewed in opposing directions. While transformation tended to improve distribution for one group, it worsened it for another. Even where transformations would have been effective for all groups, this created other issues, e.g., by making the interpretation of findings more difficult (Grayson, 2004). Therefore, we did not use transformations.

Despite sporadic violation of the assumption of normality, we decided to use parametric testing for the majority of variables. Skewness and kurtosis z-scores and Kolmogorov-Smirnov tests can be overly sensitive in relatively large samples (Field, 2013). Thus, they should be considered with caution, especially when visual inspection of histograms suggests a normal distribution, which was often the case

(Field, 2013). Further, the main analytic approach for this thesis (analysis of variance; ANOVA) is known to be robust to violations of normality (Blanca et al., 2017; Glass et al., 1972). Schmider et al. (2010) advise that skew and kurtosis associated with a less than |2.0| and |9.0| respectively are unlikely to negatively impact ANOVA results (Schmider et al., 2010). This applied to all of our data, apart from SWEAA Pica subscale (see Table 2 in Appendix 12). Thus, this was the only variable for which non-parametric tests were used.

Outliers

It is recommended to identify and address outliers before conducting statistical analysis to minimise bias (Field, 2013; Tabachnick & Fidell, 2013). The presence of outliers in the data can affect normality and accuracy of chosen test statistics, including ANOVA (Field, 2013). To identify outliers, each variable, split by group, was assessed using the outlier-labelling rule, which proposes an interquartile range multiplier approach to detect outliers (Hoaglin & Iglewicz, 1987). The current study employed a multiplier of 2.2, which is considered most sensitive (Hoaglin & Iglewicz, 1987). Outliers were checked for accuracy to ensure they were not wrongly entered scores or accidentally introduced when handling the data. Winsorizing (Dixon, 1980) was used to substitute true outliers with the nearest value that was not identified as an outlier plus/minus one unit of measurement on the respective scale (Gignac, 2019). Table 7 presents the variables for which outliers were identified and dealt with.

Table 7

Variables for which outliers have been addressed

Scale	Group	Number of outliers
EDE-Q eating concerns	'Autism only' group	2
EDE-Q shape concerns	'REDs high autistic traits' group	2

HADS-A	'REDs high autistic traits' group	1
SWEAA motor control	'REDs only' group	1
SWEAA social situation	'Autism only' group	1
SWEAA other disturbed eating behaviours	'Autism only' group	1
SWEAA hunger/satiety	'REDs high autistic traits'	1
SWEAA simulations capacity	'REDs only' group	2
SWEAA total	'Autism+REDs' group	1
SPIN	'Autism only' group	1

Data distribution was reassessed for normality after outliers were addressed and winsorizing improved rates of normality in all cases, although some groups' data still violated assumptions of normality (see Table 1 and 2, Appendix 12).

Analysis plan

Chapter 4 described and compared the four participant groups on demographics and background variables, as well as autistic traits and disordered eating-related variables to gain a better understanding of these groups' clinical characteristics. In addition, correlations between autistic traits and BMI were conducted for each group.

Chapter 5 compared groups on variables related to sensory sensitivities. Specifically, self-reported general and food-specific sensory sensitivities were compared between the four groups, and taste identification ability and pleasantness ratings were compared between two groups. In addition, correlations between sensory sensitivity and BMI and autistic traits were conducted for each group.

Data presented in Chapters 4 and 5 were analysed using SPSS v2.7 (IBM Corp, 2020).

Descriptive Statistics

Demographic variables and responses to the background questionnaire were tabulated as descriptive statistics.

Group Comparisons of Categorical Variables

For categorical demographic and background variables, where potential differences between groups were of interest, Pearson's chi-square tests were conducted, if assumptions were met. Since there were four groups for most variables (except variables specific to those with an autism diagnosis), 4x2(+) contingency tables were used. The expected count for each cell had to be greater than one and no more than 20% of expected counts could be less than five for chi-square assumptions to be met (Field, 2013; Howell, 2012). Categorical responses with multiple answer options were collapsed to the largest number of options that would allow chi-square assumptions to be met, while retaining as much detail as possible. When expected count was less than five in over 20% of cells of the respective contingency table and answer options could not be collapsed further, Fisher-Freeman-Halton exact test was used as an alternative to compare groups (Freeman & Halton, 1951).

Group Comparisons of Continuous Variables

For continuous background and demographic variables, and measures of autistic traits and disordered eating (Chapter 4), for which only total scores were of interest, one-way independent Analysis of Variance (ANOVA) was used to compare groups. Equal variance was assumed, when Levene's test was not significant (Levene, 1960). Where this assumption was violated, Welch's F-test, a robust alternative to traditional ANOVAs, was used. Welch's F-test is able retain power at an alpha level at .05, when the variances are substantially different and when the group sizes are unequal (Kohr & Games, 1974; Tomarken & Serlin, 1986). Significant ANOVAs and Welch's F-tests, indicating an overall effect of group, were followed up with Hochberg's GT2 or Games-Howell post-hoc multiple comparison

tests to determine which group differences were driving this effect. Hochberg's GT2 is considered the most appropriate post-hoc test when comparing groups with unequal sample sizes (Field, 2013), which was the case the current study. Games-Howell is the recommended post-hoc tests when the assumption of homogeneity is not met (Field, 2013; Gignac, 2019). Any significant differences with an alpha level of .05 or below were reported.

Independent samples t-tests, or Mann-Whitney U tests as a non-parametric alternative, were used for comparisons of continuous background variables, where data was only available for two of the four groups (e.g., age of autism diagnosis for 'Autism only' and 'Autism+REDs').

Group Comparison of Variables with Subscales

For measures, where it was of interest to compare total scores as well as individual subscale scores (SWEAA and EDE-Q in Chapter 4; GSQ and taste strips in Chapter 5) mixed-design (repeated measures with between subjects factor) ANOVAs were used to assess whether there was an interaction effect between group and subscales and to compare subscale scores between groups. The different subscales were used as the within subjects variable (repeated measure) and group as the between subjects variable. Box's tests were used to assess assumptions of equality of covariance (Box, 1949). If this test was significant (p>.05), this assumption was considered to be violated (Huberty & Petoskey, 2000). Because Box's test can be sensitive to departure of normality, which was known to be present in some of the data, as well as sample size, Levene's tests were also checked for heterogeneity of variance for each variable (Field, 2013). Mixed-design ANOVAs were reported regardless of violations of assumption of (co-)variance, but violations were highlighted and those results were interpreted more cautiously. Assumptions of

sphericity were tested using Mauchly's test of sphericity for models with three or more subscales. If Mauchley's test of sphericity's was significant (p>.05), this assumption was considered to be violated (Field, 2013). When assumption of sphericity was violated and Greenhouse-Geisser ε was smaller than .75, Greenhouse-Geisser corrections were applied. If assumption of sphericity was violated and Greenhouse-Geisser ε was equal to or larger than .75, Huynh-Feldt corrections were applied (Field, 2013). Main effects for subscale, group and an interaction between subscale and group were reported. For variables where we were interested in both total and subscale scores, instead of running a separate analysis to compare group's total scores, the main effect of group was interpreted as test of group difference on the total score for the respective scale, since total scores are generated by adding the subscales. Significant mixed-design ANOVAs were followed up with post-hoc pairwise comparisons for each subscale with Bonferroni corrections to account for violation of sphericity (Keselman & Keselman, 1988).

In Chapter 4, Kruskal-Wallis H test was used as a non-paramedic alternative to compare groups on the SWEAA pica subscale, which did not meet assumptions of normality, and thus was not included in the mixed-design ANOVA on SWEAA subscales. Because the mixed-design ANOVA did not include all SWEAA subscales, a separate ANOVA for the SWEAA total score was reported. The same was done for the EDE-Q global score to ensure consistency in reporting.

Selection of Co-variates

In addition to the unadjusted group comparisons, we also conducted two separate Analyses of Covariance (ANCOVAs) for each dependent variable in Chapters 4 and 5. Due to the observational nature of the data there were likely to be differences between groups on certain participant characteristics. Demographic and

background variables that varied between groups and were theoretically associated with the dependent variables were considered as co-variants to control for their effect on potential group differences in subsequent analyses.

Of the demographic and background variables that varied between groups (see Chapter 4), age was considered as co-variate, as one group ('Autism only') was significantly older than the other three groups, which is not related to the nature of the groups themselves, but was likely to be explained by other reasons, e.g. differences in recruitment pathway and selection bias. Age might affect constructs measured by dependent variables, including presentation of autistic traits (Smith et al., 2012), camouflaging behaviour (Cook, Hull, et al., 2021) , disordered eating-related symptoms (Ackard et al., 2013), and sensory sensitivities (Boyce & Shone, 2006; Pohl et al., 2003). Therefore, there was a need to assess whether any potential group differences still existed when controlling for group differences in age.

In addition, we expected the presence of additional co-occurring mental health difficulties, which are common in both autism and ED populations (Blinder et al., 2006; Lai et al., 2019; Swinbourne & Touyz, 2007), to create extraneous variation in participant's responses. Groups differed on levels of co-occurring mental health difficulties (see Chapter 4) and their presence might affect the presentation of autistic traits, disordered eating and sensory sensitivities (see into Chapter 4 and 5). Therefore, it was of interest to understand the role of co-occurring mental health difficulties for potential differences on the dependent variables.

All other group differences on demographic and background variables (see Chapter 4) were considered to be either related to the nature of the groups (e.g. BMI), or related to age (e.g. highest level of education and employment status). Adjusting for these variables, would have reduced the clinical relevance of the

findings and/or would have made them more difficult to interpret. Thus, they were not included as covariates.

Analysis of Covariance

ANCOVAs provide a means to control for bias attributable to the groups not being matched on important characteristics and can increase the precision of the results, by adjusting the dependent variable of interest for differences among groups in the covariate (Wildt & Ahtola, 1978). We re-ran analyses with different levels of adjustment to gain further insight into the clinical presentation of participant groups.

Since age was unrelated to the nature of participant groups, whereas current levels of co-occurring mental health difficulties could be intertwined with participants' autism and/or RED presentation, we ran two separate models with different levels of adjustment. The first ('partially adjusted') model compared the four groups while adjusting for group differences in age. The second ('fully adjusted') model we compared groups, while adjusting for group differences in age as well as current levels of depression, anxiety, and social anxiety. Levene's test was used to assess assumptions of homogeneity of variance. ANCOVAs were conducted regardless of violation of homogeneity of variance, as robust alternatives were not available through the statistical package used for analysis (SPSS; IBM Corp, 2020). Since robust alternatives for the unadjusted model (ANOVA), which provide more accuracy in their results, were available, both the unadjusted model and models with different levels of adjustment were reported. ANCOVAs conducted despite violation of homogeneity of variance assumption should be interpreted cautiously. Significant ANCOVAs were followed up with post-hoc pairwise comparisons with Bonferroni corrections (Field, 2013). When results for the post-hoc pairwise comparisons changed from the unadjusted to the partially or fully adjusted model, this was

indicative of group differences in age and/or levels of co-occurring mental health difficulties having a significant impact on differences explored in the respective analysis.

Correlations

Where correlations between variables were tested, Pearson's correlations were used, if both variables were normally distributed (see Table 1 and 2, Appendix 12). Spearman correlations were used as a non-paramedic alternative, when one or both variable was not normally distributed.

Effect sizes

Cramer's V (ϕ_c) was used as an effect size for chi-square tests to report the strength of association between two categorical variables. This coefficient ranges from 0 (no association) to 1 (perfect association). In can be interpreted following benchmarks for small (ϕ=.10), medium (ϕ=.30), and large (ϕ=.50) effect sizes (Cohen, 1988).

Eta-squared (η^2) and partial eta-squared (η^2_p) were used as a measure of effect size for ANOVA and ANCOVA. Cohen (1988) has provided benchmarks to define small (η^2= 0.01), medium (η^2= 0.059), and large (η^2= 0.138) effects.

Hedge's g was used as a measure of effect size for differences between two groups, e.g. for post-hoc compressions. Hedges' g is weighted according to the relative size of each sample, and is recommended as an effect size, when groups have different sample sizes (Lakens, 2013). It can be interpreted following the same guidelines as Cohen's d, where effect sizes are considered to small (g = 0.2), medium (g = 0.5), and large (g = 0.8; Cohen, 1988; Cohen, 1992).

Pearson's or Spearman's r were used as measure of effect size for correlations and Man-Whitney U tests, indicating the strength of the bivariate

relationship. Pearson's and Spearmans's *r* can vary between -1 (a perfect negative correlation) to +1 (a perfect positive correlation). An *r* value of 0.1 is considered small, of 0.3 medium, and of more than 0.5 large (Cohen, 1988; Cohen, 1992).

Chapter 4: Autistic Traits and Disordered Eating-Related Presentation of Autistic Women with REDs

Introduction

Our qualitative findings from Study 1 suggest that REDs might present differently in autistic women compared to other individuals, and that autism-specific factors might be implicated in the development and maintenance of restrictive eating difficulties in autistic individuals (see Chapter 2). The current chapter further examines the clinical presentation of autistic women with REDs. Specifically, we describe and compare the demographic and clinical background variables, as well as autistic traits and disordered eating-related symptoms, of four participant groups: (1) autistic women without REDs ('Autism only'), (2) autistic women with REDs ('Autism+REDs'), (3) non-autistic women with REDs ('REDs only'), and (4) women with REDs and high autistic traits ('REDs high autistic traits'). In doing so, this study addresses aim 3 of the overarching aims of this thesis (see Chapter 1); testing elements of the theoretical model developed in Study 1, using quantitative methods. We refer to this investigation as Study 2.

Understanding the potentially differing presentation of autistic women with REDs is important for several reasons. Autistic women are overrepresented in RED populations (Huke et al., 2013; Westwood & Tchanturia, 2017), and tend to have poorer treatment outcomes (Nazar et al., 2018; Stewart et al., 2017; Tchanturia et al., 2016). It may be that women with certain autism profiles may be particularly vulnerable to developing REDs. In addition, REDs in autistic women might differ in important ways from REDs in non-autistic women (Brede et al., 2020; Chapter 2), which may explain why commonly available treatments lack efficacy in this group (Babb et al., 2021; Kinnaird, Norton, Stewart, et al., 2019). Moreover, autistic women

in ED settings often do not have an autism diagnosis when entering treatment (Mandy & Tchanturia, 2015; Westwood et al., 2017b), and there are considerable difficulties in accurately identifying autistic women in ED settings (Kinnaird & Tchanturia, 2020), in part because disordered eating-related behaviours and cognitions, the effect of starvation, and high levels of anxiety in individuals with REDs might mimic autistic traits (Hiller & Pellicano, 2013; Kinnaird & Tchanturia, 2020; Lai & Baron-Cohen, 2015; Treasure, 2013). A better understanding of the nature of autistic traits and disordered eating-related symptoms in autistic women is thus necessary to inform effective support and treatment adaptations. The insights generated from this chapter also have the potential to improve the identification of autistic women in ED settings.

We initially intended to compare autistic women with and without REDs, and non-autistic women with REDs. However, as noted above, we included women with REDs and high autistic traits as an additional comparison group.

A subset of participants with REDs in our sample self-reported very high autistic traits, but did not have a formal autism diagnosis. We initially intended to screen women with REDs using a combination of self-report and observational measures to identify undiagnosed autistic women (see Chapter 3 for more detail). However, due to the impact of COVID-19, we moved data collection online, and were no longer able conduct in-person assessments. Given that we expected some undiagnosed autistic women in the REDs group, as well as the challenges of accurately identifying undiagnosed autistic women in the RED population, it was not appropriate to include them in either the autistic or non-autistic RED groups. We therefore analysed this group separately, with an interest in whether their pattern of autistic traits and disordered eating-related symptoms were more like those of

autistic or non-autistic women with REDs. This analysis can offer insights into whether women with high autistic traits in ED settings likely comprise undiagnosed autistic women, or whether their traits represent superficial similarities between the conditions but are lower or qualitatively distinct from those seen in formally diagnosed autistic women (Kinnaird & Tchanturia, 2020).

Autistic Traits in Women With REDs

Previous research has repeatedly demonstrated that, on average, women with REDs have higher autistic traits than women without REDs (Westwood, Eisler, et al., 2016), and that there is a subgroup of women in REDs samples who have very high autistic traits, and could therefore be considered to be autistic, given that autism diagnostic criteria represent the extreme of a trait continuum (Abu-Akel et al., 2019; De Groot & Van Strien, 2017). However, the extent to which high levels of autistic traits in REDs populations represent 'true autism' as opposed to the effects of acute REDs, e.g. starvation and anxiety, is not yet clear.

Most studies on autistic traits in individuals with REDs use the AQ (Baron-Cohen et al., 2001) as a self-report measure of autistic traits (Westwood, Eisler, et al., 2016). The AQ was developed to measure autistic-like traits and behaviours in the general population (Baron-Cohen et al., 2001). Recently, the AQ has been criticised for being less reliable in predicting autism diagnosis in clinical populations with high levels of suspected traits (Ashwood et al., 2016; Conner et al., 2019; Sizoo et al., 2015). This is thought to be in part because the AQ only focuses on current autistic traits, without considering the person's developmental history (Lugnegård et al., 2015). Autism is a life-long neurodevelopmental condition, and for diagnostic criteria to be met, traits should be present from early childhood, even though they may not always be fully recognised at this earlier stage (APA, 2013). Thus, owing to

its lack of consideration of developmental history, the AQ may be particularly prone to overestimating ‘true autism’ rates in REDs population.

Further, most research does not include a control group of autistic women without REDs. Therefore, it is unclear whether there are any differences in the levels and nature of autistic traits between autistic women with and without REDs. This could provide valuable insights into how autism operates as a risk factor for REDs.

To the author’s knowledge, there has only been one study that directly compared the profile of autistic traits in autistic individuals without REDs and individuals with REDs: Kerr-Gaffney et al. (2021) compared autistic females, females with AN, and a non-autistic healthy control group on three different autism measures, namely the AQ-10 (Allison et al., 2012), the Social Responsiveness Scale (SRS-2; Constantino & Gruber, 2012), and the ADOS-2 (Lord et al., 2012). They excluded participants with an existing autism diagnosis from the AN group. Across all measures, autistic females had the highest levels of autistic traits, followed by females with AN, with the control group scoring lowest. However, the scores of autistic individuals and those with AN did not differ significantly on one of the three measures (SRS-2; Kerr-Gaffney et al., 2021). This suggests that, although autistic individuals generally have higher autistic traits than those with AN, further investigation is warranted. Autistic traits in the study’s AN group may have been inflated by undiagnosed autistic individuals. Further, because participants with AN who also had an autism diagnosis were excluded, it is not clear whether their presentation differs from that of other autistic women. There is a need to replicate these findings, ensuring that autistic traits in the RED group are not inflated by undiagnosed autistic women, while also including a group of formally diagnosed autistic women with REDs.

One way to build on previous research is to use a measure both current and historic (i.e. childhood) autistic traits. The RAADS-14 (Eriksson et al., 2013) is a self-report autism screening measure designed to consider the developmental presentation of autistic traits in psychiatric populations (Eriksson et al., 2013). It provides multiple response options, which are weighted in the scoring process, asking participants to specify whether the experience or behaviour applied only when the person was younger, only now, neither, or both. In this way the RAADS-14 takes into account that some difficulties that autistic individuals experience have affected them since childhood and will persist throughout their life (Billstedt et al., 2007), whereas other difficulties might not have affected them until later in life, perhaps because of increasing demands when growing up (W. Mandy et al., 2018). Moreover, as autistic individuals learn ways to overcome difficulties or develop camouflaging behaviours, they may find that some difficulties that were present when they were younger no longer affect them in adulthood (Fountain et al., 2012; Hull et al., 2017). In the current study, both the RAADS-14 and the AQ (Baron-Cohen et al., 2001) were used to assess autistic traits. Given the importance of a developmental history, we used the RAADS-14 to consider the presence of autistic traits in childhood. We created a ratio of the number of items endorsed to have been present in childhood (regardless of whether they persisted into adulthood) relative to the total number of items endorsed. This ratio ranges between 0 and 1, with larger ratios supporting the presence of 'true autism.' To the author's knowledge, the current study is the first to employ the RAADS-14 in RED populations, although the more comprehensive diagnostic interview RAADS-R (Ritvo et al., 2011) has been used in women with EDs to consider development and thereby disentangle the heterogeneity present in these patients (Vagni et al., 2016).

Another important consideration for our understanding of autistic traits in autistic women with REDs is whether they engage in camouflaging behaviours. Autistic women often present in less 'traditional' ways, which can involve higher levels of camouflaging behaviour (Cook, Hull, et al., 2021; Hull et al., 2020). Camouflaging behaviours are thought to relate to missed or late autism diagnoses (Bargiela et al., 2016; Tierney et al., 2016) and have been associated with higher levels of co-occurring mental health difficulties (Camm-Crosbie et al., 2019; Hull et al., 2021). Their co-occurring REDs and the under-recognition of autistic women in ED settings (Westwood et al., 2017b), suggests that autistic women with REDs may be particularly likely to present with high levels of camouflaging behaviours. To better understand potential variation in the presentation of autism characteristics in autistic women with REDs, we included the CAT-Q as a measure of camouflaging behaviour (Hull et al., 2019). The current study is the first to investigate camouflaging behaviours in autistic women with REDs.

Traditional RED Presentations and Unusual Eating Behaviours in Autistic Individuals

In addition to comparing autistic traits, this study also compares disordered eating-related symptoms among the four groups to gain a better understanding of the similarities and differences of REDs in autistic and non-autistic women. REDs, particularly AN, are commonly assumed to be driven by underlying weight and shape concerns (APA, 2013; Fairburn et al., 1999). Our qualitative study (Chapter 2) suggests that autistic women with AN may deviate from traditional REDs presentations, in that weight and shape concerns might be less relevant (Brede et al., 2020). Instead, restrictive eating difficulties in autistic individuals may be a direct consequence of autistic traits, such as atypical sensory processing and rigidity, or

may arise as an attempt to cope with other autism-related difficulties and stresses (Brede et al., 2020).

REDs in autistic women could be an extreme manifestation of unusual eating behaviours, which are common in autistic individuals (Bandini et al., 2010; Rastam, 2008; Schreck et al., 2004). Unusual eating behaviours encompass behaviours such as selective eating (i.e., eating a limited number of foods), unusual eating patterns (e.g., only eating specific brands of food), and food refusal. In a large scale comparison study of unusual eating behaviours in 1,462 autistic children, 327 children with other neurodevelopmental conditions and 313 typical children (mean age 7.3 years; Mayes & Zickgrad, 2019) demonstrated that unusual eating behaviours were significantly more common in autistic children (70.4%), compared to children with other conditions (13.1%) and typically developing children (4.8%; Mayes & Zickgrad, 2019). Although some autistic individuals seem to overcome these difficulties as they grow older (Folta et al., 2020), they can also persist into adulthood (Kuschner et al., 2015; Rastam, 2008).

To test the prediction that weight and shape concerns are less prominent in driving the REDs of autistic women, and that their REDs might instead be driven by more autism-specific mechanisms, we compared our participant groups on both a measure of traditional disordered eating symptoms and a measure of autism-specific unusual eating behaviours. We use the EDE-Q (Fairburn & Beglin, 2008) as a measure of traditional disordered eating symptoms due to its focus on ED behaviours and cognitions seen in individuals with AN, as well as its inclusion of weight and shape concern-related subscales. We used the SWEAA (Karlsson et al., 2013) to capture autism-specific unusual eating behaviours.

Several studies have compared the presentation of more traditional disordered eating symptoms and autism-specific unusual eating behaviours in autistic adults without REDs and non-autistic individuals with REDs; some have also included healthy non-autistic control groups. These studies suggest that autistic individuals without REDs also present with some traditional ED symptoms, although, unsurprisingly, to a lesser extent than women with a formal RED diagnosis (Demartini et al., 2021; Nisticò et al., 2021). Further, supposedly autism-specific unusual eating behaviours are also present in non-autistic individuals with REDs, to a similar (Nisticò et al., 2021) or even higher degree than in autistic adults without REDs (Karjalainen et al., 2019). However, the presentation of autism-specific unusual eating behaviours and more traditional disordered eating symptoms in autistic women with REDs, in comparison to autistic women without REDs and non-autistic women with REDs, has not been assessed.

The Role of Other Co-Occurring Mental Health Problems

Co-occurring mental health problems are common in both autistic individuals and RED populations (Blinder et al., 2006; Lai et al., 2019; Steinhausen et al., 2021; Swinbourne & Touyz, 2007) and may affect both autistic traits and disordered eating-related symptoms within these groups. In a naturalistic observation of individuals in inpatient treatment for AN, autistic traits, as measured by the AQ-10 (Allison et al., 2012), were positively correlated with levels of anxiety and depression (Tchanturia et al., 2017). This suggests that measures of current autistic traits in individuals with REDs may in part be capturing symptoms associated with more general psychopathology. For example, social withdrawal may be a symptom of social anxiety or depression rather than autism. It is therefore important to consider levels

of co-occurring mental health difficulties when comparing groups on autistic traits and disordered eating-related presentations.

The Current Study

Research comparing autistic traits and disordered eating-related symptoms in individuals with either or both conditions will help improve identification of and support for autistic women ED settings, which is currently lacking. The current study adds to the literature by describing and comparing (1) autistic women without REDs ('Autism only'), (2) autistic women with REDs who have an independent formal autism diagnosis ('Autism+REDs'), (3) women with REDs who do not have a formal autism diagnosis and exhibit low to normal levels of autistic traits ('REDs only'), and (4) women with REDs who do not have a formal autism diagnosis but exhibit high autistic traits ('REDs high autistic traits'). We compare these groups with respect to demographics and background variables as well autistic traits and disordered eating symptoms. The comparison of demographic and clinical background variables will situate the sample and provide insight into the clinical presentation of autistic women in ED settings.

Research Questions. We will address the following research questions:

- ***Autistic traits***
    - Does the level or nature of autistic traits in autistic women with REDs differ from that seen in autistic women without REDs and other women with REDs?
- ***Traditional disordered eating symptoms***
    - Does the overall level or pattern of traditional disordered eating symptoms in autistic women with REDs differ compared to autistic women without REDs and other women with REDs?

- ***Autism-specific unusual eating behaviours***
    - Does the overall level or pattern of autism-specific unusual eating behaviours in autistic women with REDs differ compared to autistic women without REDs and other women with REDs?

We repeated each analysis, controlling for differences in levels of co-occurring mental health difficulties, to better understand the effect of additional co-occurring difficulties on participants' autistic traits and disordered eating-related symptoms. In addition, we tested whether autistic traits were correlated with BMI to assess whether those with more autistic traits weighted less, which would support the theory that autistic traits in RED populations are in part driven by the effects of starvation.

Hypotheses. We made several hypotheses about expected group differences for the 'Autism only,' 'Autism+REDs,' and 'REDs only' group a priori. The 'REDs high autistic traits' group was not included in our a priori predictions, but is included in the analysis for the purpose of exploring these participants' characteristics and learning more about whether they are likely to be autistic. The hypotheses tested in the current chapter are as follows:

- ***Autistic traits***
    - 'Autism+REDs' will present with the highest levels of autistic traits followed by 'Autism only', because the self-report measures used will pick up on their 'true' autistic traits, as well as additional disordered eating-related behaviours and cognitions, the effect of starvation, and high levels of anxiety mimicking autistic traits. 'REDs only' will present with lower levels of autistic traits than the other two groups.
    - 'Autism only' and 'Autism+REDs' will present with a larger proportion of autistic traits in childhood compared to adulthood than 'REDs only'.

- ‘Autism+REDs’ will show the highest levels of camouflaging behaviours followed by ‘Autism only.’ ‘REDs only’ participants will present with lower levels of camouflaging behaviours than the other groups.

- ***Traditional disordered eating symptoms***
  - ‘REDs only’ will present with the highest levels of traditional disordered eating symptoms, especially weight and shape concerns, followed by ‘Autism+REDs’, then ‘Autism only’.

- ***Autism-specific unusual eating behaviours***
  - ‘Autism+REDs’ will present with the highest levels of autism-specific unusual eating behaviours, followed by ‘REDs only,’ who in turn will score higher than ‘Autism only.’

Methods

The following provides a brief outline of the methodology. More methodological details for this study are outlined in Chapter 3.

Participants

Participants included 47 autistic women without REDs (‘Autism only’), 51 autistic women with REDs (‘Autism+REDs’), 76 non-autistic women with REDs (‘REDs only’), and 36 women with REDs and high autistic traits (‘REDs high autistic traits’). Recruitment procedures and inclusion criteria are detailed in Chapter 3. Demographics for each group are presented in Table 8 below.

Table 8

Means (SD) and frequencies (%) for demographic variables for each group

		Autism only (n = 47)	**Autism+REDs** (n = 51)	**REDs only** (n = 76)	**REDs high autistic traits** (n = 36)	**Group comparison and significant post-hoc comparisons**
Gender	Female	43 (91.5%)	45 (88.2%)	76 (100%)	36 (100%)	Fischer-Freeman-Halton Exact Test (2-sided): ***p* = .002**
	Agender/gender neutral/non-binary/gender-fluid/other/prefer not to say	4 (8.5%)	6 (11.8%)	0 (0%)	0 (0%)	
Age	Current Age in years Mean (SD), *Range*, Median	38.85 (11.50) *18–69*, 38	30.92 (11.48) *18–61*, 29	29.72 (8.72) *18–60,* 28	30.67 (10.28) *19–63,* 28	$F(3, 206) = 8.44$, ***p* < .001**, $\eta^2 = .109$ Post-hoc Hochberg GT2 sig differences **Autism only > Autism+REDs** mean difference = 7.93 years, ***p* = .001**, *g* = .690, 95% CI [4.03–14.23] **Autism only > REDs only** Mean difference = 9.13 years, ***p* < .001**, *g* = .935, 95% CI [4.03–14.23]

		Autism only (n = 47)	**Autism+REDs** (n = 51)	**REDs only** (n = 76)	**REDs high autistic traits** (n = 36)	**Group comparison and significant post-hoc comparisons**
						Autism only > REDs low autistic traits Mean difference = 8.18 years, ***p* = .003**, *g* = .744, 95% CI [2.10–14.27]
Ethnicity	Any white	39 (83%)	46 (90.2%)	73 (96%)	35 (97.2%)	**Any white vs. other:** Fischer-Freeman-Halton Exact Test (2-sided): *p* = .068
	White British	33 (70.2%)	43 (84.3%)	70 (92.1%)	31 (86.1%)	
	White Irish	2 (4.3%)	0	2 (2.6%)	0	
	Other white	4 (8.5%):	3 (5.9%):	1 (1.3%)	4 (11.1%)	
	Other	8 (17%)	5 (9.8%)	3 (3.9%)	1 (2.8%)	
	Black Caribbean	2 (4.3%)	2 (3.9%)	0	0	
	Indian	0	2 (3.9%)	0	0	
	Chinese	0	1 (2%)	0	0	
	Any other ethnicity	2 (4.3%)	0	0	0	
	White and Black Caribbean	1 (2.1%)	0	2 (2.6%)	0	
	White and Asian	1 (2.1%)	0	1 (1.3%)	1 (2.8%)	
	Any other mixed background	2 (4.2%)	0	0	0	

		Autism only (n = 47)	**Autism+REDs** (n = 51)	**REDs only** (n = 76)	**REDs high autistic traits** (n = 36)	**Group comparison and significant post-hoc comparisons**
Highest education level	No qualifications/ GCSE	2 (4.2%)	5 (9.80%)	7 (9.2%)	4 (11.1%)	Pearson χ^2 (9) = 19.72, ***p* = .020**, ϕ_c = .177
	A Level or foundation degree	7 (14.9%%)	26 (51.00%)	32 (42.1%)	14 (38.9%)	
	Bachelor's Degree	21 (44.7%)	9 (17.60%)	25 (32.9%)	10 (27%)	
	Master's Degree or PhD	17 (36.2%)	11 (21.60%)	12 (15.7%)	8 (22.2%)	
Currently in education	In full-time educating	3 (6.4%)	14 (27.5%)	13 (17.1%)	5 (7.8%)	Studying part- or full-time vs not studying and other: Pearson χ^2(3) = 5.415, p = .144, ϕ_c = .161
	In part-time education	8 (17%)	4 (7.8%)	5 (6.6%)	0	
	Other	1 (2.1%)	4 (7.8%)	9 (11.8%)	0	
	No	35 (74.5%)	29 (56.9%)	49 (64.5%)	31 (86.1%)	
Employment status	Yes, I am working voluntarily	2 (4.3%)	6 (11.8%)	2 (2.6%)	1 (2.6%)	Working vs not working: Pearson χ^2(3) = 13.11, ***p* = .004**, ϕ_c = .250
	Yes, I am in part-time paid work	22 (46.8%)	8 (15.7%)	17 (22.4%)	1 (2.8%)	
	Yes, I am in full-time paid work	9 (19.1%)	8 (15.7%)	29 (38.2%)	12 (33.3%)	
	No, but I am looking for work	2 (4.3%)	7 (19.4%)	4 (5.3%)	7 (19.4%)	

		Autism only (n = 47)	**Autism+REDs** (n = 51)	**REDs only** (n = 76)	**REDs high autistic traits** (n = 36)	**Group comparison and significant post-hoc comparisons**
	No, and I am NOT looking for work	7 (14.9%)	20 (39.2%)	15 (19.7%)	11 (30.6%)	
	Other	5 (10.6%)	7 (13.7%)	9 (11.8%)	4 (11.1%)	

With regard to participant's demographics, there are a few noteworthy differences between groups. While all women in the 'REDs only' and 'REDs high autistic traits' groups identified as female, 'Autism only' and 'Autism+REDs' included a sizable minority who did not identify as female (8.5% and 11.8%, respectively), including individuals with gender-neutral, non-binary and gender-fluid gender identifies. None of the individuals in our sample identified as transgender. Women in the 'Autism only' group were significantly older than in the other groups. They also had significantly higher level of educational attainment, with a greater portion of participants in this group having university qualifications. Participants in the 'REDs only' and 'REDs high autistic traits' group were twice as likely to be in full-time paid work compared to 'Autism only' and 'Autism+REDs.' Most 'Autism only' participants were working part-time, whereas most 'Autism+REDs' participants were not working. A proportion of participants in each group said they were 'not working and not looking for work' or endorsed 'other.' In the open response, many of these participants specified that they were unable to work due to disability or being on long-term sick leave.

Measures

The characteristics and psychometric properties of the measures used are presented in Chapter 3. In the current analysis, we used the AQ (Baron-Cohen et al., 2001) and the RAADS-14 (Eriksson et al., 2013) to measure autistic traits. The RAADS-14 (Eriksson et al., 2013) was also used to calculate the childhood ratio, i.e., the ratio of the number of items endorsed that were present in childhood, regardless of whether these items persisted relative to the total number of items endorsed. The RAADS-14 childhood ratio ranges between 0 and 1.

The CAT-Q (Hull et al., 2019) was used to measure camouflaging behaviours.

The EDE-Q (Fairburn & Beglin, 2008; Fairburn & Beglin, 1994) was used as a measure of traditional ED symptoms. There is a global EDE-Q scale and are four EDE-Q subscales: dietary restraint, eating concern, weight concern, and shape concerns.

The SWEAA (Karlsson et al., 2013) was used as a measure of autism-related unusual eating behaviours. It consists of a total score and ten subscales: perception, motor control, purchase of food, eating behaviour, mealtime surroundings, social situation at mealtime, other behaviour associated with disturbed eating, hunger/ satiety, simultaneous capacity, and Pica.

BMI was calculated based on participants' self-reported or measured weight and height.

Analytic approach

We describe the four groups in terms of demographic and background variables. Pearson's chi-square tests, Fishers-Freeman-Halton exact tests, one-way independent ANOVAs, independent samples t-tests, or robust alternatives were used to compare groups, depending on the nature of the data and the number of comparison groups.

Correlations between autistic traits (RAADS-14 total) and BMI were calculated for each group to assess the relationship between autistic traits and starvation.

Groups were compared on levels of autistic traits (RAADS-14 total, RAADS childhood ratio, AQ total, and CAT-Q total) and disordered eating-related symptoms (EDE-Q global and SWEAA total) using one-way independent ANOVAs or robust alternatives.

To assess group differences in the pattern of subscale scores on measures of traditional disordered eating symptoms (EDE-Q subscale scores) and autism-specific

unusual eating behaviours (SWEAA subscale scores), we conducted two mixed-design ANOVAs. Nine of the ten SWEAA subscales were included. The SWEAA pica subscale was analysed separately using a non-parametric test due to the fact that its data varied widely from a normal distribution (see above Chapter 3 for details on assessment of normality).

We repeated each analysis, adjusting for age (partially adjusted model), and adjusting for age, depression, anxiety, and social anxiety (fully adjusted model). When adjusting for differences in age and co-occurring mental health difficulties, the mean age and the mean scores for anxiety, depression, and social anxiety in all groups were held constant at the respective estimated mean across the total sample.

Results

Clinical Background Variables

As part of the background questionnaire participants were asked about their autism and/or ED diagnostic and ED treatment experience. We also collected information on their historical and current clinical presentation. Table 9 presents the means and frequencies of these variables of each group, as well as select tests of group comparisons.

Table 9

Means (SD) and frequencies (%) for clinical background variables for each group

		Autism only (n = 47)	**Autism+REDs** (n = 51)	**REDs only** (n = 76)	**REDs high autistic traits** (n = 36)	**Group comparison and significant post-hoc comparisons**
Age of Autism and ED diagnoses	**Age of autism diagnosis** Mean (SD), *Range*, Median	35.26 (12.74) *9–68*, 35	27.65 (11.83) *11–58,* 25 (n = 49)	NA	NA	*t*(94) = 3.02, ***p* = .003**, *g* = .204, 95% CI [2.60–12.61]
	Age of ED diagnosis Mean (SD), *Range*, Median	N/A	18.92 (7.72), *9–54,* 17 (n = 48)	22.55 (8.65), *11–54*, 20	20.89 (10.14), *11–59*, 18	*F*(2, 157) = 2.553, *p* = .081, η^2 = .031
	Age ED symptoms start Mean (SD), *Range*, Median	N/A	15.64 (7.91), *5–53,* 14 (n = 47)	17.09 (6.44), *7–44*, 15 (n = 75)	16.67 (8.13), *3–46,* 15.5	*F*(2, 155) = .578, *p* = .562, η^2 = .007
	Illness duration (years since ED diagnosis) Mean (SD), *Range*, Median	N/A	11.94 (12.21), *1–52,* 7 (n = 48)	7.17 (7.49), *0–29,* 4.5	9.78 (8.07), *1–33,* 7	*F*(2, 157) = *3.98, p* = .021*,* η^2 = .048 Post-hoc Hochberg GT2 sig differences **Autism+REDs > REDs only** Mean difference = 4.77 years, ***p* = .018**, *g* = .495, 95% CI [.64–8.89].

		Autism only (n = 47)	**Autism+REDs** (n = 51)	**REDs only** (n = 76)	**REDs high autistic traits** (n = 36)	**Group comparison and significant post-hoc comparisons**
ED treatment	**Any**	N/A	43 (93.5%) (n = 46)	74 (97.4%)	34 (97.1%) (n = 35)	Fischer-Freeman-Halton Exact Test (2-sided): p = .560
	Inpatient		28 (60.8%)	40 (52.6%)	23 (65.7%)	Pearson $\chi 2$ (2) = .941, p = .625
BMI	**BMI Missing**	1 (2.1%)	5 (9.8%)	3 (3.9%)	5 (13.9%)	Fischer-Freeman-Halton Exact Test (2-sided): p = .141
	BMI† Mean (SD), *Range*	28.92 (6.41), *15.24–42.77* (n = 46)	18.32 (3.17), *13.11–30.04* (n = 46)	17.22 (2.82), *12.34–26.20 (n = 73)*	17.23 (2.5), *13.11–30.04* (n = 31)	Welch F(3, 89.72) = 40.25, $\boldsymbol{p < .001}$, η^2 = .565 Post-hoc Games-Howell sig differences **Autism only > Autism+REDs** Mean difference = 9.95, $\boldsymbol{p < .001}$, g = 2.096, 95% CI [7.73–12.18] **Autism only > REDs only** Mean difference = 10.93, $\boldsymbol{p < .001}$, g = 2.565, 95% CI [8.92–12.94] **Autism only > REDs high autistic traits**

		Autism only (n = 47)	**Autism+REDs** (n = 51)	**REDs only** (n = 76)	**REDs high autistic traits** (n = 36)	**Group comparison and significant post-hoc comparisons**
						Mean difference = 11.04, ***p* < .001**, *g* = 2.243, 95% CI [8.92–12.94]
	BMI <18.5	2 (4.2%)	26 (51%)	53 (68.4%)	25 (69.4%)	Pearson $\chi^2(3) = 61.83$, ***p* < .001**, $\phi_c = .560$
	Lowest ever BMI (18+) Mean (SD), *Range*	NA	14.19 (2.13), *10.30–19.76* (n = 27)	14.59 (2.61), *10.16–23.04* (n = 61)	13.68 (1.63), *10-78–17.31* (n = 27)	$F(2, 112) = 1.50$, $p = .227$, $\eta^2 = 03$
BMI for each RED diagnosis	**AN BMI** Mean (SD), *Range*	NA	17.74 (2.37), *13.11–22.34* (n = 38)	16.71 (2.39), *12.34–26.20* (n = 62)	17.00 (2.4), *11.76–23.36* (n = 29)	$F(2, 126) = 2.23$, $p = .112$, $\eta^2 = .03$
	Atypical AN BMI Mean (SD), *Range*	NA	19.00 (1.59), *17.85–21.22* (n = 4)	21.19 (2.15), *17.72–24.21* (n = 8)	20.53 (1.35), *19.57–21.49* (n = 2)	$F(2, 11) = 1.68$, $p = .231$, $\eta^2 = .23$
	ARFID BMI Mean (SD), *Range*	NA	23.08 (6.66), *17.21–30.04* (n = 4)	N/A	N/A	N/A

		Autism only (n = 47)	**Autism+REDs** (n = 51)	**REDs only** (n = 76)	**REDs high autistic traits** (n = 36)	**Group comparison and significant post-hoc comparisons**
	Other RED diagnosis: BMI Mean (SD), *Range*	NA	N/A	20.06 (3.66), *15.84–22.32* (n = 3)	N/A	N/A
Eating/Feeding difficulties or unusual eating behaviours in childhood	**Any**	23 (48.9%)	34 (66.7%)	32 (42.1%)	19 (52.8%)	Pearson $\chi^2(3) = 7.45$, $p = 0.059$, $\phi_c = .189$
	Qualitative responses available	23 (100%)	33 (97%)	30 (94%)	18 (94%)	
Current medication status	**Any**	24 (51%)	38 (74.5%)	47 (61%)	27 (75%)	Pearson $\chi^2(3) = 7.92$, $\mathbf{p = 0.048}$, $\phi_c = .194$
	Anti-depressants	15 (32%)	30 (58.8%)	43 (56.6%)	25 (69.4%)	
	Other (Neuroleptics, ADHD-medication, other)	13 (27.7%)	12 (23.7%)	13 (17.2%)	7 (19.5%)	
Current mental health	**HADS Depression**† Mean (SD), *Range*	6.34(4.37), *0–18*	10.18 (5.54), *0–21*	9.92 (3.93), *1–18*	12.47 (3.66), *4–20*	Welch F (3, 100.42) = 16.101, $\mathbf{p < .001}$, $\eta^2 = .169$ Post-hoc Games-Howell sig differences **Autism only < Autism+REDs**

		Autism only (n = 47)	**Autism+REDs** (n = 51)	**REDs only** (n = 76)	**REDs high autistic traits** (n = 36)	**Group comparison and significant post-hoc comparisons**
						Mean difference = 3.836, ***p* < .001**, *g* = .766, 95% CI [-6.21–(-1.46)] **Autism only < REDs only** Mean difference = 3.581, ***p* < .001**, *g* = .873, 95% CI [-5.76–(-1.4)] **Autism only < REDs high autistic traits** Mean difference = 6.132, ***p* < .001**, *g* = 1.503, 95% CI [-5.76–(-1.4)] **REDs only < REDs high autistic traits** Mean difference = -2.551, ***p* = .029**, *g* = .663, 95% CI [-4.93-(-.17]
	HADS anxiety Mean (SD), *Range*	11.06 (4.49), *3–21*	14.88 (4.26), *2–21*	13.97 (4.16), *5–20*	15.64 (3.32), *6–21*	*F*(3, 206) = 11.09, ***p* < .001,** η^2 = .139 Post-hoc Hochberg GT2 sig differences **Autism only < Autism+REDs**

		Autism only (n = 47)	**Autism+REDs** (n = 51)	**REDs only** (n = 76)	**REDs high autistic traits** (n = 36)	**Group comparison and significant post-hoc comparisons**
						Mean difference = 3.691, *g* = .874, ***p* < .001**, 95% CI [-5.78–(-1.60)] **Autism only < REDs only** Mean difference = 2.78, *p* = .001, *g* = .679, 95% CI [-4.70–(-.87)] **Autism only < REDs high autistic traits** Mean difference = 4.45, ***p* < .001,** *g* = 1.137, 95% CI [-6.73–(-2.16)]
	Social anxiety Mean (SD), *Range*	35.13 (13.17), *8–64*	45.00 (11.76), *6–68*	36.49 (13.48), *5–65*	47.61 (11.35), *9–68*	*F*(3, 206)=11.249, ***p* < .001,** η^2 Post-hoc Hochberg GT2 sig differences **Autism only > Autism+REDs** Mean difference = 9.87, ***p* = .001**, *g* = .792 95% CI [-16.67–(-3.07)] **Autism+REDs > REDS only**

		Autism only (n = 47)	**Autism+REDs** (n = 51)	**REDs only** (n = 76)	**REDs high autistic traits** (n = 36)	**Group comparison and significant post-hoc comparisons**
						Mean difference = 8.513, ***p* = .002**, *g* = .664, 95% CI [2.43–14.60] **Autism only > REDs high autistic traits** Mean difference = 12.48, ***p* < .001**, *g*=1.005, 95% CI [-19.93-(-5.04)] **REDs only < REDs high autistic traits** Mean difference = -11.12, ***p* < .001**, *g* = .866, 95% CI [-17.93–(-4.32)]
Additional mental health diagnoses (ever)	**Number of additional diagnoses (ever)** Mean (SD), *Range*	1.98 (1.31), *0–5*	3.02 (1.6), *0–7*	1.83 (1.45), *0–5*	2.86 (1.38), *0–6*	$F(3, 206) = 9.401$, ***p* < .001,** $\eta^2 = .120$ Post-hoc Hochberg GT2 sig differences **Autism only < Autism+REDs** Mean difference = 1.04, ***p* = .003**, *g* = .708, 95% CI [-1.82–(-.26)] **Autism+REDs > REDs only**

		Autism only (n = 47)	**Autism+REDs** (n = 51)	**REDs only** (n = 76)	**REDs high autistic traits** (n = 36)	**Group comparison and significant post-hoc comparisons**
						Mean difference = 1.19, ***p* < .001**, *g* = .787, 95% CI [.49–1.89] **Autism only < REDs high autistic traits** Mean difference = .88, ***p* = .038,** *g* = .656, 95% CI [-1.74–(-.03)] **REDs only < REDs high autistic traits** Mean difference = -1.03, ***p* = .003**, *g* = .721, 95% CI [-1.81–(-.25)]
	Depression	30 (63.2%)	42 (82.4%)	44 (57.9%)	30 (83.3%)	Pearson $\chi^2(3) = 12.77$, ***p* = .005**, $\phi_c = .247$
	Generalised Anxiety Disorder	27 (57.4%)	33 (64.7)	38 (50%)	21 (58.3)	Pearson $\chi^2(3) = 2.770$, $p = .430$, $\phi_c = .115$
	PTSD (including complex PTSD)	8 (16.7%)	14 (27.5%)	19 (25%)	7 (19.4%)	Pearson $\chi^2(3) = 1.954$, $p = .592$, $\phi_c = .096$
	OCD	4 (8.5%)	19 (37.3%)	11 (14.5%)	10 (27.8%)	Pearson $\chi^2(3)= 15.515$, ***p* < .001**, $\phi_c = .272$
	Social Anxiety	7 (14.9%)	13 (25.5%)	11 (14.5%)	12 (33.3%)	Pearson $\chi^2(3)= 7.023$, $p = .072$, $\phi_c = .247$
	Personality Disorder	5 (10.6%)	9 (17.6%)	5 (6.6%)	10 (27.8%)	Pearson $\chi^2(3)= 10.268$, ***p* = .016**, $\phi_c = .221$

		Autism only (n = 47)	**Autism+REDs** (n = 51)	**REDs only** (n = 76)	**REDs high autistic traits** (n = 36)	**Group comparison and significant post-hoc comparisons**
	Specific Phobia	1 (2.1%)	6(11.8%)	4 (5.3%)	2 (5.6%)	Fischer-Freeman-Halton Exact Test (2-sided): p = .274
	Bipolar Disorder	2 (4.3%)	2 (3.9%)	0	2 (5.6%)	Fischer-Freeman-Halton Exact Test (2-sided): p = .147
	Addiction Disorder	0	0	0	1 (2.8%)	Fischer-Freeman-Halton Exact Test (2-sided): p = .171
	Other:	3 (6.4%)	13 (25.5%)	6 (7.9%)	2 (5.6%)	Pearson $\chi^2(3)$= 13.309, **p = .004**, ϕ_c = .252
	mentions undiagnosed/suspected mental health problem or symptoms in other	7 (14.9%)	6 (11.8%)	7 (9.2%)	6 (17.4%)	
	mentions body dysmorphia in other	0	4 (7.8%)	0	0	
	mentions psychosis in other	1 (2.1%)	2 (3.9%)	0	0	
	mentions ADHD in other	1 (2.1%)	2 (3.9%)	0	1 (2.8%)	
	mentions self-harm and/or suicidality in other	1 (2.1%)	2 (3.9%)	3 (3.9%)	2 (5.6%)	

		Autism only (n = 47)	**Autism+REDs** (n = 51)	**REDs only** (n = 76)	**REDs high autistic traits** (n = 36)	**Group comparison and significant post-hoc comparisons**
	mentions unusual eating in other	4 (8.5%)	3 (5.9%)	1 (1.3%)	0	

Note. †assumption of homogeneity of variance not met (see Table 1, Appendix 13).

Age at diagnosis and treatment experience. There are a few noteworthy differences between groups with regard to participant's diagnostic ages and treatment experiences. As shown in Table 9, participants in both autism groups were on average diagnosed in adulthood. However, 'Autism only' were significantly older at the time of their autism diagnosis compared to 'Autism+REDs,' with a mean difference of 7.61 years. The effect size of this difference was small. Participants in the RED groups reported a wide range for both age of RED diagnosis and age at which their disordered eating symptoms started. Across RED groups, age of diagnosis ranged from 9-59 years, and age of symptom onset ranged from 3-53 years of age, however there were no significant differences between groups. We also calculated illness duration, (i.e., the years that had passed since participants had received their RED diagnosis). The average length of illness was above 7 years for all RED groups. However, there was a significant difference in illness duration between 'Autism+REDs' and 'REDs only', with 'Autism+REDs' having lived significantly longer with their illness (mean difference = 4.77 years). This difference had a small effect size. There were no significant differences in the proportion of participants in each RED group, who were receiving treatment for their ED, and who had been in inpatient treatment.

BMI. As expected, BMI differed significantly between groups. As shown in Table 9, this was driven by significantly higher BMI in the 'Autism only' group compared to the three RED groups. In line with this, there was a significant association between group and the proportion of participants who were underweight with a medium effect size ($\chi^2(3) = 61.83$, $p < .001$, $\phi_c = .560$). Fewer participants in 'Autism only' had a current BMI below 18.5 compared to the three RED groups.

It is worth noting that there was a wide range of BMIs among participants. In 'Autism only,' BMIs ranged from 15.24–42.77, meaning that this group included individuals who are considered underweight as well as individuals considered overweight/obese. Across the RED groups, BMIs ranged from 12.34-30.04. Higher BMIs in the RED groups occurred mainly among participants with RED diagnoses other than AN. Across RED groups, those with an AN diagnosis (n = 129) had significantly lower BMIs (M = 17.08, SD = 2.41), than other RED participants (n = 21; M = 20.90, SD = 3.45) (t(148) = -6.32, p < .001, g = 1.48). This difference had a large effect size. BMIs of participants with the same ED diagnosis did not differ significantly between groups (see Table 9). We also asked RED participants to report their lowest ever weight, if they were 18 years or older at the time. Mean lowest ever BMI was in the underweight range for all RED groups and did not significantly differ between RED groups.

Feeding and eating difficulties in childhood. Participants were asked whether they had experienced any feeding or eating difficulties or unusual eating behaviours in childhood, and to provide further detail in an open response box. It should be noted that no information about the severity or impact of these difficulties was collected.

Content analysis was used to categorise participants' open responses and group them together (Elo & Kyngäs, 2008). The number of participants who reported having experienced unusual eating/feeding behaviors in childhood ranged from 51% in 'Autism only' to 76% in 'REDs high autistic traits.' Overall, the proportion of participants reporting unusual eating/feeding behaviors in childhood did not significantly differ between groups. Almost all participants who reported having experienced unusual eating/feeding behaviors provided details about these in the

open response box (94% or more for each group). Interestingly, there was a different pattern in the nature of difficulties experienced between groups. An overview of the nature of difficulties mentioned by participants in each group is presented in Table 10.

Of those participants who reported having experienced any eating/feeding difficulties in childhood, 40% described themselves as picky/fussy eaters. This was particularly common in ‘Autism only’ and ‘Autism+REDs’ compared to ‘REDs only’ and ‘REDs high autistic traits’ groups.

Behaviours in response to sensory aversion to food characteristics were mentioned by 24% of participants, most commonly in response to food texture. This was particularly the case for ‘Autism only’ and ‘Autism+REDs,’ and to some extend in ‘REDs high autistic traits,’ whereas fewer participants in ‘REDs only’ reported these behaviours.

The opposite pattern emerged for the 26% of participants who described restrictive eating behaviours resembling early onset symptoms of traditional ED (e.g., driven by fat phobia and/or a desire to influence weight and shape). This was most common in ‘REDs only’ followed by ‘REDs high autistic traits,’ and less common in ‘Autism+REDs’ and ‘Autism only.’

Table 10

Content analysis of details of eating/feeding difficulties in childhood provided in open response, including percentage of those who reported childhood issues and the total from each group.

Group		fussy/picky, selective eating	sensory aversion (food texture, taste, smell, touching of food)	food neophobic	ritualised eating (e.g., only equal numbers or in specific order)	slow eating	not feeling hungry	intolerances, physical issues	fear of vomiting, choking; ARFID; PICA	restricting amount of food	fat phobia; body image issues	binging/overeating; cravings; secretive eating	issues with social environment during mealtime	parents enforced restriction; abuse, trauma
'Autism only' (n = 23/47)	% of childhood issues	61	30	0	0	4	0	9	9	13	17	17	0	0
	% group total	30	15	0	0	2	0	4	4	6	9	9	0	0
Autism +REDs (n = 34/51)	% of childhood issues	55	36	9	12	6	6	18	15	9	18	9	6	6
	% group total	35	24	6	8	4	4	12	10	6	12	6	4	4
'REDs only' (n = 32/76)	% of childhood issues	23	10	3	3	0	0	17	7	3	40	3	3	7
	% group total	9	4	1	1	0	0	7	3	1	16	1	1	3
'REDs high autistic traits' (n = 19/36)	% of childhood issues	22	22	11	0	0	0	22	6	0	33	22	0	11
	% group total	11	11	6	0	0	0	11	3	0	17	11	0	6
Total sample	% of childhood issues	40	24	6	5	3	2	16	11	6	26	11	3	5
	% total across groups	20	12	3	2	1	1	8	6	3	13	6	1	2

Current medication status. Participants were asked whether they were currently taking any medication, and, if so, to specify the type of medication. Anti-depressants was the most commonly endorsed response option across all groups. All other response options were collapsed to 'other.' There was a significant difference in response pattern across groups, with 'Autism+REDs' and 'REDs high autistic traits' being particularly likely to be taking medication.

Other mental health difficulties. Participants completed measures to assess current levels of anxiety and depression (HADS; Zigmond & Snaith, 1983), and social anxiety (SPIN; Connor et al., 2000) as part of the testing battery. On the HADS depression scale, the mean scores of 'Autism only' fell into the mild range (0–7), the scores of 'Autism+REDs' and 'REDs only' into the moderate range (8–10), and the scores of 'REDs high autistic traits' into the severe range (11+). 'Autism only' scored significantly lower than the other three groups, and 'REDs high autistic traits' scoring significantly higher than 'REDs only.' On the HADS anxiety scale, all groups' mean scores were in the severe range, however, 'Autism only' scored significantly lower than the other three groups. On the SPIN, 'Autism+REDs' and 'REDs high autistic traits' scored significantly higher than the other two groups. The effect sizes for group differences for depression, anxiety and social anxiety were all medium to large.

Additional mental health diagnoses. We also asked participants whether they had ever received any additional mental health diagnoses other than REDs and autism. The average number of additional mental health diagnoses received ranged from 1.83 (*SD* = 1.45) in 'REDs only' to 3.02 (*SD* = 1.6) in 'Autism+REDs.' 'Autism+REDs' and 'REDs high autistic traits' reported significantly more additional metal health diagnoses than 'Autism only' and 'REDs only' (see Table 9). Group

differences all had a medium effect size. Across groups, depression (57.9%–83.3%) and general anxiety disorder (GAD; 50%–64%) were the most commonly reported additional diagnoses, followed by post-traumatic stress disorder (PTSD; 16.7%–27.5%), obsessional compulsive disorder (OCD; 8.5%–37.3%), social anxiety (14.5%–-33.3%), and personality disorders (6.6%–27.8%). For depression, OCD, and personality disorders, the portion of participants who reported having received an additional diagnosis differed significantly between groups, with the largest proportions of participants endorsing them being in the 'Autism+REDs' and 'REDs high autistic traits' groups.

Correlation Between Autistic Traits and BMI

The correlation between autistic traits and BMI in each group was assessed to explore whether these were negatively correlated, which would be consistent with the idea that autistic trait scores can be elevated due to effects of starvation. Correlation coefficients are reported in Table 11. There was a significant positive correlation between autistic traits and BMI in the 'Autism only' group, which consisted predominantly of participants with healthy weight as well as some in the overweight range. In this group those with higher BMI tended to present with more autistic traits. There were no significant correlations between autistic traits and BMI in any of the RED groups, which included predominantly underweight participants.

Table 11

Correlations between autistic traits (RAADS-14) and BMI for each group

	BMI
Autism only (n = 46)*	r_S = .450, [.151–.667], ***p* = .002**, R_S^2 = .203
Autism+REDs (n = 46)*	r = .141, [-143–.367], p = .351, R^2 = .020
REDs only (n = 73)*	r_S = -.003, [-.251–.248], p = .983, R_S^2 < .001
REDs high autistic traits (n = 31)*	r_S = -.100, [-.427–.245], p = .592, R_S^2 = .010,

Note. The correlation coefficient (r/r_s) for each correlation is reported as an indicator of strength of the bivariate relationship. Bootstrapped 95% CIs are reported in square brackets. The coefficients of determination (R^2/ R_s^2) are reported as an indicator of shared variance.
*reduced sample sizes due to missing BMI data.

Group Differences in Autistic Traits

In this section, group comparisons of mean total scores on measures of autistic traits are presented. The impact of covariates on main effects of group and any changes to significance levels of post-hoc comparisons are highlighted. For all autistic traits-related measures, Table 12 presents mean total scores, estimated means after adjustments, F statistics for each model, post-hoc comparisons for the unadjusted model, and changes for adjusted models.

Table 12

Mean total scores, estimated mean scores after adjustments, and F statistic for each autistic traits-related measure. The table also shows post-hoc comparisons for the unadjusted model and changes for the adjusted model.

Measure	Model	Mean (SD) /Estimated Mean After Adjustment				Statistical Result	Significant Post-hoc Comparisons in Unadjusted Model and Changes for Adjusted Model
		Autism only (n = 47)	**Autism+ REDs (n = 51)**	**REDs only (n = 76)**	**REDs high autistic traits (n = 36)**		
RAADS-14	Unadjusted	33.28 (7.03)	35.06 (5.83)	11.05 (5.80)	31.00 (5.81)	$F(3, 206) = 218.55$, ***p* < .001**, $\eta^2 = .76$	Hochberg's GT2: **Autism only > REDs only** Mean difference = 22.22, ***p* < .001**, $g = 3.531$, 95% CI [19.22–25.23] **Autism+REDs > REDs only** Mean difference = 24.01, ***p* < .001**, $g = 4.131$, 95% CI [21.07–26.94] **Autism+REDs > REDs high autistic traits** Mean difference = 4.06, ***p* = .015**, $g = .094$, 95% CI [.53–7.59]

							REDs only < REDs high autistic traits Mean difference = -19.95, ***p* < .001**, *g* = 3.438, 95% CI [-23.23–(-16.67)]
	Partially adjusted	33.00[a]	35.11[a]	11.16[a]	31.07[a]	*F*(3, 205) = 209.37, ***p* < .001**, η^2_p = .754	No change
	Fully adjusted	34.73[b]	34.05[b]	11.70[b]	29.16[b]	*F*(3, 202) = 221.47, ***p* < .001**, η^2_p = .767	Additional significance: **Autism only > REDs high autistic traits** Mean difference = 5.57, ***p* < .001**, 95% CI [1.83–9.30]
RAADS-14 childhood ratio	Unadjusted†	.91 (.17)	.93 (.13)	.64 (.35)	.84 (.20)	Welch's *F*(3, 102.75) = 15.06, ***p* < .001**, η^2 = .212	Games-Howell: **Autism only > REDs only** Mean difference = .29, ***p* < .001**, *g* = .916, 95% CI [.15–.41] **Autism+REDs > REDs only** Mean difference = .29, ***p* < .001**, *g* = 1.024, 95% CI [.18–.41] **REDs only < REDs high autistic traits** Mean difference = -.21, ***p* = .001**, *g* = .645, 95% CI [-.34–(-.07)]
	Partially adjusted†	.91[a]	.93[a]	.64[a]	.85[a]	*F*(3, 205) = 17.76, ***p* < .001**, η^2_p = .206	No change

	Fully adjusted†	.90[b]	.93[b]	.64[b]	.87[b]	$F(3, 202) = 17.58$, $\boldsymbol{p < .001}$, $\eta^2_p = .207$	No change
AQ‡	Unadjusted†	35.37 (7.49)	38.45 (4.15)	21.05 (6.13)	33.24 (6.68)	Welch $F(3, 57.52) = 102.02$, $\boldsymbol{p < .001}$, $\eta^2 = .609$	Games-Howell: **Autism only > REDs only** Mean difference = 14.31, $\boldsymbol{p < .001}$, $g = 2.144$, 95CI [9.19–19.44] **Autism+REDs > REDs only** Mean difference = 17.40, $\boldsymbol{p < .001}$, $g = 3.207$, 95% CI [14.75–20.05] **Autism+REDs > REDs high autistic traits** Mean difference = 5.22, $\boldsymbol{p = .002}$, $g = .976$, 95% CI [1.63–8.81] **REDs only < REDs high autistic traits** Mean difference = -12.18, $\boldsymbol{p < .001}$, $g = 1.932$, 95% CI [-15.74–(-8.62)]
	Partially adjusted†	34.85[c]	38.62[c]	21.11[c]	33.25[c]	$F(3, 156) = 80.76$, $\boldsymbol{p < .001}$, $\eta^2_p = .608$	No change
	Fully adjusted†	35.76[d]	38.10[d]	21.62[d]	32.11[d]	$F(3, 153) = 70.03$, $\boldsymbol{p < .001}$, $\eta^2_p = .579$	No change

CAT-Q	Unadjusted	120.70 (25.20)	130.84 (19.64)	97.72 (23.58)	121.14 (23.53)	$F(3, 206) = 24.04$, ***p* < .001**, $\eta^2 = .259$	Hochberg's GT2: **Autism only > REDs only** Mean difference = 2.98, ***p* < .001**, *g* = .949, 95% CI [11.61–34.34] **Autism+REDs > REDs only** Mean difference = 33.21, ***p* < .001**, *g* = 1.499, 95% CI [22.03–44.21] **REDs only < REDs high autistic traits** Mean difference = -23.42, ***p* < .001**, *g* = .994, 95% CI [-35.81–(-11.02)]
	Partially adjusted	123.07[a]	130.38[a]	96.84[a]	120.59[a]	$F(3, 205) = 25.89$, ***p* < .001**, $\eta^2_p = .275$	No change
	Fully adjusted	127.24[b]	126.29[b]	100.04[b]	114.17[b]	$F(3, 202) = 21.75$, ***p* < .001**, $\eta^2_p = .244$	Additional significance: **Autism+REDS > REDs high autistic traits** Mean difference = 12.12, ***p* = .044**, 95% CI[.18–24.05]

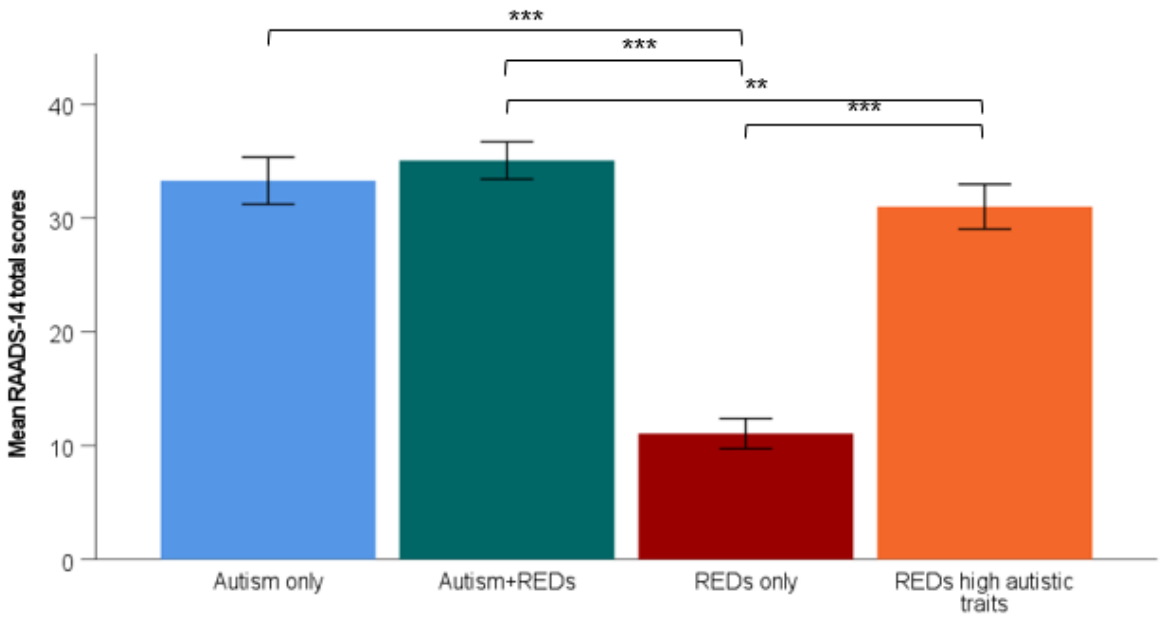
Note. †Assumption of homogeneity of variance not met (see Table 1, Appendix 13).
‡Reduced sample size for AQ comparison due to missing data: Autism only (n = 19), Autism+REDs (n = 33), REDs only (n = 75), REDs high autistic traits (n = 34).
[a] Covariate is evaluated at the following value: Age (years) = 32.22.
[b] Covariates are evaluated at the following values: Age (years) = 32.22, HADS depression = 9.62, HADS anxiety = 13.86, SPIN total = 40.16.
[c] Covariate is evaluated at the following value: Age (years) = 30.80.

[d] Covariates are evaluated at the following values: Age (years) = 30.80, HADS depression = 10.16, HADS anxiety = 14.29, SPIN total = 40.64.

RAADS-14. As shown in Table 12, there was a significant effect of group on RAADS-14 total scores ($F(3, 206) = 218.55$, $p < .001$, $\eta^2 = .76$). The pattern of unadjusted mean RAADS-14 total scores for each group with indication of significant post-hoc differences is presented in Figure 4.

Figure 4

Unadjusted mean scores for each group and significant group differences for RAADS-14 total



Note. Error bars indicate 95% CI. Significant post-hoc differences: ***$p \leq .001$, **$p \leq .01$.

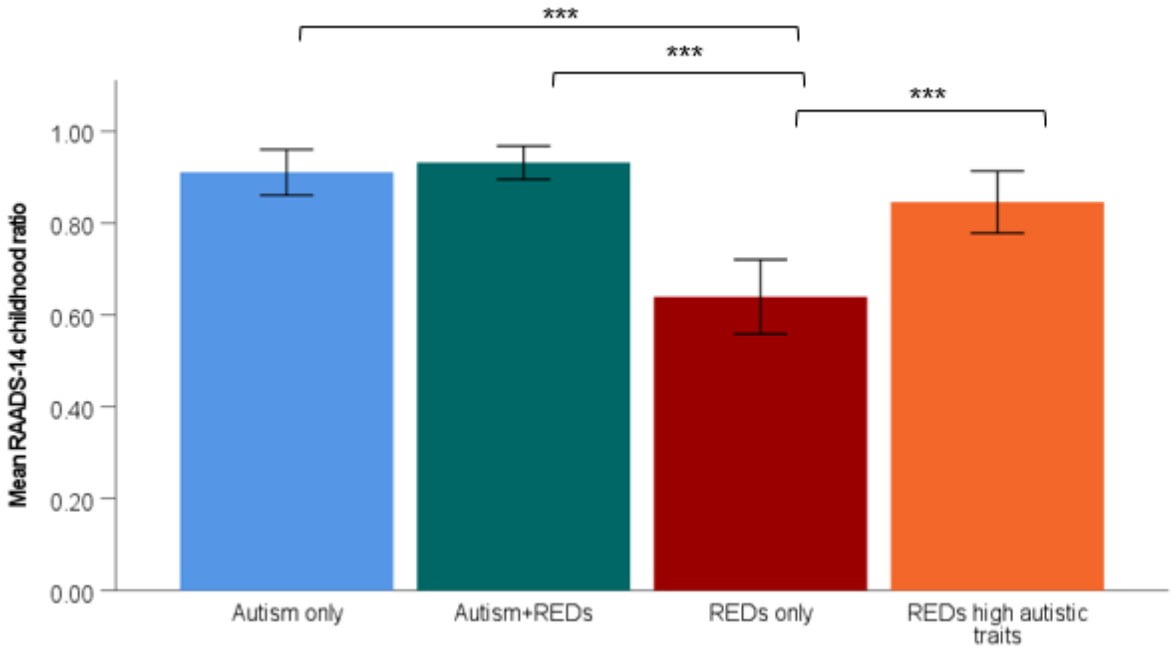
As presented in Table 12, post-hoc tests revealed that, as expected, 'Autism only,' 'Autism+REDs' and 'REDs high autistic traits' all scored significantly higher on the RAADS-14 than 'REDs only.' The effect sizes for these differences were very large. In addition, 'Autism+REDs' scored significantly higher than 'REDs high autistic traits.' This difference had a large effect size. There was no significant difference between 'Autism only' and 'Autism+REDs'.

The overall effect of group was maintained in the partially adjusted (F(3, 205) = 209.37, p < .001, η^2_p = .754) and the fully adjusted model (F(3, 202) = 221.47, p < .001, η^2_p = .767). The effect sizes across all three models were large and stayed almost the same across the three models. The same post-hoc comparisons reached significance in the partially and fully adjusted model. In addition, in the fully adjusted model, the estimated mean RAADS-14 total score in 'Autism only' was significantly higher than the estimated mean in 'REDs high autistic traits' (see Table 12).

RAADS childhood ratio. As shown in Table 12, there was a significant effect of group on the RAADS childhood ratio (Welch's F(3, 102.75) = 15.06, p < .001, η^2 = .212). Figure 5 presents unadjusted means for the RAADS childhood ratio for each group, with indication of significant post-hoc differences.

Figure 5

Unadjusted mean scores for each group and significant group differences for RAADS-14 childhood ratio



Note. Error bars indicate 95% CI. Significant post-hoc differences: ***$p \leq .001$.

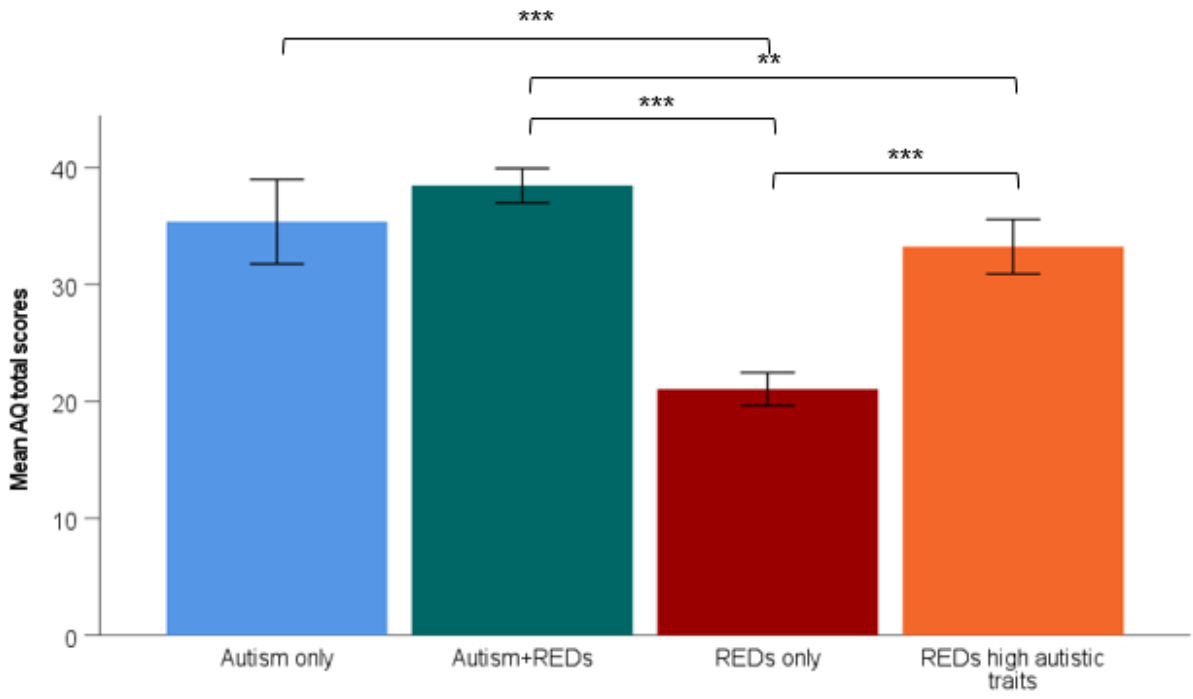
Post-hoc tests revealed that ‘Autism only,’ ‘Autism+REDs,’ and ‘REDs high autistic traits’ had a significantly higher RAADS-14 childhood ratio than ‘REDs only.’ These group differences had medium to large effect sizes.

The overall effect of group was maintained in the partially adjusted ($F(3, 205) = 17.76$, $p < .001$, $\eta^2_p = .206$) and the fully adjusted model ($F(3, 202) = 17.58$, $p < .001$, $\eta^2_p = .207$). The effect size for all three models was large and stayed almost the same across models, but got slightly smaller with more adjustments. The same post-hoc comparisons reached significance in the partially and fully adjusted models.

AQ. As shown in Table 12, there was a significant effect of group on AQ total scores (Welch $F(3, 57.52) = 102.02$, $p < .001$, $\eta^2 = .609$). Figure 6 presents unadjusted means for AQ total scores for each group with indication of significant post-hoc differences.

Figure 6

Unadjusted mean scores for each group and significant group differences for AQ total scores



Note. Error bars indicate 95% CI. Significant post-hoc differences: ***$p \leq .001$, **$p \leq .01$.

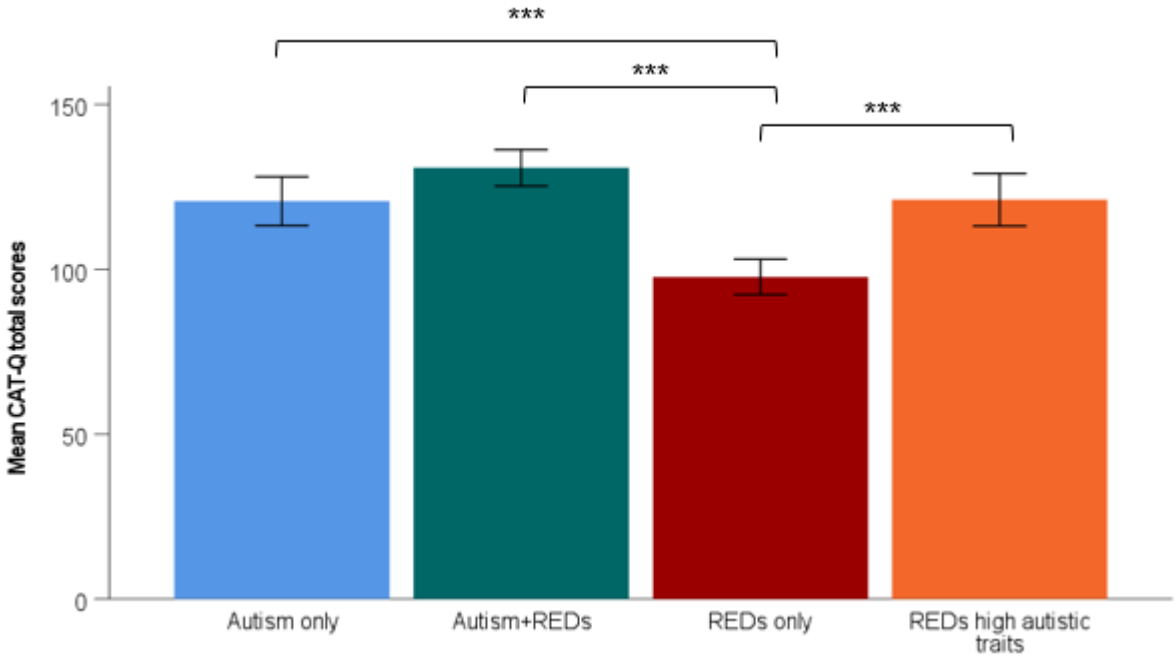
Post-hoc tests revealed that, as expected, 'Autism only,' 'Autism+REDs,' and 'REDs high autistic traits' scored significantly higher than the 'REDs only' group, indicating more autistic traits. In addition, 'Autism+REDs' had significantly higher AQ scores than 'REDs high autistic traits.' These group differences had large to very large effect sizes. There was no significant difference between 'Autism only' and 'Autism+REDs'.

The overall effect of group was maintained in the partially adjusted ($F(3, 156) = 80.76$, $p < .001$, $\eta^2_p = .608$) and the fully adjusted model, ($F(3, 153) = 70.03$, $p < .001$, $\eta^2_p = .579$). The effect size for all three models was large and stayed almost the same across models, but got slightly smaller with more adjustments. The same post-hoc comparisons reached significance in the partially and fully adjusted models.

CAT-Q. As shown in Table 12, there was a significant effect of group on CAT-Q total scores ($F(3, 206) = 24.04$, $p < .001$, $\eta^2 = .259$). Figure 7 presents unadjusted means for CAT-Q total scores for each group with indication of significant post-hoc differences.

Figure 7

Unadjusted mean scores for each group and significant group differences for CAT-Q total score



Note. Error bars indicate 95% CI. Significant post-hoc differences: ***$p \leq .001$.

Post-hoc tests revealed that 'Autism only,' 'Autism+REDs,' and 'REDs high autistic traits' had significantly higher CAT-Q scores (indicating more camouflaging behaviours) than 'REDs only.' These group differences had large effect sizes.

The overall effect of group was maintained in the partially adjusted ($F(3, 205) = 25.89$, $p < .001$, $\eta^2_p = .275$) and the fully adjusted model, ($F(3, 202) = 21.75$, $p < .001$, $\eta^2_p = .244$). The effect size for all three models was large and stayed almost the same across models, but got slightly larger when adjusting for age, and smaller with for the fully adjusted model. The same post-hoc comparisons reached significance in the partially and fully adjusted models. In addition, in the fully adjusted model the estimated mean for 'Autism+REDs' was significantly higher than the estimated mean for 'REDs high autistic traits.'

Group Differences in Traditional Disordered Eating Symptoms

In this section, group comparisons of the EDE-Q global scale, measuring overall traditional disordered eating symptoms, are presented, followed by group

comparisons of individual EDE-Q subscales. The impact of covariates on main effects of group and any changes to significance levels of post-hoc comparisons are highlighted.

EDE-Q global. Table 13 presents mean EDE-Q global scores, estimated means after adjustments for each group, F statistics, post-hoc comparisons for the unadjusted model, and changes for adjusted models.

Table 13

Mean EDE-Q global scores for each group, estimated mean scores after adjustments, and F statistic. The table also shows post-hoc comparisons for the unadjusted model and changes for the adjusted models.

Measure	Model	Mean (SD) /Estimated Mean After Adjustment				Statistical Result	Significant Post-hoc Comparisons in Unadjusted Model and Changes for Adjusted Model
		Autism only (n = 47)	**Autism+ REDs (n = 51)**	**REDs only (n = 76)**	**REDs high autistic traits (n = 36)**		
EDE-Q global	Unadjusted	1.73 (1.31)	3.46 (1.43)	4.13 (1.19)	4.49 (1.13)	$F(3, 206) = 44.12$, ***p* < .001**, $\eta^2 = .391$	Hochberg's GT2: **Autism only < Autism+REDs** Mean difference = 1.73, ***p* < .001**, *g* = 1.259, 95% CI [1.05–2.41] **Autism only < REDs only** Mean difference = 2.40, ***p* < .001**, *g* = 1.940, 95% CI [1.78–3.03] **Autism only < REDs high autistic traits** Mean difference = 2.76, ***p* < .001**, *g* = 2.23, 95% CI [2.01–3.51] **Autism+REDs < REDs only**

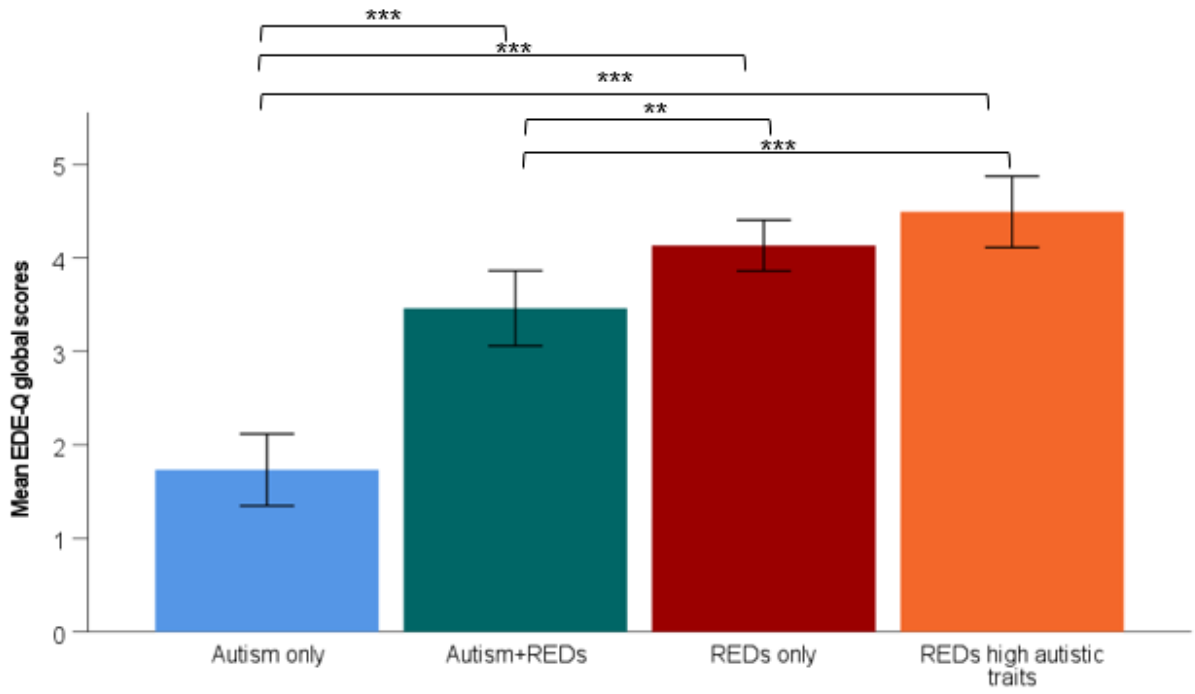
							Mean difference = .36, ***p* = .023**, *g* = .519, 95% CI [.06–1.28] **Autism+REDs < REDs high autistic traits** Mean difference = 1.03, ***p* = .001**, *g* = .783, 95% CI [.30–1.76]
	Partially adjusted	1.69[a]	3.47[a]	4.15[a]	4.50[a]	*F*(3, 205) = 41.38, ***p* < .001**, η^2_p = .377	No changes
	Fully adjusted	2.21[b]	3.24[b]	4.22[b]	4.01[b]	*F*(3, 202) = 28.54, ***p* < .001**, η^2_p = .298	No changes

Note. [†]Assumption of homogeneity of variance not met (see Table 1, Appendix 13).
[a] Covariate is evaluated at the following value: Age (years) = 32.22.
[b] Covariates are evaluated at the following values: Age (years) = 32.22, HADS depression = 9.62, HADS anxiety = 13.86, SPIN total = 40.16.
[c] Covariate is evaluated at the following value: Age (years) = 30.80.
[d] Covariates are evaluated at the following values: Age (years) = 30.80, HADS depression = 10.16, HADS anxiety = 14.29, SPIN total = 40.64.

As shown in Table 13, there was a significant effect of group on EDE-Q global scores ($F(3, 206) = 44.12$, $p < .001$, $\eta^2 = .391$). Figure 8 presents unadjusted means for EDE-Q global scores for each group with indication of significant post-hoc differences.

Figure 8

Unadjusted mean scores for each group and significant group differences for EDE-Q global scores



Note. Error bars indicate 95% CI. Significant post-hoc differences: ***$p \leq .001$, **$p \leq .01$.

Post-hoc tests revealed that, as expected, 'Autism only' scored significantly lower than 'Autism+REDs,' 'REDs high autistic traits,' and 'REDs only' (indicating that 'Autism only' had fewer traditional disordered eating symptoms). Further, 'Autism+REDs' scored significantly lower than 'REDs only' and 'REDs high autistic traits.' These group differences had medium to large effect sizes.

The overall effect of group was maintained in the partially adjusted (F(3, 205) = 41.38, p < .001, η^2_p = .377), and the fully adjusted model, (F(3, 202) = 28.54, p < .001, η^2_p = .298). The effect size for all three models was large, but got slightly smaller with more adjustments. The same post-hoc comparisons reached significance in the partially and fully adjusted models.

EDE-Q subscales. In addition to EDE-Q global scores, patterns in responses across EDE-Q subscales were compared, to assess the role of weight and shape concerns for traditional disordered eating symptoms in autistic women with REDs.

Box's test of equality of covariance was violated (Box's M = 84.87, F(30, 76704.71) = 2.73, p < .001). According to Levene's test (see Table 1, Appendix 13), the assumption of equality of variance for individual subscale scores was met for all subscales, apart from the EDE-Q shape concern and weight concern subscales. Mauchly's test of sphericity indicated that the assumption of sphericity had been violated (χ^2(5) = 55.88, p < .001), so Huynh-Feldt corrections were applied (ε = .89).

Unadjusted and adjusted main effects for subscale, group and interaction of subscale by group for reach EDE-Q subscale are presented in Table 14.

Table 14

Mixed-design ANOVA main effects of subscale, group, and interaction for EDE-Q subscales in the unadjusted, partially and fully adjusted model

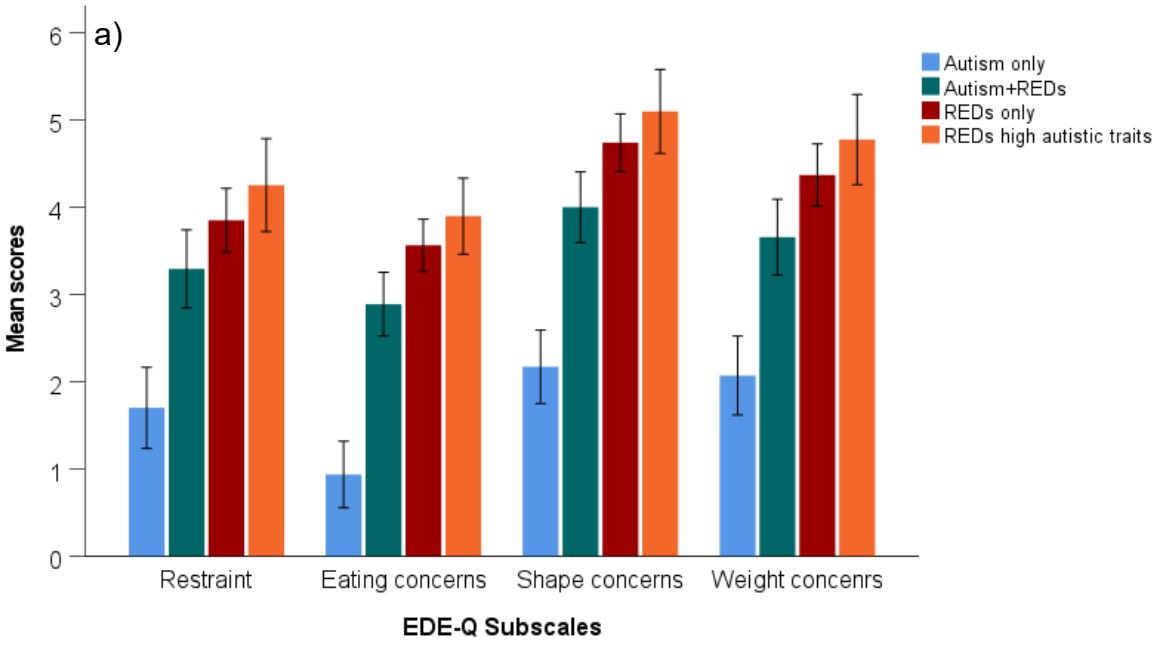
Measure	Mein effect	Model	Statistical Result
EDE-Q subscales	Subscale	Unadjusted	F(2.67, 550.75) = 58.79, **p < .001**, η^2 = .222
		Partially adjusted	F(2.70, 552.87) = 8.69, **p < .001**, η^2_p = .041
		Fully adjusted	F(2.74, 553.64) = 1.19, p = .313, η^2_p = .006
	Group	Unadjusted	F(3, 206) = 45.51, **p < .001**, η^2 = .399

	Partially adjusted	$F(3, 205) = 42.59$, $\mathbf{p < .001}$, $\eta^2_p = .384$
	Fully adjusted	$F(3, 202) = 29.35$, $\mathbf{p < .001}$, $\eta^2_p = .304$
Subscale by Group	Unadjusted	$F(8.02, 550{,}75) = .642$, $p = .742$, $\eta^2 = .009$
	Partially adjusted	$F(8.09, 552.87) = .440$, $p = .901$, $\eta^2_p = .006$
	Fully adjusted	$F(8.22, 553.64) = .396$, $p = .927$, $\eta^2_p = .006$

The patterns of unadjusted mean scores for EDE-Q subscales by group are presented in Figure 9. Subscale scores for the EDE-Q followed the same pattern for all groups.

Figure 9

Subscale scores for EDE-Q (a) and SWEAA subscales (b) by group



Note. Error bars indicate 95% CI.

We observed a significant main effect of subscale (F(2.67, 550.75) = 58.79, p < .001, η^2 = .222), indicating that there were differences between subscales across groups. In line with our comparison of group's EDE-Q global scores, which combines EDE-Q subscale scores, there was a significant main effect of group (F(3, 206) = 45.51, p < .001, η^2 = .399), indicating that there were differences between groups across EDE-Q subscales. There was no significant interaction effect between subscale and group (F(8.02, 550,75) = .642, p = .742, η^2 = .009). This indicates that the pattern of scores across EDE-Q subscales remained the same across groups.

Post-hoc pairwise comparisons between groups for each subscale are presented in Table 15.

Table 15

Mean EDE-Q subscale scores and estimated mean scores after adjustment. The table also shows post-hoc comparisons for the unadjusted model and changes for the adjusted model.

Measure	Model	Mean (SD) /Estimated Mean After Adjustment				Significant Pairwise Comparisons with Bonferroni Adjustment for Multiple Comparison.
		Autism only (n = 47)	**Autism+ REDs (n = 51)**	**REDs only (n = 76)**	**REDs high autistic traits (n = 36)**	
EDE-Q restraint	Unadjusted	1.70 (1.63)	3.30 (1.66)	3.86 (1.58)	4.26 (1.64)	**Autism only < Autism+REDs:** Mean difference = -1.59, ***p* < .001**, *g* = .982, 95% CI [-2.47–(-.72)] **Autism only < REDs only:** Mean difference = -2.15, ***p* < .001**, *g* = 1.351, 95% CI [-2.95–(-1.35)] **Autism only < REDs high autistic traits:** Mean difference = -2.55, ***p* < .001**, *g* = 1.566, 95% CI [-3.51–(-1.60)] **Autism+REDs < REDs high autistic traits:** Mean difference = -.96, ***p* = .042**, *g* = .581, 95% CI [-1.90–(-.02)]

	Partially adjusted	1.57[a]	3.32[a]	3.90[a]	4.29[a]	No changes
	Fully adjusted	1.87[b]	3.12[b]	3.96[b]	4.06[b]	**Autism+REDS < REDs high autistic traits is no longer significant** **Additional significance:** **Autism+REDS < REDS only:** Mean difference = -1.90, ***p* < .001**, 95% CI [-2.74–(-1.05)]
EDE-Q eating concerns	Unadjusted	0.94 (1.13)	2.89 (1.50)	3.57 (1.29)	3.90 (1.36)	**Autism only < Autism+REDs:** Mean difference = -1.95, ***p* < .001**, *g* = 1.46, 95% CI [-2.67–(-1.24)] **Autism only < REDs only:** Mean difference = -2.63, ***p* < .001**, *g* = 2.135, 95% CI [-3.28–(-1.97) **Autism only < REDs high autistic traits:** Mean difference = -2.96, ***p* < .001**, *g* = 2.397, 95% CI [-3.74–(-2.18)] **Autism+REDs < REDs only:** Mean difference = -.67, ***p* = .032**, *g* = .494, 95% CI [-1.31–(-.04)] **Autism+REDs < REDs high autistic traits:** Mean difference = -1.01, ***p* < .001**, *g* = .700, 95% CI [-1.78–(-.42)]
	Partially adjusted	0.93[a]	2.89[a]	3.90[a]	3.90[a]	No changes

	Fully adjusted	1.33[b]	2.68[b]	3.66[b]	3.49[b]	No changes
EDE_Q shape concerns	Unadjusted[†]	2.17 (1.58)	4.00 (1.75)	4.74 (1.32)	5.10 (1.10)	**Autism only < Autism+REDs:** Mean difference = -1.83, ***p* < .001**, *g* = 1.100, 95% CI [-2.62–(-1.04) **Autism only < REDs only:** Mean difference = -2.57, ***p* < .001**, *g* = 1.804, 95% CI [-3.29–(-1.85) **Autism only < REDs high autistic traits:** Mean difference = -2.93, ***p* < .001**, *g* = 2.103, 95% CI [-3.79–(-2.06) **Autism+REDs < REDs only:** Mean difference = -.74, ***p* = .035**, *g* = .491, 95% CI [-1.45–(-.033)] **Autism+REDs < REDs high autistic traits:** Mean difference = -1.10, ***p* = .004**, *g* = .725, 95% CI [-1.95–(-.25)]
	Partially adjusted[†]	2.13[a]	4.01[a]	4.76[a]	5.11[a]	No changes
	Fully adjusted[†]	2.54[b]	3.72[b]	4.89[b]	4.71[b]	No changes
EDE_Q weight concerns	Unadjusted	2.07 (1.49)	3.66 (1.84)	4.37 (1.57)	4.78 (1.23)	**Autism only < Autism+REDs:** Mean difference = -1.59, ***p* < .001**, *g* = .946, 95% CI [-2.43–(-.74)] **Autism only < REDs only:**

					Mean difference = -2.30, ***p* < .001,** *g* = 1.493, 95% CI [-3.08–(-1.52)] **Autism only < REDs high autistic traits:** Mean difference = -2.71, ***p* < .001**, *g* = 1.959, 95% CI [-3.63–(-1.78)] **Autism+REDs < REDs high autistic traits:** Mean difference = -1.12, ***p* = .008**, *g* = .693, 95% CI [-2.03–(-.21)]
Partially adjusted	2.09[a]	3.66[a]	4.37[a]	4.77[a]	No changes
Fully adjusted[†]	2.48[b]	3.42[b]	4.49[b]	4.32[b]	**Autism only < Autism+REDs no longer significant** **Additional significance:** **Autism+REDs < REDs only:** Mean difference = -1.04, ***p* = .001**, 95% CI [-1.76–(-.32)]

Note. [†]Assumption of homogeneity of variance not met (see Table 1, Appendix 13).
[a] Covariate is evaluated at the following value: Age (years) = 32.22.
[b] Covariates are evaluated at the following values: Age (years) = 32.22, HADS depression = 9.62, HADS anxiety = 13.86, SPIN total = 40.16.

There were significant differences between ‘Autism only’ and the three RED groups for all subscales of the EDE-Q, with ‘Autism only’ scoring lower than the other three groups on all subscales. In addition, ‘Autism+REDs’ scored significantly lower than ‘REDs high autistic traits’ on all subscales. ‘Autism+REDs’ also scored significantly lower than ‘REDs only’ on the EDE-Q eating concern and EDE-Q shape concern subscale, but not on the restraint and weight concerns subscales. The majority of effect sizes for these group difference were large, with some medium effect sizes (see Table 15).

Impact of adjustment on main effects and group differences on EDE-Q subscales. Main effects were maintained in the partially and fully adjusted model, apart from the main effect of subscale for the EDE-Q, which was no longer significant in the fully adjusted model (see Table 15). This suggests that differences between subscale scores across the sample were in part driven by differences in co-occurring mental health difficulties. Unadjusted mean scores, estimated means for the adjusted models, post-hoc comparisons between groups for the unadjusted model and changes for the adjusted models for each subscale are presented in Table 15. For individual EDE-Q subscales, the same pairwise comparisons reached significance in the partially adjusted models. In the fully adjusted model, the same pairwise comparisons reached significance for the EDE-Q eating concerns and EDE-Q shape concerns subscale. However, for the EDE-Q restraint subscale the difference between ‘Autism+REDs’ and ‘REDs high autistic traits’ was no longer significant, and for the EDE-Q weight concerns subscale the difference between ‘Autism only’ and ‘Autism+REDs’ was no longer significant. Instead, ‘REDs only’ scored significantly higher than ‘Autism+REDs’ on the EDE-Q restraint and weight concerns subscales in the fully adjusted model.

Group Differences in Autism-Specific Unusual Eating Behaviours

In this section, group comparisons of SWEAA total scores, measuring overall autism-specific unusual eating behaviours are presented, followed by group comparisons for individual SWEAA subscales. The impact of covariates on main effects of group and any changes to significance levels of post-hoc comparisons are highlighted.

SWEAA total. Table 16 presents mean SWEAA total scores for each group, estimated means after adjustments, F statistics, post-hoc comparisons for the unadjusted model, and changes for adjusted models.

Table 16

Mean SWEAA total scores for each group, estimated mean scores after adjustments, and F statistic. The table also shows post-hoc comparisons for the unadjusted model and changes for the adjusted model.

Measure	Model	Mean (SD) /Estimated Mean After Adjustment				Statistical Result	Significant Post-hoc Comparisons in Unadjusted Model and Changes for Adjusted Model
		Autism only (n = 47)	**Autism+ REDs (n = 51)**	**REDs only (n = 76)**	**REDs high autistic traits (n = 36)**		
SWEAA total	Unadjusted	31.47 (12.15)	50.31 (11.09)	36.86 (12.55)	50.43 (9.89)	$F(3, 206)= 32.14$, ***p* < .001**, $\eta^2 = .319$	Hochberg's GT2: **Autism only < Autism+REDs** Mean difference = 18.84, ***p* < .001**, *g* = 1.623, 95% CI[12.56–25.12] **Autism+REDs > REDs only** Mean difference = 13.46, ***p* < .001**, *g* = 1.122, 95% CI [7.83–19.08]. **Autism only < REDs high autistic traits**

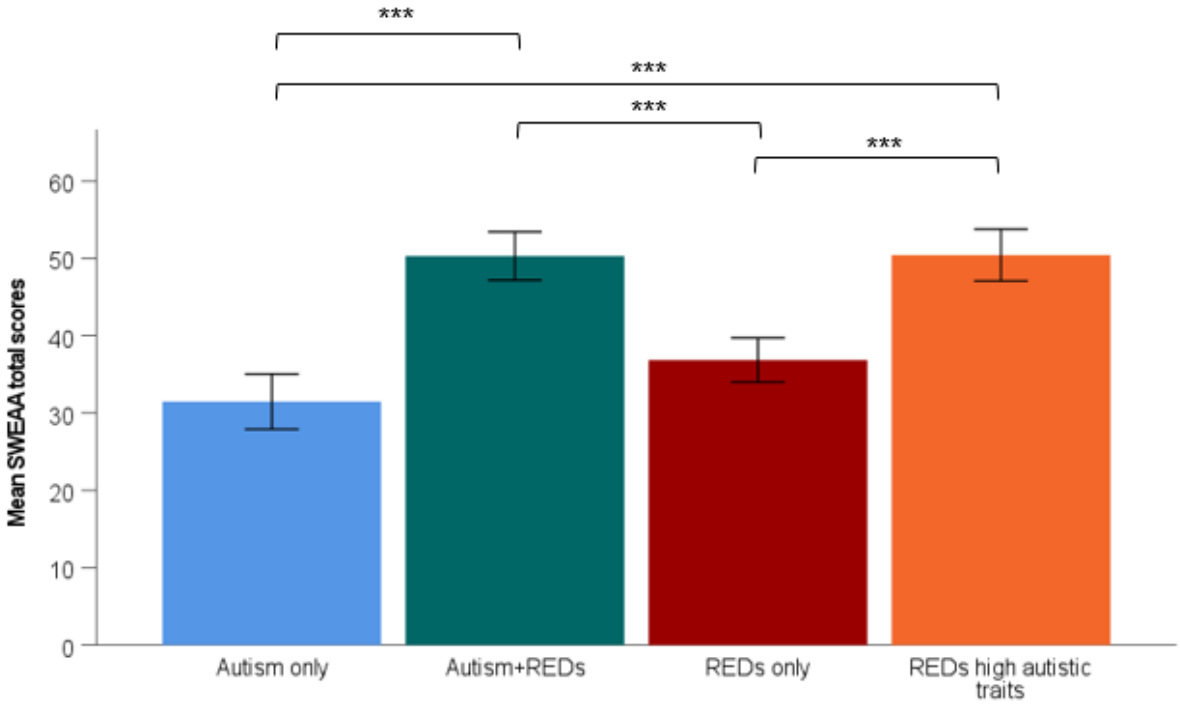
						Mean difference = 18.96, ***p* < .001**, *g* = 1.688, 95% CI [12.08–25.84]. **REDs only < REDs high autistic traits** Mean difference = -13.57, ***p* < .001**, *g* = 1.153, 95% CI [-19.86–(-7.29)]
Partially adjusted	30.73[a]	50.46[a]	37.14[a]	50.61[a]	*F*(3, 205) = 32.91, ***p* < .001**, η^2_p = .325	Additional significance: **Autism only < REDs only** Mean difference = 6.41, ***p* = .032**, 95% CI [-12.49–(-.34)].
Fully adjusted	34.78[b]	48.54[b]	37.83[b]	46.58[b]	*F*(3, 202) = 16.37, ***p* < .001**, η^2_p = .196	No changes

Note. [a] Covariate is evaluated at the following value: Age (years) = 32.22.
[b] Covariates are evaluated at the following values: Age (years) = 32.22, HADS depression = 9.62, HADS anxiety = 13.86, SPIN total = 40.16.

As shown in Table 16, there was a significant effect of group on SWEAA total scores, (F(3,206) = 32.14, p < .001, η^2 = .319). Figure 10 presents unadjusted means for SWEAA total scores for each group with indication of significant post-hoc differences.

Figure 10

Unadjusted mean scores for each group and significant group differences for SWEAA total scores



Note. Error bars indicate 95% CI. Significant post-hoc differences: ***p ≤ .001.

Post-hoc tests revealed that ‘Autism only’ and ‘REDs only’ both had significantly lower SWEAA total scores than ‘Autism+REDs’ and ‘REDs high autistic traits’ (indicating fewer autism-related unusual eating behaviours). These group differences had large effect sizes.

The overall effect of group was maintained in the partially adjusted (F(3, 205) = 41.38, p < .001, η^2_p = .377) and the fully adjusted model (F(3, 202) = 28.54, p <

.001, η^2_p = .298). The effect size for all three models was large, but became slightly smaller with more adjustments. The same post-hoc comparisons reached significance in the partially and fully adjusted models. In addition, in the partially adjusted model the estimated mean SWEAA total score for the 'Autism only' group was significantly smaller than the estimated mean for the 'REDs only' group.

SWEAA subscales. In addition to SWEAA total scores, patterns in responses across SWEAA subscales were assessed to explore potential drivers for autism-specific unusual eating behaviours in autistic women with REDs.

Box's test of equality of covariance was violated (Box's *M* = 2000.93, *F*(135, 61188.06) = 1.363, *p* = .003). According to Levene's test (see Table 1, Appendix 13), the assumption of quality of variance for individual subscale scores was met for all subscales, apart from SWEAA motor control, SWEAA purchase of food, SWEAA disturbed eating behaviour. Mauchly's test indicated that the assumption of sphericity had been violated (χ^2(35) = 319.19, *p* < .001); therefore, Greenhouse-Geisser corrections were applied (ε = .70).

Unadjusted and adjusted main effects for subscale, group and interaction of subscale by group for SWEAA subscales are presented in Table 17.

Table 17

Mixed-design ANOVA main effects of subscale, group, and interaction for SWEAA subscales in the unadjusted, partially and fully adjusted model

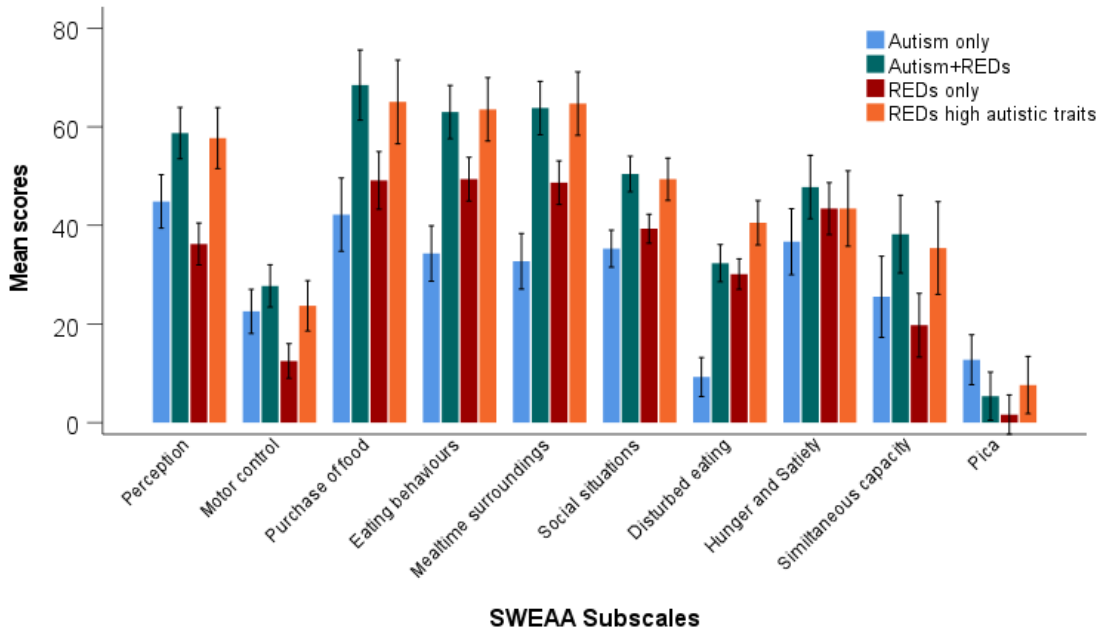
Measure	Mein effect	Model	Statistical Result
SWEAA subscales	Subscale	Unadjusted	*F*(5.56, 2246.20) = 101.90, **p < .001**, η^2 = .331
		Partially adjusted	*F*(5.55, 1137.93) = 7.345, **p < .001**, η^2_p = .034
		Fully adjusted	*F*(5.85, 1107.35) = 4.74, **p = .031**, η^2_p = .023

Group	Unadjusted	$F(3, 206) = 27.29$, $\boldsymbol{p < .001}$, $\eta^2 = .284$
	Partially adjusted	$F(3, 205) = 28.02$, $\boldsymbol{p < .001}$, $\eta^2_p = .291$
	Fully adjusted	$F(3, 202) = 13.81$, $\boldsymbol{p < .001}$, $\eta^2_p = .170$
Subscale by group	Unadjusted	$F(16.69, 1146) = 6.206$, $\boldsymbol{p < .001}$, $\eta^2 = .083$
	Partially adjusted	$F(16.65, 1137.93) = 6.15$, $\boldsymbol{p < .001}$, $\eta^2_p = .083$
	Fully adjusted	$F(5.85, 1107.35) = 4.86$, $\boldsymbol{p < .001}$, $\eta^2_p = .064$

The pattern of unadjusted mean scores for SWEAA subscales by group is presented in Figure 11. Pattern of subscale scores on the SWEAA varied between groups.

Figure 11

Subscale scores for SWEAA subscales by group



Note. Error bars indicate 95% CI.

There was a significant main effect of subscale on SWEAA subscale scores ($F(5.56, 2246.20) = 101.90$, $p < .001$, $\eta^2_p = .331$), a significant main effect of group ($F(3, 206) = 27.29$, $p < .001$, $\eta^2_p = .284$), and a significant interaction effect between subscale and group ($F(16.69, 1146) = 6.206$, $p < .001$, $\eta^2_p = .083$). This indicates that there were differences between subscales across groups, and between groups across subscales, and that groups had different patterns of scores across SWEAA subscales.

Post-hoc pairwise comparisons of groups for each SWEAA subscale are presented in Table 18.

Table 18

Mean SWEAA subscale scores and estimated mean scores after adjustment. The table also shows post-hoc comparisons for the unadjusted model and changes for the adjusted model.

Measure	Model	Mean (SD) /Estimated Mean After Adjustment				Significant Pairwise Comparisons with Bonferroni Adjustment for Multiple Comparison.
		Autism only (n = 47)	**Autism+ REDs (n = 51)**	**REDs only (n = 76)**	**REDs high autistic traits (n = 36)**	
SWEAA perception	Unadjusted	44.87 (20.56)	58.73 (18.59)	36.24 (18.73)	57.70 (16.96)	**Autism only < Autism+REDs:** Mean difference = -13.86, **p = .002**, *g* = .673, 95% CI [-24.01–(-3.71)] **Autism+REDs > REDs only:** Mean difference = 22.49, ***p* < .001**, *g* = 1.204, 95% CI [13.41–31.57] **Autism only < REDs high autistic traits:** Mean difference = -12.83, ***p* = .014**, *g* = .631, 95% CI [-23.94–(-1.71)] **REDs only < REDs high autistic traits:**

						Mean difference = -21.46, ***p* < .001**, *g* = 1.180, 95% CI [-31.61–(-11.31)]
	Partially adjusted	43.96[a]	58.91[a]	36.58[a]	57.91[a]	No change
	Fully adjusted	48.31[b]	56.13[b]	37.67[b]	52.59[b]	**Autism only < Autism+REDs no longer significant** **Autism only < REDs high autistic traits no longer significant** **Additional significance:** **Autism only > REDs only:** Mean difference = 11.65, ***p* = .010**, 95% CI [1.94–21.36]
SWEAA motor control	Unadjusted[†]	22.57 (16.21)	27.73 (20.07)	12.51 (10.49)	23.71 (16.22)	**Autism only > REDs only:** Mean difference = 10.06, ***p* = .004**, *g* = .776, 95% CI [2.38–17.73] **Autism+REDs > REDs only:** Mean difference = 15.22, ***p* < .001**, *g* = 1.010, 95% CI [7.73–22.71] **REDs only < REDs high autistic traits:** Mean difference = -11.20, ***p* = .003**, *g* = .889, 95% CI [2.83–19.57]
	Partially adjusted[†]	23.16[a]	27.62[a]	12.29[a]	23.57[a]	No change
	Fully adjusted[†]	25.86[b]	26.52[b]	12.65[b]	20.85[b]	**REDs only < REDs high autistic traits no longer significant**

SWEAA purchase of food	Unadjusted†	42.20 (25.14)	68.46 (23.76)	49.12 (21.06)	65.05 (20.30)	**Autism only < Autism+REDs:** Mean difference = -26.27, ***p* < .001**, *g* = 1.075, 95% CI [-40.18–(-12.36)] **Autism only < REDs high autistic traits:** Mean difference = -22.85, ***p* = .001**, *g* = .986, 95% CI [-38.08–(-7.61)] **Autism+REDs > REDs only:** Mean difference = 19.34, ***p* < .001**, *g* = .872, 95% CI [6.89–31.79] **REDs high autistic traits> REDs only:** Mean difference = 15.92, ***p* = .016**, *g* = .765, 95% CI [2.01–29.84]
	Partially adjusted†	41.41[a]	68.62[a]	49.42[a]	65.23[a]	No change
	Fully adjusted	44.76[b]	66.42[b]	50.96[b]	60.72[b]	**Autism only < REDs high autistic traits no longer significant** **REDs only < REDs high autistic traits no longer significant**
SWEAA eating behaviour	Unadjusted	34.31 (19.16)	62.99 (17.87)	49.40 (21.06)	63.54 (19.14)	**Autism only < Autism+REDs:** Mean difference = -28.68, ***p* < .001**, *g* = 1.550, 95% CI [-39.23–(-18.14)] **Autism only < REDs only:**

						Mean difference = -15.09, ***p* < .001**, *g* = .741, 95% CI [-24.76–(-5.41)] **Autism only < REDs high autistic traits:** Mean difference = -29.23, ***p* < .001**, *g* = 1.526, 95% CI [-40.78–(-17.68)] **Autism+REDs > REDs only:** Mean difference = 13.59, ***p* = .001**, *g* = .685, 95% CI [4.16–23.03] **REDs only < REDs high autistic traits:** Mean difference = -14.15, ***p* = .003**, *g* = .691, 95% CI [-24.70–(-3.60)]
	Partially adjusted	31.75[a]	63.49[a]	50.36[a]	64.14[a]	No change
	Fully adjusted	36.04[b]	61.93[b]	50.49[b]	60.48[b]	**REDs only < REDs high autistic traits no longer significant**
SWEAA mealtime surroundings	Unadjusted	32.74 (19.77)	63.81 (16.52)	48.68 (22.20)	64.70 (17.47)	**Autism only < Autism+REDs:** Mean difference = -31.08, ***p* < .001**, *g* = 1.712, 95% CI [-41.64–(-20.51)] **Autism only < REDs only:** Mean difference = -15.95, ***p* = .001**, *g* = .748, 95% CI [-25.64–(-6.25)] **Autism only < REDs high autistic traits:** Mean difference = -31.97, ***p* < .001**, *g* = 1.699, 95% CI [-43.55–(-20.40)]

						Autism+REDs > REDs only: Mean difference = 15.13, ***p* < .001**, *g* = .752, 95% CI [5.67–24.59] **REDs only < REDs high autistic traits:** Mean difference = -16.03, ***p* < .001**, *g* = .770, 95% CI [-26.60–(-5.45)]
	Partially adjusted	31.58[a]	64.04[a]	49.12[a]	64.98[a]	No change
	Fully adjusted[†]	37.86[b]	60.32[b]	50.94[b]	58.22[b]	**REDs only < REDs high autistic traits no longer significant**
SWEAA social situations at mealtime	Unadjusted	35.28 (11.39)	50.44 (13.56)	39.34 (13.36)	49.38 (13.46)	**Autism only < Autism+REDs:** Mean difference = -15.15, ***p* < .001**, *g* = 1.206, 95% CI [-22.16–(-8.14)] **Autism+REDs> REDs only:** Mean difference = 11.10, ***p* < .001**, *g* = .826, 95% CI [4.82–17.37] **Autism only < REDs high autistic traits:** Mean difference = -14.09, ***p* < .001**, *g* = 1.144, 95% CI [-21.77–(-6.41)] **REDs only < REDs high autistic traits:** Mean difference = -10.03, ***p* = .001**, *g* = .750, 95% CI [-17.05–(-3.02)]
	Partially adjusted	34.40[a]	50.62[a]	39.68[a]	49.58[a]	No change

	Fully adjusted	36.79[b]	50.21[b]	39.29[b]	47.85[b]	No changes
SWEAA other disturbed eating behaviours	Unadjusted†	9.26 (9.70)	32.35 (12.97)	30.14 (12.91)	40.54 (19.64)	**Autism only < Autism+REDs:** Mean difference = -23.09, ***p* < .001**, *g* = 2.004, 95% CI [-30.48–(-15.70)] **Autism only < REDS only:** Mean difference = -20.88, ***p* < .001**, *g* = 1.771, 95% CI [-27.66–(-14.10)] **Autism only < REDs high autistic traits:** Mean difference = -31.28, ***p* < .001**, *g* = 2.108, 95% CI [-39.37–(-23.18)] **Autism+REDs < REDs high autistic traits:** Mean difference = -8.19, ***p* = .040**, *g* = .510, 95% CI [-16.14–(-.23)] **REDs only < REDs high autistic traits:** Mean difference = -10.40, ***p* = .001**, *g* = .676, 95% CI [-17.79–(-3.01)]
	Partially adjusted†	9.20[a]	32.37[a]	30.16[a]	40.55[a]	No changes
	Fully adjusted†	12.63[b]	30.76[b]	30.79[b]	37.04[b]	**Autism+REDs < REDs high autistic traits no longer significant** **REDs only < REDs high autistic traits no longer significant**

SWEAA hunger and satiety	Unadjusted	36.70 (26.25)	47.79 (22.74)	43.42 (22.68)	43.43 (20.85)	No significant differences
	Partially adjusted	37.11[a]	47.72[a]	43.27[a]	43.34[a]	No changes
	Fully adjusted	40.05[b]	47.16[b]	42.9[b]	41.05[b]	No changes
SWEAA simultaneous capacity	Unadjusted	25.53 (28.78)	38.24 (30.96)	19.76 (25.98)	35.42 (30.10)	**Autism+REDs > REDs only:** Mean difference = 18.47, ***p* = .003**, *g* = .661, 95% CI [4.69–32.26] **REDs only < REDs high autistic traits:** Mean difference = -15.65, ***p* = .044**, *g* = .572, 95% CI [-31.06–(-.24)]
	Partially adjusted	23.98[a]	38.54[a]	20.35[a]	35.78[a]	No changes
	Fully adjusted	28.96[b]	36.04[b]	21.15[b]	31.13[b]	**REDs only < REDs high autistic traits no longer significant**

Note. [†]Assumption of homogeneity of variance not met (see Table 1, Appendix 13).

[a] Covariate is evaluated at the following value: Age (years) = 32.22.

[b] Covariates are evaluated at the following values: Age (years) = 32.22, HADS depression = 9.62, HADS anxiety = 13.86, SPIN total = 40.16.

On almost all SWEAA subscales, either ‘Autism+REDs’ or ‘REDs high autistic traits’ scored highest, generally without statistically significant differences between these groups. The only exception was the SWEAA other disturbed eating behaviour subscale, on which ‘REDs high autistic traits’ scored significantly higher than ‘Autism+REDs.’

Both ‘Autism only’ and ‘REDs only’ scored significantly lower than the other two groups on the SWEAA perception, SWEAA purchase of food, SWEAA eating behaviour, SWEAA mealtime surroundings, and the SWEAA social situation subscales. For the SWEAA perception, SWEAA purchase of food, and SWEAA social situation subscales ‘Autism only’ and ‘REDs only’ scored similarly, whereas ‘REDs only’ scored significantly higher than ‘Autism only’ on the SWEAA eating behaviour and SWEAA mealtime surroundings subscales.

On the SWEAA motor control subscale, ‘Autism only’ scored similarly to ‘Autism+REDs’ and ‘REDs high autistic traits,’ and ‘REDs only’ scored significantly lower than the other three groups.

On the SWEAA other disturbed eating behaviour subscale, ‘REDs only’ scored similarly to ‘Autism+REDs,’ but significantly lower than ‘REDs high autistic traits.’ ‘Autism only’ scored significantly lower than all three other groups on this subscale.

On the SWEAA hunger and satiety subscale, there were no statistically significant differences between any of the groups.

On the SWEAA simulations capacity subscale, ‘Autism only’ scored similarly to ‘Autism+REDs’ and ‘REDs high autistic traits.’ ‘REDs only’ scored significantly lower than ‘Autism+REDs’ and ‘REDs high autistic traits,’ but not significantly lower than ‘Autism only.’

The majority of effect sizes for these group differences were large, with some medium effect sizes (see Table 18).

Impact of adjustment on main effects and group difference on SWEAA subscales. Main effects were maintained in the partially and fully adjusted model. Unadjusted mean scores, estimated means for the adjusted models, post-hoc comparisons between groups for the unadjusted model and changes for the adjusted models for subscale are presented in Table 18. For individual SWEAA subscales, the same pairwise comparisons reached significance in the partially adjusted model for all subscales. For the SWEAA hunger and satiety and SWEAA social situations at mealtime subscales, pairwise comparisons also did not change significance in the fully adjusted models. For the remaining subscales, there were some changes in the fully adjusted model. For the SWEAA motor control, SWEAA purchase of food, SWEAA other eating behaviours, SWEAA mealtime surroundings, SWEAA other disturbed eating behaviours, and SWEAA simultaneous capacity subscales, the difference between 'REDs high autistic traits' and 'REDs only' was no longer significant. In addition, for the SWEAA other disturbed eating behaviours subscale, the difference between 'Autism+REDs' and 'REDs high autistic traits' was also no longer significant. For the SWEAA purchase of food and SWEAA perception subscales, the difference between 'Autism only' and 'REDs high autistic traits' was no longer significant. For the SWEAA perception subscale, the difference between 'Autism only' and 'Autism+REDs' was also no longer significant. However, in the fully adjusted model 'Autism only' scored significantly higher than 'REDs only' on the SWEAA perception subscale.

SWEAA pica subscale. The SWEAA pica subscale was analysed separately using a non-parametric test due to non-normality (see above, Chapter 3, for details

on assessment of normality). The scores of all groups were heavily skewed, with the majority of participants scoring zero on this subscale. Table 19 presents descriptive statistics and group comparison for the SWEAA pica subscale by group.

Table 19

Descriptive statistics and group comparison for the SWEAA pica subscale

	'Autism only' (n = 47)	**'Autism+REDs'** (n = 51)	**'REDs only'** (n = 76)	**'REDs high autistic traits'** (n = 36)	**Group Comparison**
Mean (SD)	12.77 (27.52)	5.39 (17.55)	1.64 (8.50)	7.64 (15.61)	$H(3) = 11.270$, $\mathbf{p = 0.010}$

A Kruskal-Wallis H test showed that there were statistically significant differences in SWEAA pica subscale scores between groups ($H(3) = 11.270$, $p = .010$). Post-hoc pairwise comparison revealed that this was driven by the following group differences: 'REDs only' scored significantly lower than 'REDs high autistic traits' ($p = .010$) and 'Autism only' ($p = .004$). We did not re-run this analysis controlling for age and levels of other co-occurring conditions.

Discussion

The current chapter describes and compares the demographics and background variables of participants in Study 2, as well as their presentation of autistic traits and disordered eating-related symptoms. This situates the sample and allows us to gain a better understanding of the clinical presentation of autistic women with REDs. Thus, the current chapter provides initial insights into the validity of the theoretical model presented in Chapter 2.

Autistic women with REDs ('Autism+REDs') were compared to autistic women without REDs ('Autism only'), and non-autistic women with REDs ('REDs only'), with these comparison groups having been planned a priori. In addition, in the course of

the study we identified a fourth group, women with REDs and high autistic traits but no autism diagnosis (‘REDs high autistic traits’), who were also included in the analyses. We repeated each analysis controlling for differences in age and levels of co-occurring mental health difficulties to determine whether these differences affect the presentation of autistic traits and disordered eating between groups.

With regard to the level and nature of autistic traits in autistic women with REDs, the ‘Autism+REDs’ group presented similarly to ‘Autism only’ in terms of their autistic traits, and the levels of autistic traits were significantly higher in both autism groups compared to ‘REDs only’. With regard to traditional disordered eating-symptoms, ‘Autism+REDs’ presented with lower overall symptoms, as well as lower shape, but not weight concerns, than ‘REDs only’. They also presented with significantly lower eating concerns (i.e., preoccupation with eating, fear of losing control, and feelings of shame and guilt around eating; EDE-Q; Fairburn & Beglin, 2008). Differences in the presentation of traditional disordered eating symptoms between ‘Auitms+REDs’ and ‘REDs only’ became more distinct after controlling for differences in co-occurring mental health difficulties. With regard to autism-specific unusual eating disorder symptoms, ‘Auitsm+REDs’ presented with significantly higher levels than both ‘Autism only’ and ‘REDs only’.

The ‘REDs high autistic traits’ group, despite comprising people without a formal autism diagnosis, resembled ‘Autism+REDs’ in terms of their presentation of autistic traits and autism-specific unusual eating behaviours. After controlling for differences in co-occurring mental health difficulties, these traits and behaviours were slightly lower in ‘REDs high autistic traits’ than in ‘Autism+REDs,’ but still significantly higher than in ‘REDs only’. The ‘REDs high autistic traits’ group

presented with high levels of traditional disordered eating symptoms, significantly higher than in ‘Autism+REDs’ and similar to those in ‘REDs only.’

The clinical presentation of both the ‘Autism+REDs’ and ‘REDs high autistic traits’ group appeared particularly complex, with a combination of autistic traits, traditional disordered eating symptoms, and additional autism-specific unusual eating behaviours, as well as high levels of co-occurring mental health difficulties.

Autistic Traits in Autistic Women with REDs

This the first study to compare autistic traits in autistic women with and without REDs and non-autistic women with REDs. We hypothesised that ‘Autism+REDs’ would score higher on measures of autistic traits than ’Autism only’, but did not find evidence to support this. Both autism groups (‘Autism only’) and ‘Autism+REDs’) presented with similar levels of autistic traits, proportion of autistic traits present in childhood. The lack of difference in autistic traits between the two autism groups suggests that core autism characteristics are unlikely to directly contribute to REDs in autistic women. Instead, as suggested in Chapter 2, there might be other autism-related difficulties which may make some autistic women more vulnerable to developing REDs than others.

Contrary to our hypothesis, there were no significant differences in reported levels of camouflaging behaviours between ‘Autism+REDs’ and ‘Autism only’. However, levels of camouflaging behaviours were high in both autism groups (mean Cat-Q: ‘Autism only’ = 121, ‘Autism+REDs’ = 131) compared to autistic women from community samples in other studies (e.g., mean CAT-Q=114 in Hull et al., 2021). Indeed, negative effects of high levels of camouflaging behaviours that were anticipated in ‘Autism+REDs’ can be observed in both autism groups. Camouflaging is thought to relate to late autism diagnoses (Bargiela et al., 2016; Tierney et al.,

2016) and has been associated with higher levels of co-occurring mental health difficulties (Cassidy et al., 2018; Hull et al., 2021). Participants in both autism groups typically received their autism diagnosis in adulthood, and their mean scores for current levels of anxiety were in the high range.

As expected, 'REDs only' presented with significantly lower levels of autistic traits than the two autism groups, which is in line with findings from Kerr-Gaffney et al. (2021), who found that females with AN tended to score lower than autistic females on autism measures. Importantly, 'REDs only' also presented with a lower RAADS childhood ratio, suggesting that, of the autistic traits they did report, fewer traits had been present in their childhood. Thus, the current study demonstrates that non-autistic women with REDs not only present with lower levels of autistic traits, but also that the nature of these traits are likely to be distinct from those of autistic women. It should be noted that levels of autistic traits in 'REDs only' were comparable to AN samples in other studies, even though we excluded participants with very high autistic traits from this group (see Westwood et al., 2016 for meta-analysis of AQ scores in AN samples). This supports the sampling strategy employed in the current study, as it suggests that 'REDs only' are representative of women with REDs in ED services.

The similarity of autism presentation of autistic women with and without REDs, in combination with lower levels of autistic traits in 'REDs only,' supports the suggestion that the effect of starvation and superficial similarities between autism and REDs cannot explain the high proportion of women who present as autistic in ED settings (Westwood et al., 2017b). This is also supported by the lack of correlation between autistic traits and BMI in all three RED groups ('Autism+REDs,' 'REDs high autistic traits,' and 'REDs only'), which suggests that among individuals

with REDs, those who have a lower BMI do not necessarily present with more autistic traits. This accords with past research suggesting autistic traits in adults with AN are independent of BMI and persist in individuals recovered from AN (Kerr-Gaffney et al., 2021). However, BMI is only a proxy measure for state of starvation (Gutin, 2018). Prospective longitudinal studies are needed to explore the impact of starvation on presentation of autistic traits. Another potential avenue for future research could be studying the impact of refeeding in inpatient settings on autistic traits.

Traditional Disordered Eating Symptoms in Autistic Women with REDs

We predicted that 'Autism+REDs' would present with significantly lower levels of traditional disordered eating symptoms than 'REDs only', which was supported by our findings. Mean EDE-Q global scores in the 'Autism+REDs' group were midway between 'Autism only' and 'REDs only'. This means that, although potentially less severe, some traditional disordered eating symptoms still present in autistic women with REDs. We also predicted that lower levels of traditional disordered eating symptoms in 'Autism+REDs' would be driven by lower weight and shape concerns. This was partially supported. Looking at EDE-Q subscales, 'Autism+REDs' scored significantly lower than 'REDs only' on the eating and shape concerns subscale, but not the restraint and weight concerns subscale. After controlling for differences in co-occurring mental health difficulties, which were significantly higher in 'Autism+REDs', traditional eating disorder symptoms in the 'Autism+REDs' and 'REDs only' group became more distinct, and there were also significant differences for the restraint and weight concerns subscale. This suggests that the presence of co-occurring mental health difficulties may have elevated traditional disordered eating symptoms in autistic women with REDs.

This variation in the presentation of traditional disordered eating symptoms between groups is in line with others' findings of high within-group heterogeneity in symptom presentation among individuals with AN, including a subgroup without over-evaluation of weight and shape concerns (Dalle Grave et al., 2008), also conceptualised as a non-fat-phobic AN presentation (Carter & Bewell-Weiss, 2011; Korn et al., 2020; Wildes et al., 2013). Our findings suggest that autistic individuals might be overrepresented among this subgroup, although autistic women with REDs might differ in terms of shape concerns, i.e. body image issues, more so than weight concerns, i.e. fear or weight gain or desire to lose weight.

In the ED literature, weight and shape concerns are often conceptualised as being interlinked, in that a desire to have low body weight is thought to be driven by body image issues (Gowers & Shore, 2001; Taylor, 2016). However, they could also exist independently. For example, shape concerns might be driven by body image issues related to feeling pressure to fit in with perceived social expectations (Goodman, 2005; McLean & Paxton, 2019), whereas weight concerns could also be linked to a need for control or fear of change, unrelated to body image issues. The current findings suggest that this could be the case in autistic women with REDs, which may explain why they presented with lower shape concerns but not weight concerns. In our qualitative study (Chapter 2), autistic women with AN described that they controlled their weight because of a desire for numbers on the scale to fit into a pattern, to introduce predictability into their lives, or because they noticed that they are less overwhelmed by their emotions when their body weight was low (Chapter 2, Brede et al., 2020). Future research should confirm the pattern of group difference suggested by the current findings and include independent, detailed measures of drivers associated with weight and shape concerns.

An unexpected finding was that ‘Autism+REDs’ presented with significantly lower scores on the EDE-Q eating concern subscale (EDE-Q REF), than ‘REDs only’. This subscale contains items related to preoccupation with eating, fear of losing control, and feelings of shame and guilt around eating. Based on our qualitative findings (Chapter 2), one would have expected preoccupation with eating and fear of losing control to be similar, if not higher, in autistic compared to non-autistic women with REDs, due to obsessive thinking styles and an autism-related need for control and predictability.

There are several potential explanations for this finding.

Fear of losing control and shame as captured by this subscale could be driven by an underlying worry about getting fat, linked to shape concerns. Thus, fear of losing control and associated shame or guilt may be less of an issue for autistic women given shape concerns are also less pronounced for this group.

Lower levels of eating concerns in autistic women with REDs may also be explained by a difference in the function their REDs fulfil. Our qualitative findings (Chapter 2) suggest that autistic women restrict their eating to reduce stressors in their life and cope with autism-related difficulties. Autistic women’s restrictive eating appears to be motivated by the associated effects of restriction, rather than the desire to reduce their food intake itself. Therefore, they might be less occupied with thoughts about food and eating, less worried about losing control around eating, and feel less shame and guilt around eating.

Another potential explanation could be that eating concerns, particularly shame and guilt around eating, are in part driven by social comparison and perceived social pressures (Connan et al., 2007), which could be less pronounced in autistic women. Although autistic women in our qualitative study felt difficulties with

social relationships and their sense of self had contributed to the development of their REDs, these might be qualitatively distinct, and may not result in the same levels of shame and guilt around eating as experienced by other women with REDs (Blythin et al., 2020).

Finally, the presence of additional autism-specific factors contributing to restrictive eating behaviours in autistic women may prevent the development of eating concerns in this group. For example, some autistic women may be less preoccupied with food or worry less about losing control around eating, because interoceptive difficulties and sensory aversion to food characteristics mean they notice hunger less or find food less appealing in the first place.

The presentation of eating concerns and related factors, such as cognitive styles, need for control and predictability, and susceptibility to social pressures requires further investigation.

One limitation of the current study was that we did not include an independent measure of ED severity. Thus, lower overall levels of traditional disordered eating symptoms in the 'Autism+REDs' group compared to 'REDs only', could be interpreted as RED presentation in 'REDs only' being more severe. However, 'Autism+REDs' and 'REDs only' were similar on a number of clinical characteristics (e.g., age of onset of eating disorder, BMI, and proportion of participants who have accessed inpatient treatment), which suggests that their ED presentations are similar in terms of their severity. They also scored similarly on the disturbed eating subscale of the SWEAA, which assesses levels of disordered eating behaviours, without assuming the drivers for these behaviours. Nonetheless, future research should include independent measures of the EDs' impact on functioning or wellbeing, or

could use more narrow inclusion criteria (i.e., only recruiting individuals currently accessing ED treatment), to ensure similarity in groups' ED severity.

Autism-specific Unusual Eating Behaviours in Autistic Women with REDs

In line with our hypothesis, 'Autism+REDs' presented with higher levels of autism-related unusual eating behaviours than both 'Autism only' and 'REDs only.' The fact that 'Autism+REDs' presented with high levels of autism-specific unusual eating behaviours in addition to traditional disordered eating symptoms suggests that autistic women's RED presentations are particularly complex and have autism-specific features.

The comparison of the 'Autism only,' 'Autism+REDs,' and 'REDs only' groups on SWEAA subscales gives insight into which specific autism-related eating behaviour might be driving this group difference. The subscales, on which 'Autism+REDs' scored higher than both other groups, map onto three different constructs, which could be of relevance for REDs in autistic people. Firstly, the SWEAA perception subscale focuses on preference and avoidance of food with certain sensory properties, such as the taste, smell, and texture of food. Sensory sensitivities are common in autistic individuals (Ben-Sasson et al., 2019), and have been linked to fussy eating in autistic children (Hubbard et al., 2014). Secondly, the SWEAA purchase of food, eating behaviour and mealtime surroundings subscales all relate to intolerance of uncertainty and a need for sameness, which is characteristic of autistic people (Goris et al., 2020; Vasa et al., 2018). Finally, the SWEAA social situation subscale relates to the social environment and social interactions during mealtime. Social communication differences are a core feature of autism (APA, 2013). It is possible that autistic individuals who have had negative social experiences during mealtimes, or who struggle with social norms during

mealtimes, might develop unusual eating behaviours as a consequence. Sensory sensitivities, intolerance of uncertainty, and difficulties with social interaction and relationships are all included in our proposed model of an autism-specific mechanism underlying restrictive eating difficulties (Chapter 2; Brede et al., 2020). Thus, these factors present promising candidates for future investigation as potential contributing factors to REDs in autistic women.

It should be noted that after controlling for differences in co-occurring mental health difficulties, scores on the SWEAA perception subscale were similar for the two autism groups, and significantly lower in the 'REDs only' group. This suggests that strong preference for and avoidance of food with certain sensory properties interact with co-occurring mental health difficulties, which were particularly high in 'Autism+REDs,' and that sensory preference and avoidance could be related to being autistic, rather than being specific to RED presentations in autistic women. Further research is needed to confirm whether strong preference for and avoidance of food with certain sensory properties are specific to autistic women with REDs, and could therefore play a causal role in the development and maintenance of their REDs.

Overlap with ARFID

The fact that disordered eating symptoms traditionally associated with AN were less prominent in autistic women with REDs, but that they instead presented with high levels of autism-specific unusual eating behaviours driven in part by factors such as sensory sensitivities, suggests that their REDs presentations could resemble ARFID, which is by definition not driven by body weight or shape concerns (APA, 2013; Becker et al., 2019). There were a small number of ARFID participants in the REDs sample (n = 4), all of whom were in the 'Autism+REDs' group (see Chapter 3).

This supports our prediction that REDs presentations in autistic individuals are less likely to be driven by weight and shape concerns. ARFID is a relatively new diagnosis; it was introduced in the latest DSM 5 (APA, 2013). Prior to this, ARFID would have been captured under feeding and eating difficulties in childhood (Bryant-Waugh et al., 2010; Sharp & Stubbs, 2015), and adults with an ARFID presentation might have been diagnosed as having AN, atypical AN, or an 'eating disorder-not otherwise specified' (APA, 2013). Even though there is growing recognition that ARFID can present across the lifespan (Bourne et al., 2020), it may still be overlooked or misdiagnosed as AN in adult women with low weight (Becker et al., 2018). This might also be the case for some autistic women who receive an AN diagnosis. However, the fact that traditional disordered eating symptoms, including weight and shape concerns, were still elevated in 'Autism+REDs' suggests that differences in RED presentations between autistic and non-autistic women with REDs cannot fully be accounted for by autistic women with REDs being misdiagnosed as AN when really presenting with ARFID.

The Presentation of Women With REDs and High Autistic Traits

Among participants initially recruited as individuals with REDs without a formal autism diagnosis, about one third presented with very high autistic traits ('REDs high autistic traits' group). The similarity in autistic traits and autism-related eating behaviours between this group and formally diagnosed autistic women with REDs suggests that a significant proportion of 'REDs high autistic traits' participants may be undiagnosed autistic women. This is in line with previous findings suggesting undiagnosed autistic individuals are overrepresented in ED settings (Huke et al., 2013; Westwood et al., 2017). In addition, the current findings provide insight into RED presentations of (potentially) undiagnosed autistic women. These presentations

appear to be conditioned by their high levels of autistic traits, as they also present with high levels of autism-specific eating behaviours.

It should be noted that the current study relied on self-report measures of autistic traits, rather than full diagnostic assessments. Thus, it is highly likely that some individuals in the 'REDs high autistic traits' group would not meet full autism diagnostic criteria, despite having elevated traits. Further, after controlling for group differences in levels of co-occurring mental health difficulties, which were similar in 'Autism+REDs' and 'REDs high autistic traits,' autistic traits in 'REDs high autistic traits' were slightly lower than in the two autism groups and their presentation of autism-specific unusual eating behaviours deviated from 'Autism+REDs' on some SWEAA subscales. Emerging differences between 'Autism+REDs' and 'REDs high autistic traits' after controlling for co-occurring mental health difficulties may suggest that autistic traits in 'REDs high autistic traits' participants were qualitatively different to other autistic women, in that they interact with co-occurring mental health difficulties to a greater extent. Careful assessment of their full clinical presentation is therefore needed before concluding that these women meet autism diagnostic criteria.

Disordered eating-related presentations in the 'REDs high autistic traits' group appeared particularly severe and complex, as they presented with both high levels of traditional disordered eating symptoms and autism-specific unusual eating behaviours. Traditional disordered eating symptoms in 'REDs high autistic traits' were significantly higher than in 'Autism+REDs' across all subscales, similar to levels in 'REDs only'. High levels of traditional disordered eating symptoms could be one of the reasons why undiagnosed autistic women are not noted, as clinicians might be less likely to query the presence of co-occurring autism.

Clinical Presentation and Demographics of Autistic Women with REDs

In addition to comparing the presentation of autistic traits and disordered eating-related symptoms between groups, the current chapter also provided an overview of demographics and other clinical background variables of Study 2 participants. These are informative with regard to the generalisability of our findings and provide additional insight into the type of autistic women who might present to ED services and additional difficulties they may experience. Several characteristics of the current sample, and the 'Autism+REDs' group in particular, are worth highlighting.

It is noteworthy that, whilst all participants reported female birth sex, both autism groups included a sizable minority of participants who did not report their gender as female. This finding is not atypical for autism samples; autistic individuals are known to more commonly identify as outside the gender binary and different from birth sex than non-autistic comparison groups (Dewinter et al., 2017). This is important to consider in the context of autistic individuals presenting with REDs, as underlying factors driving REDs might be different for those who identify as gender diverse, and because they might face additional stressors (Bennett & Goodall, 2016) which could complicate their clinical presentation (Hartman-Munick et al., 2021).

On average, participants in both autism groups reported receiving their autism diagnosis in adulthood. This is likely due to the sampling strategy, with autistic women with late diagnosis being known to be particularly responsive to social media research recruitment (Sedgewick et al., 2020). This could limit the generalisability of our sample, as those with late diagnosis might present differently and are likely to face different challenges related to their autism than those whose autism has been recognised since childhood (Bargiela et al., 2016). At the same time, lack of

understanding and support prior to receiving an autism diagnosis is thought to contribute to the development of additional mental health difficulties in autistic adults (Gotham, Brunwasser, et al., 2015). Thus, autistic women in ED settings may be more likely to have received their autism diagnosis in adulthood (Babb et al., 2021). It will be important to improve our understanding of how the timing of women's autism diagnosis could be implicated in RED development, and whether those with earlier diagnosis are equally likely to develop REDs.

Although RED illness duration was significantly longer in the 'Autism+REDs' group, many individuals across the RED groups would be considered to have an enduring or chronic presentation (i.e., illness duration longer than 7 years; Tierney & Fox, 2009). This may have implications for conclusions drawn from the current study. The longer illness duration in 'Autism+REDs' could reflect reduced treatment efficacy in autistic individuals (Nazar et al., 2018; Stewart et al., 2017; Tchanturia et al., 2016). However, RED presentations tend to evolve over time (Treasure et al., 2020), and adults who have had REDs for many years might present differently to those with a more recent onset (Davis et al., 2020). For example, cognitive drivers, such as weight and shape concerns, are known to become less intense in those with enduring presentations (Wildes et al., 2013), whereas entrenched habits and altered reward processing may maintain their RED to a greater extent (Davis et al., 2020; Uniacke et al., 2018). However, the trajectory of disordered eating symptoms over time might be different among autistic women compared to non-autistic women. Anecdotally, some autistic women report that they initially experience no weight and shape concerns, but that these develop over time (e.g., after being exposed to others with AN in treatment settings; see Chapter 2). Thus, it would be of interest to explore RED presentations in autistic women with more recent onset and changes in

RED presentation over time, to confirm the patterns of group differences observed in the current study and to gain a better understanding of factors that might have initially contributed to their RED development.

In addition to higher levels of current co-occurring mental health difficulties, 'Autism+REDs' and 'REDs high autistic traits' also reported significantly more diagnoses of additional mental health difficulties across their lifetime. This further demonstrates that these women's presentation might be particularly complex, but also that there could be a greater risk of misdiagnosis due to diagnostic overlap in these women (Brown et al., 2019). Indeed, several autistic women with REDs specified in their open response box that they disagreed with certain diagnoses, or that diagnoses had been revised after their autism was recognised. This is in line with other autistic adults' experiences of seeking support in autism mental health services (see Chapter 6), and might affect their relationship to ED services (Babb et al., 2021).

Clinical Implications

The findings presented in the current chapter can inform the identification and treatment of autistic women in ED settings. The similarity of the two autism groups in terms of level and nature of autistic traits suggests that their autism and related differences in their skills and abilities are likely to affect autistic women's functioning in ED settings, which should be taken into consideration by ED services. Their autism might make it more difficult for autistic women with REDs to engage with treatment and might create additional challenges in their day-to-day lives, which could increase the complexity of their presentation (see Chapter 6 for systematic review). As for other autistic women, presentation of autism characteristics in autistic women with REDs might deviate from how autism is commonly perceived (Hull et al.,

2020). For example, our study has demonstrated that these women present with high levels of camouflaging behaviour, which might make them seem less autistic, but could be an additional source of stress and exhaustion for these women (Bargiela et al., 2016; Cage & Troxell-Whitman, 2019). Thus, it will be important to train staff in ED settings on female-specific autism presentations (Hull et al., 2020), in order for them to be better able to recognise and support autistic women in their care.

The similarity in presentation of 'REDs high autistic traits' to formally diagnosed autistic women with and without REDs suggests that there is a need to improve identification of potentially undiagnosed autistic women in ED settings, as they are likely to experience similar autism-related issues, and might benefit equally from autism-informed adaptations. Given the challenges of conducting formal diagnostic assessments in currently unwell individuals with REDs (Kinnaird & Tchanturia, 2020), it might be sufficient to rely on the recognition of autistic traits and on accommodating their presence. This supports recent thinking in the autism field, which favours a more dimensional, heterogeneous characterisation of autism over a rigid categorical approach (Happé & Frith, 2020), and could enable more appropriate support for a greater proportion of individuals. The high levels of traditional disordered eating symptoms in the 'REDs high autistic traits' group, as well as the fact that traditional disordered eating symptoms were still elevated in the 'Autism+REDs' group, suggest that clinicians should not only consider the possibility of autism if the individuals disordered eating-related presentation is atypical; instead the presence of additional unusual eating behaviours may indicate autism.

The presence of additional autism-related disordered eating symptoms should be considered for both assessment and treatment. When assessing autistic

individuals' RED presentations, a narrow focus on traditional disordered eating symptoms might overlook or underestimate additional potentially serious eating issues. If treatment only targets more traditional disordered eating symptoms, the persistence of other autism-specific unusual eating behaviours might hinder progress towards recovery or increase risk of relapse. In the current study, the SWEAA (Karlsson et al., 2013) presented itself as a useful measure to identify unusual eating behaviours common among autistic individuals that contribute to eating difficulties of disordered quality in this population. Its clinical utility should be investigated further.

Finally, ED services should consider the presence of additional co-occurring mental health difficulties and how these might interact with autistic traits and disordered eating-related symptoms, particularly in autistic individuals and those with high autistic traits. In the current study, 'Autism+REDs' and 'REDs high autistic traits' presented with particularly high levels of co-occurring mental health difficulties, and changes to group differences after controlling for differences in co-occurring mental health difficulties that mostly affected these groups. It is unclear whether this effect is characteristic of these groups, in that their autism and/or disordered eating presentations interact with mental health difficulties more than in the other groups, or whether this effect could be linked to the levels of co-occurring mental health difficulties experienced, which happened to be highest in these groups. Regardless, the presence of co-occurring mental health difficulties should be carefully considered as an additional factor complicating clinical presentation, both when assessing undiagnosed women with REDs for potential autism and when formulating the presentation of disordered eating-related symptoms.

Conclusion

The current study is the first to explore the clinical presentation of autistic women with REDs. It makes important contributions to the clinical understanding of this population and suggests several avenues for future research. In summary, we established that the level and nature of autistic traits in autistic women with REDs are similar to other autistic women without REDs. This suggests that core autism characteristics themselves are unlikely to directly contribute to RED presentation in autistic women. Instead, there might be other autism-related difficulties that make some autistic women more vulnerable to developing REDs than others. Autistic women with REDs presented with higher levels of autism-related unusual eating behaviours than autistic women without REDs and non-autistic woman with REDs, and these appear to be driven by preference for and avoidance of food with certain sensory properties, intolerance of uncertainty, and social difficulties during mealtimes. These factors present promising candidates for future investigation as potential contributing factors to REDs in autistic women. Another important finding was that autistic women with REDs presented with lower traditional disordered eating symptoms, suggesting they may play less of a role in the development and/or maintenance of their REDs, although they were still elevated compared to autistic women without REDs.

Women with REDs and high autistic traits, but without a formal autism diagnosis, presented similarly to formally diagnosed autistic women with REDs in terms of autistic traits and autism-specific unusual eating behaviours, suggesting that they might represent undiagnosed autistic women.

These findings contribute to a better understanding of autistic traits and disordered eating presentations in autistic women with REDs, and are of value for improving the identification of and support offered to autistic women in ED settings.

Chapter 5: The Role of Sensory Sensitivities in REDs Among Autistic Women

Introduction

One element of the theoretical model of underlying restrictive eating difficulties in autistic individuals, developed in Study 1 (see Chapter 2), was sensory sensitivities. The current chapter further examines the role of sensory sensitivities for REDs in autistic individuals. Specifically, we compare the general and food-specific sensory sensitivities of participants from Study 2 in order to test the potential link between sensory sensitivities and REDs in autistic individuals. In doing so, this study addresses aim 3 of the overarching aims of this thesis (see Chapter 1); testing elements of the theoretical model developed in Study 1, using quantitative methods.

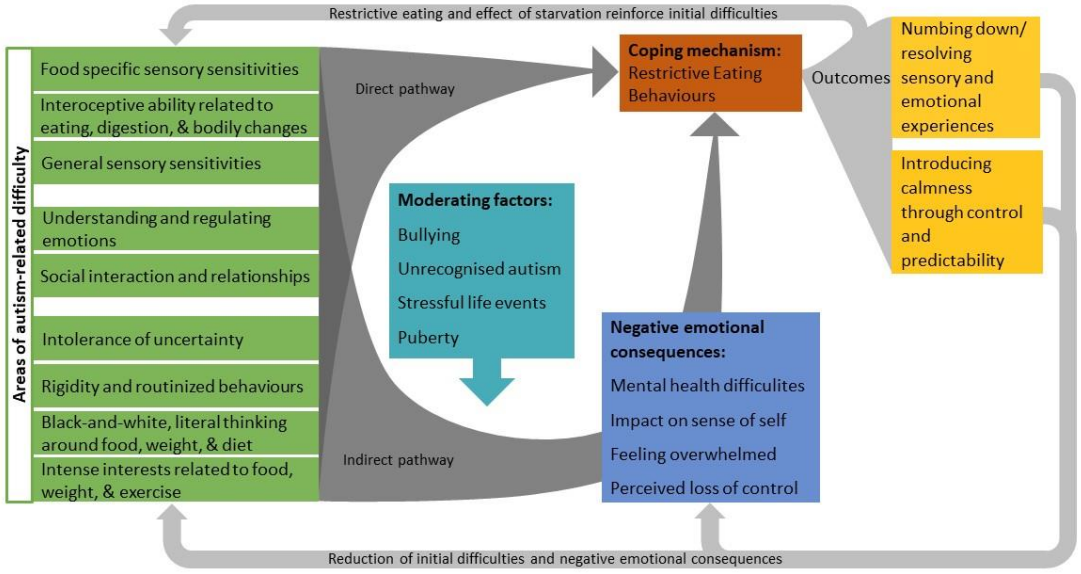
Autistic women are overrepresented in RED populations (Huke et al., 2013; Westwood & Tchanturia, 2017), and commonly available ED treatment approaches appear to lack efficacy in this client group (Nielsen et al., 2015; Stewart et al., 2017; Tchanturia et al., 2016). A better understanding of potential contributing factors to REDs in autistic women is needed to inform treatment adaptations and improve service provision for affected individuals. In Study 1, we developed a theoretical model of autism-related difficulties that might contribute to the development and maintenance of restrictive eating behaviours in autistic individuals (Chapter 2; Brede et al., 2020). The aim of the current chapter is to test elements of the model developed in Chapter 2 using the sample introduced in Chapter 4.

Specifically, the current chapter will focus on difficulties related to general and food-specific sensitivities. The term ‘general sensitivities’ refers to sensitives across all sensory domains, whereas the term ‘food-specific sensitivities’ is used to describe sensitivities that affect the specific sensory domains involved in eating and sensory responses to food characteristics, specifically taste, smell, and texture. Sensitivities

were a prominent theme in our qualitative investigation and form part of the theoretical model of proposed mechanisms underlying restrictive eating behaviours in autistic individuals (see Chapter 2; Brede et al., 2020). As depicted in Figure 12, sensitivities are proposed to result in restrictive eating behaviours either via a direct pathway (e.g., restriction in response to a sensory aversion to food characteristics) or an indirect pathway (e.g., general sensitivities being a stressor in women's lives, and restrictive eating helping them to modulate this by numbing their sensory experiences).

Figure 12

Sensory sensitivities in the model of proposed mechanisms underlying restrictive eating behaviours in autistic individuals



Sensory sensitivities are of particular interest as a potential contributing factor to REDs in autistic individuals, given reports of high levels of sensitivities in both autistic individuals and people with REDs (Ben-Sasson et al., 2019; Zucker et al., 2013). However, direct comparisons between these populations are currently lacking

(Kinnaird & Tchanturia, 2020). Comparing general and food-specific sensitivities in autistic women with REDs to those in autistic women without REDs and non-autistic women with REDs will help to determine whether these factors are present more strongly in autistic individuals with REDs. Such a finding would support the hypothesis that these sensitivities contribute to an autism-specific RED presentation. Future research could then test potential mechanisms and whether there is a direct and indirect pathway as proposed by the model.

General Sensitivities in Autistic Individuals

Many autistic people show hypersensitivity and/or hyposensitivity to stimuli, feeling these stimuli more or less intensely than non-autistic people (Miller et al., 2007). Autistic individuals may also react differently to sensory input, experiencing it as more pleasant or distressing, and might consequently seek out or avoid stimulation (Miller et al., 2007). These differences in sensory reactivity form part of the 'restricted, repetitive patterns of behaviour, interests, or activities' domain of the diagnostic criteria for autism in the DSM-5 and ICD-11 (W. Mandy et al., 2012; APA, 2013; WHO, 2018).

In the autism literature, a variety of terms are used to refer to sensitivities (see Schaaf & Lane, 2015 for an overview); with sensory over- or under-reactivity and sensory seeking being most commonly used, in line with DSM diagnostic criteria (APA, 2013). 'Sensory reactivity differences' describe autistic individuals' sensitivities at a behavioural level, rather than focusing on potential differences in the underlying processing and perception of sensory stimuli (Tavassoli et al., 2014). In the current thesis, including in the description of existing research that follows, we will use the terms sensory sensitivities and hyper- or hyposensitivities more generally, without specifying the level at which differences are assumed to occur. This terminology

most closely aligns with that used by the developers of the GSQ (Robertson & Simmons, 2013), which is the measure of sensitivities used in the current chapter. The current chapter does not explore sensory seeking behaviours, as these are not systematically captured by the GSQ, and were considered to be less relevant to REDs, which are restricting and therefore avoiding in nature.

Autistic individuals consistently report greater sensitivities than non-clinical populations, individuals with other developmental conditions, and other clinical groups (Ben-Sasson et al., 2019). Ninety-four percent of autistic adults report extreme levels of sensitivities, with their scores falling in the range at least one SD above/below the scores of a non-autistic comparison group (Crane et al., 2009). Sensitivities can affect various and multiple sensory modalities, including touch, sight, sound, taste, smell, and movement (Miller et al., 2007). Autistic people can experience both hyper- and hyposensitivity across different modalities (Elwin et al., 2017; Leekam et al., 2007), or the same modality—for example, an individual may be either hyper- or hyposensitive to sensory stimuli depending on their emotional state (Smith & Sharp, 2013).

Hypersensitivity is more common than hyposensitivity in autistic adults (Ben-Sasson et al., 2019; Tavassoli et al., 2013), particularly in females (Taylor et al., 2020), although there is considerable within-group variability (Crane et al., 2009; MacLennan et al., 2021). While some autistic people may experience hypersensitivity as pleasurable and/or advantageous (Jones et al., 2003), it can also cause great distress, and multiple or enduring stimulation can result in sensory overload (Elwin et al., 2012; Smith & Sharp, 2013). In qualitative accounts, autistic adults have described how sensory stimuli can become overwhelming, affecting their functioning (Chamak et al., 2008; MacLennan et al., 2021). In the longer term, this

has been proposed to contribute to poor physical and mental health outcomes (MacLennan et al., 2021). Indeed, hypersensitivity in autistic adults has been linked to high rates of depression and anxiety and lower quality of life (Hwang et al., 2020; Kinnealey et al., 2011).

This link between general sensitivities and poor mental health in autistic people might extend to REDs. Our qualitative findings suggest that many autistic women with AN struggle with sensitivities, particularly hypersensitivity, in their day-to-day lives (Chapter 2; Brede et al., 2020). Some women reported that restricting their eating functioned as a way to numb their receptiveness to sensory input, making it more bearable (Chapter 2; Brede et al., 2020). Autistic individuals with higher levels of hypersensitivity may thus be particularly likely to engage in restrictive eating behaviours in order to cope with sensory overwhelm.

General Sensitivities in Individuals with REDs

High levels of general sensitivities have also been reported by individuals with REDs, specifically AN (Zucker et al., 2013; Brand-Gothelf et al., 2016). Brand-Gothelf et al. (2016) found greater self-reported sensitivities in women with AN compared to women with bulimia nervosa and a healthy control group. Women with AN reported higher hypersensitivity, but not hyposensitivity, than the other two groups.

There are several hypotheses regarding the mechanisms driving these findings of sensitivities in AN. The state of starvation, and associated low body weight, have been robustly shown to alter sensory experience in animal models, and may impact individuals with REDs in similar ways (Slankster et al., 2020; Wang et al., 2006). It is theorised that vigilance to sensations could be heighted to facilitate escape, given the threat to survival associated with a dangerously low BMI (Zucker

et al., 2013). However, sensitivities in AN do not appear to be purely driven by low weight. Zucker et al. (2013) found that both women who had a current AN diagnosis and women who had restored their weight self-reported greater sensitivities and were more likely to actively avoid sensations compared to a healthy control group. The fact that sensitivities remained high in weight restored women suggests a link between sensitivities and AN that extends beyond the influence of malnutrition and low weight (Zucker et al., 2013). On this basis, it has been proposed that disordered eating behaviours in AN may be motivated, in part, by a desire to alter the subjective sensory experience of the body—not merely by a perception of one's body appearance (Sachdev et al., 2008; Zucker et al., 2013). This may be particularly true for autistic individuals with REDs, given the high prevalence of sensory processing differences in autism (Ben-Sasson et al., 2019). It may be that (unrecognised) autistic individuals are driving findings of general sensitivities in RED populations. The first aim of the current study is to assess whether autistic women with REDs present with higher levels of general sensitivities than other autistic women and non-autistic women with REDs.

Food-Specific Sensitivities in Autistic People

Another potential pathway through which sensory sensitivities may relate to REDs in autistic individuals is food-specific sensitivities. Eating is a multisensory experience that relies on various modalities, including gustatory, olfactory, and tactile channels, to process the taste, smell, and texture of food (Rolls, 2015).

Research using psychophysical measures to assess sensory processing differences in response to gustatory, olfactory, and tactile stimuli suggests that there is much variability across autistic individuals. With regard to taste sensitivity, autistic adults tend to present with a poorer ability to correctly identify different tastes than

non-autistic individuals, but their taste detection threshold appears to be similar (Bennetto et al., 2007; Damiano et al., 2014; Tavassoli & Baron-Cohen, 2012). With regard to odour sensitivity, meta-analyses on odour identification and detection thresholds in autistic individuals have found much heterogeneity, with evidence for both hyper- and hyposensitivity (Larsson et al., 2017; Tonacci et al., 2017). Research on tactile sensitivities in autistic individuals tends to focus on touch and sensitivity to non-edible textures on the skin, rather than the mouthfeel of food, making it difficult to hypothesise about the potential role of tactile sensitivities in REDs. However, as for other modalities, there appears to be much heterogeneity in autistic individuals' tactile sensitivity (Mikkelsen et al., 2018). For example, Cascio et al. (2012) found no difference between autistic and non-autistic adults' ratings of roughness and pleasantness of different textures using different pieces of sandpaper, but autistic adults' ratings were more extreme, and their ratings for neutral textures were more variable. Haigh et al. (2016) found greater within-person variation in the ratings across trials of autistic adults compared to non-autistic adults, but overall, autistic adults perceived surfaces as rougher than non-autistic adults did. Given the variability in the presentation of sensory sensitivities and the modalities affected (Crane et al., 2009; MacLennan et al., 2021), there may be a sub-group of autistic individuals who have specific sensitives related to food characteristics or may experience food-specific sensitivities as particularly distressing.

Indeed, sensitivities related to the taste, smell, and texture of food have been linked to restrictive eating behaviours in autistic individuals. Kuschner et al. (2015) assessed food texture preferences and general taste seeking/avoiding behaviours using the responses of autistic adolescents and young adults to individual items in the adult/adolescent sensory profile (AASP; Brown & Dunn, 2002). Autistic

participants reported greater dislikes for foods with particular textures and strong tastes compared to a matched comparison group. Similarly, parents of autistic children reported significantly higher rates of food refusal than parents of non-autistic children, with the most common reason for their child refusing food being food texture/consistency (77.4% vs. 36.2%, respectively), followed by taste/smell (49.1% vs. 5.2%), and finally, mixtures of different foods (45.3% vs. 25.9%; Hubbard et al., 2014).

Several qualitative studies have described autistic adults' experiences of sensitivities in response to the taste, smell, and texture of food, providing insights into potential mechanisms that might link these sensitivities to REDs (Jones et al., 2003; MacLennan et al., 2021; Robertson & David, 2015). These suggest that dietary restriction in autistic individuals may be the result of them attempting to avoid unbearable stimuli and the physical consequences thereof, such as nausea (Kinnaird, Norton, Pimblett, et al., 2019; MacLennan et al., 2021), which was also reported by participants in Study 1 (Chapter 2; Brede et al., 2020).

Food-Specific Sensitivities in Individuals with REDs

Food-specific sensitivities have also been reported in individuals with REDs, particularly ARFID, and to a lesser extent, AN (Galiana-Simal et al., 2017). In the DSM-5 diagnostic criteria for ARFID, avoidance based on sensory characteristics of food is listed as one of the factors that may drive disturbances in eating behaviours (APA, 2013). This is supported by the existing literature (Bourne et al., 2020). In a retrospective chart review of 77 ARFID patients, 18% exhibited restriction that was considered to be arising primarily as a result of sensitivities (Norris et al., 2018). In another study using retrospective chart reviews of 47 ARFID cases, Reilly et al. (2019) reported that 70%–80% of individuals presented with at least one

characteristic consistent with the sensory sensitivity behavioural phenotype. Given the high rates of sensitivities in autism (Crane et al., 2009), REDs in autistic individuals might resemble ARFID-type RED presentations.

There is some evidence that individuals with AN also experience altered sensory processing of food- and eating-related stimuli; however, this evidence is less conclusive. A review of studies using psychophysical measures to assess taste sensitivity in AN suggests that individuals with AN may experience reduced taste sensitivity—but this appears to improve following recovery, suggesting that it may be a temporary symptom of AN rather than a pre-existing risk factor (Kinnaird et al., 2018). The authors highlighted considerable variability in findings across studies, which are potentially reflective of methodological problems, including low sample sizes and uncontrolled confounding variables (Kinnaird et al., 2018). A review of olfactory sensitivity in individuals with AN was also inconclusive (Islam et al., 2015). The studies included in the review found indications of altered smell sensitivity in AN compared to other EDs and healthy controls; however, the direction of this effect varied across studies. Most studies leaned toward a higher odour detection threshold and poorer odour identification in AN, although one study, considered to be of better quality than some of the other included studies (Islam et al., 2015), presented results that suggested superior odour threshold and better odour identification in AN (Fernández-Aranda et al., 2016). Again, the authors of this review suspected the heterogeneity in findings to be due in part to methodological limitations of the included studies (Islam et al., 2015). Research on tactile sensitivity in REDs tends to focus on bodily sensations, which are thought to relate to body representation disturbances (de Vignemont et al., 2005; Keizer et al., 2012), rather than on sensory experiences related to the texture of food. In a systematic review of multisensory

body perception in AN, Gaudio et al. (2014) reviewed studies focused on tactile perception, which is related to the processing of external stimuli touching the skin, and haptic sensitivity, which requires active exploration of objects. Across studies, participants with AN showed alterations in tactile perception and greater difficulty with complex haptic information, but showed no difference in their ability to identify simple shapes (Gaudi et al., 2014).

In summary, the evidence is inconclusive as to whether gustatory, olfactory, and tactile sensitivities are consistently altered in AN, and how this relates to disordered eating behaviours displayed by this population. Indeed, it may be that it there is no direct link with AN. Instead, food-specific sensitives in RED populations could be driven by individuals with co-occurring autism.

Thus far, no research on sensitivities in REDs has purposefully included autistic individuals, and studies assessing the association of food-specific sensitives with autistic traits in RED samples have yielded inconsistent findings. Bentz, Guldberg, et al. (2017) assessed olfactory sensitivity and identification in young women with AN, recovered individuals, and a control group, using both self-reports and physiological measures. They also administered the ADOS-2 (Lord et al., 2012) as a measure of social communication difficulties associated with autism. Both women with AN and recovered women presented with higher olfactory sensitivity and social communication difficulties than controls. However, controlling for social communication ability did not alter the finding of heightened smell sensitivity in women with AN, and there was no significant relationship between olfactory functioning and social communication difficulties across the sample (Bentz, Guldberg, et al., 2017). Using psychophysical measures, (Kinnaird, Stewart, et al., 2020b) compared self-reported sensitivities across different modalities, as well as

differences in gustatory and olfactory processing, in women with AN compared to healthy controls. They also assessed whether autistic traits, measured using the AQ (Baron-Cohen et al., 2001), were associated with gustatory and olfactory processing ability in women with AN. Women with AN reported significantly higher hypersensitivity to touch compared to healthy controls, but there were no significant differences between the AN group and the control group for any other sensory modalities on either the self-report or psychophysical measures. Further, no relationships between gustatory and olfactory processing ability and autistic traits were identified within the AN group (Kinnaird, Stewart, et al., 2020b). Tonacci et al. (2019) also found no difference in self-reported and psychophysical assessment of olfactory sensitivity between adolescents with AN and healthy controls. However, in contrast to the other two studies, this study found a moderate negative correlation between smell sensitivity and parent-reported (but not self-reported) autistic traits in the AN group; adolescents with AN who had higher parent-reported autistic traits displayed worse olfactory performance (Tonacci et al., 2019). Including a comparison group of autistic individuals with REDs would help to address the question of whether food-specific sensitives in REDs are driven by (unrecognised) autism. Thus, the second aim of the current study is to assess whether autistic women with REDs present with greater food-specific sensitivities than other autistic women and non-autistic women with REDs.

Other Factors Influencing Sensitivities

Importantly, several previous studies have found that other co-occurring mental health difficulties and medication use can affect sensory processing. For example, in general and psychiatric populations, depression and anxiety are associated with reduced and increased olfaction, respectively (Atanasova et al.,

2008; Lombion-Pouthier et al., 2006). A study of adolescents with AN observed increased olfactory identification ability, but only after participants with other psychiatric comorbidities were excluded (Fernández-Aranda et al., 2016). Similarly, a number of psychotropic medications are known to affect the functionality of olfactory areas (Benton et al., 2008). Further, anxiety and sensory sensitivities in autistic individuals have been both theoretically connected and empirically linked (Green & Ben-Sasson, 2010; Hwang et al., 2020; Wigham et al., 2015). Co-occurring depression, anxiety, and social anxiety are common in autistic individuals as well as people with REDs (Hollocks et al., 2019; Salbach-Andrae et al., 2008). Given the group differences in co-occurring mental health difficulties and medication use in our sample (see Chapter 4), these factors were considered as co-variants in the current study.

The Current Study

To date, no research has examined general and food-specific sensitivities in autistic individuals with REDs. Our investigation of the clinical presentation of autistic women with REDs (see Chapter 4) provides preliminary evidence for heighted sensitivities in this population. We used the SWEAA (Karlsson et al., 2013) to measure autism-specific unusual eating behaviours. This measure includes the SWEAA perception subscale, which consists of 11 items related to preference and avoidance of food with certain sensory properties. Both autistic women with REDs and women with REDs and high autistic traits scored significantly higher than autistic women without REDs and non-autistic women with REDs on this subscale (see Chapter 4). However, their difference to autistic women without REDs was no longer significant after controlling for differences in co-occurring mental health difficulties, which suggests that strong preference and avoidance of food with certain sensory

properties could be related to being autistic and having high levels of mental health difficulties more generally, rather than being specific to REDs presentations in autistic women. Further, the SWEAA perception subscale does not differentiate between different food-specific and other sensory modalities and does not consider the role of general sensitivities. Thus, the presentation of general and food-specific sensitivities warrants further investigation with more detailed, independent measures, which is the focus of this chapter.

The current study compares self-reported general hyper- and hyposensitivity, as well as sensitivities affecting food-specific and other sensory modalities, measured using the GSQ (Robertson & Simmons, 2013), among (1) autistic women without REDs ('Autism only'), (2) autistic women with REDs ('Autism+REDs'), (3) non-autistic women with REDs ('REDs only'), and (4) women with REDs and high autistic traits ('REDs high autistic traits').

To better understand the nature of sensitivities, we also tested whether general sensitivities were associated with autistic traits and with BMI in each group.

In addition to self-reported sensitives, we had planned to include a chemical taste test ('taste strips,' Burghart, Messtechnik, Germany; Landis et al., 2009), which is a standardised psychophysical measure of taste identification that has been used in research with both autism and AN populations (Kinnaird, Stewart, et al., 2020b; Tavassoli & Baron-Cohen, 2012). Unfortunately, due to COVID-19, our data collection was interrupted, and we were only able to conduct taste tests with a subset of participants from the 'Autism only' and 'Autism+REDs' groups, who had participated in person prior to the study being moved online. From the existing literature, it is not clear how self-reported sensitivities translate to performance on more objective psychophysical assessments of sensory processing differences

(Schaaf & Lane, 2015). The use of self-report measures in conjunction with psychophysical assessments may reveal discrepancies in basic perception and self-reported sensitivities (DuBois et al., 2017; Horder et al., 2014). Therefore, the current study initially included both self-report and psychophysical assessments of sensitivities, specifically of taste identification ability. Participants were asked to identify sweet, salty, sour, and bitter tastes from filter paper strips, which were impregnated with varying concentrations of different tastes. We also asked participants to rate the pleasantness of each taste. Only 25 participants in the 'Autism only' and 12 participants in the 'Autism+REDs' groups completed the taste test. The available data were treated as pilot data, as the analysis had insufficient power to detect any difference with less than a very large effect size (see Chapter 3) and only included two groups.

Research Questions. The current chapter aims to address the following research questions:

- ***General sensitivities***
    - Do autistic women with REDs present with more general sensitives, specifically more hypersensitivity, than autistic women without REDs and other women with REDs?
- ***Pattern of sensitivities across food-specific and other sensory modalities***
    - Do autistic women with REDs present with more sensitivities affecting food-specific modalities (i.e., gustatory, olfactory, and tactile sensitivities) relative to other modalities (visual, auditory, vestibular, proprioception) compared to autistic women without REDs and other women with REDs?

- ***Taste identification ability***
    - Do autistic women with REDs present with better taste identification ability than autistic women without REDS (and other women with REDs)?
- ***Taste pleasantness***
    - Do autistic women with REDs report tastes to be less pleasant than autistic women without REDs (and other women with REDs)?

Hypotheses. As in Chapter 4, we developed hypotheses about expected differences among the 'Autism only,' 'Autism+REDs,' and 'REDs only' groups. Because of the similarities between 'Autism+REDs' and 'REDs high autistic traits' in terms of autistic traits and autism-specific eating behaviours (see Chapter 4), we included 'REDs high autistic traits' in the hypothesis for the current chapter, expecting them to present with similar levels and a pattern of sensitives as 'Autism+REDs.' The hypotheses tested in the current chapter are as follows:

- ***General sensitives***
    - 'Autism+REDs' and 'REDs high autistic traits' will present with higher levels of sensitivities, especially hypersensitivity, than the other two groups.
- ***Pattern of sensitivities across food-specific and other sensory modalities***
    - 'Autism+REDs' and 'REDs high autistic traits' will present with higher sensitives in food-specific modalities, but similar levels of sensitivities for other sensory modalities, compared to the other groups.
- ***Taste identification ability***

- ‘Autism+REDs’ and ‘REDs high autistic traits’ will present with better taste identification ability than ‘Autism only’ and ‘REDs only.’

- ***Taste pleasantness***
  - ‘Autism+REDs’ and ‘REDs high autistic traits’ will rate tastes as less pleasant than ‘Autism only’ and ‘REDs only.’

Methods

The following provides a brief outline of the methodology. More methodological details for this study are outlined in Chapter 3.

Participants

Participants included 47 autistic women without REDs (‘Autism only’), 51 autistic women with REDs (‘Autism+REDs’), 76 non-autistic women with REDs(‘REDs only’), and 36 women with REDs and high autistic traits (‘REDs high autistic traits’). The analysis of taste identification ability and taste pleasantness ratings included only a subset of participants from the ‘Autism only’ and ‘Autism+REDs’ groups (n = 25 and n = 12, respectively). Demographics and clinical characteristics of each group are presented in Table 8 and 9 in Chapter 4. Key background variables for the subset of participants who completed the taste test are presented in the results section below.

Measures

The characteristics and psychometric properties of the measures used are presented in Chapter 3. In the current analysis, we used the GSQ subscales (Robertson & Simmons, 2013) as self-report measures of general hyper- and hyposensitivities, as well as sensitivities affecting food-specific (gustatory, olfactory, tactile) and other (visual, auditory, vestibular, proprioception) modalities.

The RAADS-14 (Eriksson et al., 2013) was used as a measure of autistic traits.

Self-reported or measured weight and height were used to calculate participants' BMI.

The 'taste strips' taste test (Burghart, Messtechnik, Germany; Landis et al., 2009) was used to assess taste identification ability and to obtain taste pleasantness ratings.

The ADOS-2 (Lord et al., 2012) was conducted with participants who completed the taste test to confirm presence of autism.

Analytic Approach

We conducted two mixed-design ANOVAs, including different combinations of GSQ subscales, to assess the overall effect of group on general sensitivities and to compare levels of general hyper- and hyposensitivity, as well as levels of sensitivities affecting different sensory modalities among groups.

We repeated each analysis, adjusting for age (partially adjusted model) and adjusting for age, depression, anxiety, and social anxiety (fully adjusted model). When adjusting for differences in age and co-occurring mental health difficulties, the mean age and the mean scores for anxiety, depression, and social anxiety in all groups were held constant at the respective estimated mean across the total sample. For age, the mean across the total sample was lower than the actual mean age of the 'Autism only' group, and was slightly higher than the actual mean age of 'Autism+REDs,' 'REDs high autistic traits,' 'REDs only,' and 'REDs high autistic traits' (see Chapter 4). For co-occurring mental health difficulties, the estimated means were lower than the actual mean scores for 'Autism+REDs' and 'REDs high autistic traits' and higher for 'Autism only' and 'REDs only' (see Chapter 4). In addition, whether participants were currently taking medication was considered as a potential co-variate. However, when comparing participants who were and were not currently

taking medication, there were no significant differences for GSQ total score and GSQ gustatory, olfactory, and tactile subscale scores in each group. Therefore, it was not deemed necessary to include medication as a co-variate in subsequent analysis.

Correlations between GSQ total scores and RAADS-14 total score and BMI were calculated for each group to assess the relationship of general sensitivities with autistic traits and starvation.

Finally, we conducted another two mixed-design ANOVAs to assess the overall effect of group ('Autism only' vs. 'Autism+REDs') on correctly identified tastes and pleasantness ratings and to compare these for the individual taste qualities (sweet, sour, salty, bitter) between groups. Because of the small sample size, these analyses were considered preliminary, and no adjustments were applied to control for group differences on background variables or other potential co-variates.

Results

Group Differences in General Sensitivities

Levels of general hyper- and hyposensitivity were compared between groups to assess whether 'Autism+REDs' and 'REDs high autistic traits' presented with greater sensitivities than the other two groups. Box's test of equality of covariance was violated, with Box's M = 27.03, $F(9, 220861.36) = 2.95$, and $p = .002$. According to Levene's test (see Table 1, Appendix 13), the assumption of equality of variance was not met for hypersensitivity, but was met for hyposensitivity.

The unadjusted and adjusted main effects for (1) subscale, (2) group, and (3) interaction of subscale by group are presented in Table 20 for GSQ general hyper- and hyposensitivity.

Table 20

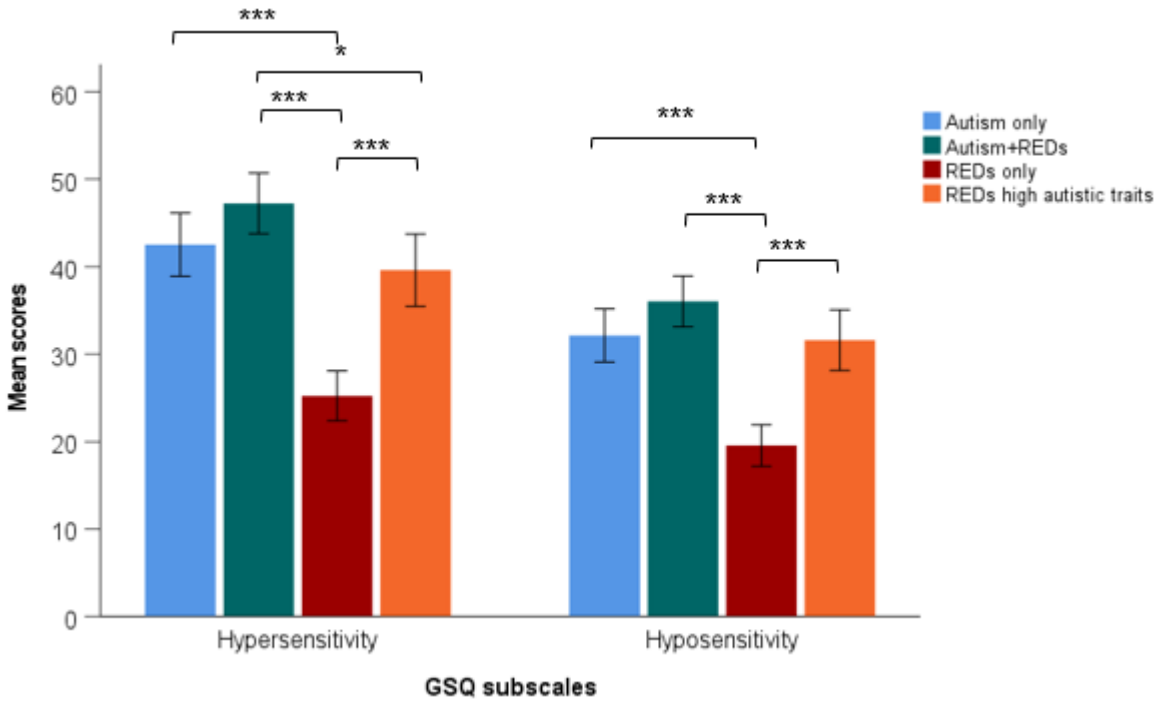
Mixed-design ANOVA main effects for GSQ general hyper- and hyposensitivity subscales, group, and interaction in the unadjusted, partially adjusted, and fully adjusted model

Main Effect	Model	Statistical Result
Subscale	Unadjusted	$F(1, 206) = 246.32$, $\mathbf{p < .001}$, $\eta_p^2 = .545$
	Partially adjusted	$F(1, 205) = 9.73$, $\mathbf{p = .002}$, $\eta_p^2 = .045$
	Fully adjusted	$F(1, 202) = 1.385$, $p = .241$, $\eta_p^2 = .007$
Group	Unadjusted	$F(3, 206) = 37.66$, $\mathbf{p < .001}$, $\eta_p^2 = .354$
	Partially adjusted	$F(3, 205) = 36.62$, $\mathbf{p < .001}$, $\eta_p^2 = .349$
	Fully adjusted	$F(3,202) = 38.13$, $\mathbf{p < .001}$, $\eta_p^2 = .362$
Subscale by Group	Unadjusted	$F(3, 206) = 6.23$, $\mathbf{p < .001}$, $\eta_p^2 = .083$
	Partially adjusted	$F(3, 205) = 5.300$, $\mathbf{p = .002}$, $\eta_p^2 = .072$
	Fully adjusted	$F(3, 202) = 5.600$, $\mathbf{p = .001}$, $\eta_p^2 = .077$

The unadjusted mean scores for GSQ general hypersensitivity and hyposensitivity by group, with indication of significant post-hoc differences, are presented in Figure 13.

Figure 13

Mean GSQ hyper- and hyposensitivity subscale scores by group



Note. Error bars indicate 95% confidence intervals (CIs). Significant post-hoc differences: ***$p \leq .001$, **$p \leq .01$, *$p \leq .05$.

We observed a significant main effect of subscale ($F(1, 206) = 246.32$, $p < .001$, $\eta_p^2 = .545$), showing that there was a significant difference between hyper- and hyposensitivity scores across groups. We also observed a significant main effect of group ($F(3, 206) = 37.66$, $p < .001$, $\eta_p^2 = .354$). The main effect of group can be interpreted as a test of group difference on the GSQ total score, since it is generated by adding both subscales.

Mean GSQ total scores for each group are presented in Table 21. Significant post-hoc pairwise comparisons of the main effect of group in the unadjusted model, and changes observed for the adjusted model, are presented in Table 22. These results revealed that ‘Autism only,’ ‘Autism+REDs,’ and ‘REDs high autistic traits’

reported higher overall levels of sensitivities than ‘REDs only’, but that there were no significant differences between these three groups.

Table 21

Unadjusted mean GSQ total scores and SDs per group

	Autism Only (n = 47)	**Autism+REDs (n = 51)**	**REDs Only (n = 76)**	**REDs With High Autistic Traits (n = 36)**
Mean (SD)	74.68 (22.60)	83.29 (24.51)	44.79 (17.34)	71.56 (25.32)

Table 22

Significant post-hoc pairwise comparisons of the main effect of group on GSQ scores for the unadjusted model, and changes for the adjusted model from the unadjusted model.

Model	
Unadjusted	**Autism only > REDs only** mean difference = 17.295, ***p* < .001**, 95% CI [11.08–23.51] **Autism+REDs > REDs only** mean difference = 22.02, ***p* < .001**, 95% CI [15.96-28.08] **REDs only < REDs high autistic traits** mean difference = -14.37, ***p* < .001**, 95% CI [-21.15–(-7.60)]
Partially adjusted	No change
Fully adjusted	Additional significance: **Autism only > REDs high autistic traits** mean difference = 8.308, ***p* = .008**, 95% CI [1.49–15.12]

Finally, there was a significant interaction effect between subscale and group ($F(3, 206) = 6.23$, ***p* < .001**, $\eta_p^2 = .083$), showing that groups had different patterns of scores across GSQ general hyper- and hyposensitivity subscales.

Unadjusted mean scores and post-hoc pairwise comparisons between groups for general hyper- and hyposensitivity scores are presented in Table 23.

Table 23

Mean GSQ hyper- and hyposensitivity scores and estimated mean scores after adjustment. The table also shows post-hoc comparisons for the unadjusted model and changes for the adjusted model.

Measure	Model	Mean (SD)/Estimated Mean After Adjustment				Significant Pairwise Comparisons With Bonferroni Adjustment for Multiple Comparison
		Autism only (n = 47)	**Autism+REDs (n = 51)**	**REDs only (n = 76)**	**REDs with high autistic traits (n = 36)**	
GSQ hyper-sensitivity	Unadjusted	42.53 (13.49)	47.25 (12.86)	25.24 (10.85)	39.61 (14.21)	**Autism only > REDs only** mean difference = 17.30, ***p* < .001**, *g* = 1.450, 95% CI [11.08–23.51] **Autism+REDs > REDs high autistic traits** mean difference = 7.64, ***p* = .034**, *g* = .569, 95% CI [.36–14.93] **Autism+REDs > REDs only** mean difference = 22.02, ***p* < .001**, *g* = 1.882, 95% CI [15.96–28.08] **REDs only < REDs high autistic traits** mean difference = -14.37, ***p* < .001**, *g* = 1.196, 95% CI [-21.15–(-7.60)]

	Partially adjusted	42.17[a]	47.33[a]	25.37[a]	39.70[a]	No changes
	Fully adjusted	46.45[b]	45.28[b]	25.99[b]	35.71[b]	Additional significance: **Autism only > REDs high autistic traits** mean difference = 10.74, ***p* = .002**, 95% CI [3.03–18.44]
GSQ hypo-sensitivity	Unadjusted[†]	32.15 (10.26)	36.04(19.55)	19.55 (7.74)	31.17 (11.59)	**Autism only > REDs only** mean difference = 12.60, ***p* < .001**, *g* = 1.368, 95% CI [7.38–17.81] **Autism+REDs > REDs only** mean difference = 16.48, ***p* < .001**, *g* = 1.556, 95% CI [11.40–21.58] **REDs only < REDs high autistic traits** mean difference = -12.06, ***p* < .001**, *g* = 1.282, 95% CI [-17.75–(-6.37)]
	Partially adjusted[†]	32.44[a]	35.98[a]	19.44[a]	31.54[a]	No changes
	Fully adjusted[†]	32.55[b]	32.55[b]	18.46[b]	27.48[b]	No changes

Note. [†]assumption of homogeneity of variance not met (see Table 1, Appendix 13).

[a] Covariate is evaluated at the following value: age (years) = 32.22.

[b] Covariates are evaluated at the following values: age (years) = 32.22, HADS depression = 9.62, HADS anxiety = 13.86, SPIN total = 40.16.

‘Autism only,’ ‘Autism+REDs,’ ‘REDs high autistic traits’ scored significantly higher than ‘REDs only’ for both hyper- and hyposensitivity, but similar to each other. The only significant difference between ‘Autism only,’ ‘Autism+REDs,’ and ‘REDs high autistic traits’ was that ‘Autism+REDs’ scored significantly higher than the ‘REDs high autistic traits’ group on the GSQ hypersensitivity subscale. This was not the case for hyposensitivity, which could account for the significant interaction effect.

The majority of effect sizes for these group differences were very large, with a medium effect size for the difference on the GSQ hypersensitivity scale between ‘Autism+REDs’ and ‘REDs high autistic traits’ (see Table 23).

Impact of Adjustments on Main Effects and Group Differences for GSQ General Hyper-and Hyposensitivity Subscales. The main effects were maintained in the partially and fully adjusted models, apart from the main effect of subscale, which was no longer significant in the fully adjusted model (see Table 20). Estimated means for the adjusted models and changes to post-hoc pairwise comparisons for each subscale are presented in Table 23. For both hyper- and hyposensitivity, the same pairwise comparisons reached significance in the partially adjusted and fully adjusted models. For the GSQ hypersensitivity subscale in the fully adjusted model, there was also a significant difference between the ‘Autism only’ group and ‘REDs high autistic traits,’ with the estimated means for the ‘REDs high autistic traits’ group being significantly lower than those of the ‘Autism only’ group (see Table 23).

Correlations Between General Sensitivities, BMI, and Autistic Traits

We tested whether GSQ total scores correlated with BMI and RAADS-14 total scores in each group. Correlation coefficients are reported in Table 24. There were no significant correlations between GSQ total scores and BMI for any of the groups, but GSQ total scores were significantly positively correlated with autistic traits for all

groups. Correlations between GSQ total scores and RAADS-14 were moderate to large, with shared variance ranging from 19%–29%.

Table 24

Correlations between general sensitivities (GSQ total score), BMI, and autistic traits (RAADS-14) within each group

	BMI	**RAADS-14 Total**
'Autism only' (n = 47)*	r = .084, [-.153–.350], p = .578, R^2 = .007	r_s = .494, [.266–.686], ***p* = .001,** R_s^2 = .244
'Autism+REDs' (n = 51)*	r_s = .050, [-.242–.330], p = .740, R_s^2 = .025	r_s = .540, [.277–.738], ***p* < .001,** R_s^2 = .292
'REDs only' (n = 76)*	r_s = -.043, [-.267–.189], p = .720, R_s^2 = .002	r_s = .479, [.274–.645], ***p* < .001,** R_s^2 = .229
'REDs high autistic traits' (n = 36)*	r = .128, [-.319–.553], p = .492, R^2 = .016	r_s = .440, [.136–.685], ***p* = .007**, R_s^2 = .194

Note. The correlation coefficient (r/r_s) for each correlation is reported as an indicator of strength of the bivariate relationship. Bootstrapped 95% CIs are reported in squared brackets. The coefficients of determination (R^2/ R_s^2) is reported as an indicator of shared variance.
*Reduced sample sizes for correlation with BMI due to missing data: 'Autism only' = 46; 'Autism+REDs' = 46; 'REDs only' = 73; 'REDs high autistic traits' = 31.

Group Differences in Food-Specific and Other Sensory Modalities

Levels of sensitivities affecting different sensory modalities were compared between groups. This was to assess whether the pattern of group differences was different for food-specific (gustatory, olfactory, and tactile) and other sensory (visual, auditory, vestibular, proprioception) modalities, in that 'Autism+REDs' and 'REDs high autistic traits' presented with higher levels of sensitivities affecting food-specific, but not other modalities, than the other two groups. If this was the case, it would suggest that 'Autism+REDs' and 'REDs high autistic traits' present with higher levels of sensitivities affecting food-specific modalities, but similar levels of sensitivities affecting other sensory modalities.

Box's test of equality of covariance was violated, with Box's M = 147.29, F(84, 63192.34) = 1.64, and p < .001. According to Levene's test (see Table 1, Appendix 13), the assumption of equality of variance was met for all GSQ modality subscales, apart from GSQ vestibular and GSQ proprioception. Mauchly's test of sphericity indicated that the assumption of sphericity was violated, (χ^2 (20) = 45.31, p = .001); therefore, Huynh-Feldt corrections were applied (ε = .97).

Unadjusted and adjusted main effects for subscale, group, and interaction of subscale by group for GSQ subscale scores for each sensory modality are presented in Table 25.

Table 25

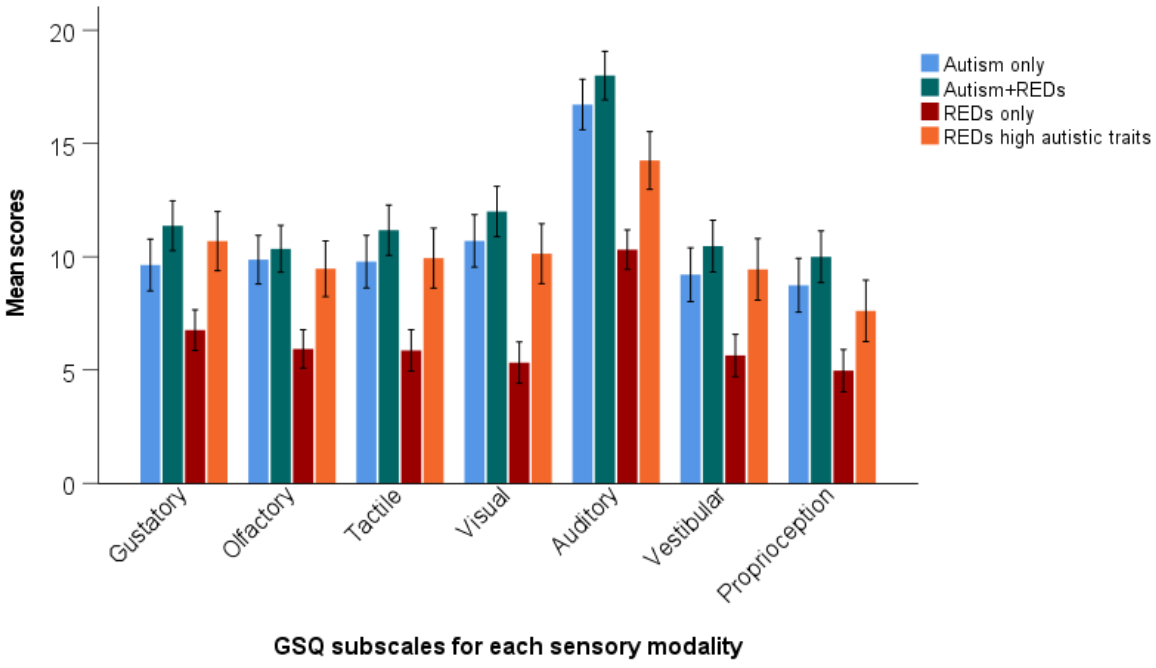
Mixed-design ANOVA main effects of subscale, group, and interaction for GSQ subscale scores for each sensory modality in the unadjusted, partially adjusted, and fully adjusted model

Main Effect	Model	Statistical Result
Subscale	Unadjusted	F(5.84, 1203.26) = 145.40, **p < .001**, η_p^2 = .414
	Partially adjusted	F(5.92, 1213.53) = 22.41, **p < .001**, η_p^2 = .099
	Fully adjusted	F(6.00, 1212.00) = 7.88, **p < .001**, η_p^2 = .038
Group	Unadjusted	F(3, 206) = 37.38, **p < .001**, η_p^2 = .353
	Partially adjusted	F(3, 205) = 36.38, **p < .001**, η_p^2 = .347
	Fully adjusted	F(3, 202) = 37.60, **p < .001**, η_p^2 = .358
Subscale by Group	Unadjusted	F(16.75, 1203.26) = 3.75, **p < .001**, η_p^2 = .052
	Partially adjusted	F(17.759, 1213.53) = 4,08, **p < .001**, η_p^2 = .056
	Fully adjusted	F(18.00, 1212.00) = 4.30, **p < .001**, η_p^2 = .060

The patterns of unadjusted mean scores for across sensory modalities by group are presented in Figure 14.

Figure 14

Mean GSQ total scores for food-specific and other sensory modalities by group



Note. Error bars indicate 95% CI.

We observed a significant main effect of subscale ($F(5.84, 1203.26) = 145.40$, $\mathbf{p < .001}$, $\eta_p^2 = .414$), a significant main effect of group ($F(3, 206) = 37.38$, $\mathbf{p < .001}$, $\eta_p^2 = .353$), and a significant interaction effect between subscales and group ($F(16.75, 1203.26) = 3.75$, $\mathbf{p < .001}$, $\eta_p^2 = .052$). This showed that there were differences between subscales across groups, between groups across subscales, and in the pattern of scores across subscales between groups.

Post-hoc pairwise comparisons between groups for each subscale are presented in Table 26.

Table 26

Mean GSQ subscale scores for each sensory modality and estimated mean scores after adjustment. The table also shows post-hoc comparisons for the unadjusted model and changes for the adjusted model.

Measure	Model	Mean (SD)/Estimated Mean After Adjustment				Significant Pairwise Comparisons With Bonferroni Adjustment for Multiple Comparison
		Autism only (n = 47)	**Autism+REDs (n = 51)**	**REDs only (n = 76)**	**REDs with high autistic traits (n = 36)**	
Gustatory total	Unadjusted	9.64 (4.36)	11.37 (4.13)	6.76 (3.32)	10.69 (4.47)	**Autism only > REDs only:** Mean difference = 2.88, ***p* = .001**, *g* = .768, 95% CI [.91–4.84] **Autism+REDs > REDs only:** Mean difference = 4.61, ***p* < .001**, *g* = 1.258, 95% CI [2.69–6.53] **REDs only < REDs high autistic traits:** Mean difference = -3.93, ***p* = .001**, *g* = 1.055, 95% CI [-6.07–(-1.79)]
	Partially adjusted	9.50 [a]	11.40 [a]	6.82 [a]	10.73 [a]	No changes
	Fully adjusted	10.24[b]	10.90[b]	7.08 [b]	9.91 [b]	No changes

Olfactory total	Unadjusted	9.87 (3.62)	10.35 (4.12)	5.93 (3.37)	9.47 (4.06)	**Autism only > REDs only:** Mean difference = 3.94, ***p* < .001**, *g* = 1.136, 95% CI [2.09–5.79] **Autism+REDs > REDs only:** Mean difference = 4.42, ***p* < .001**, *g* = 1.198, 95% CI [2.62–6.22] **REDs only < REDs high autistic traits:** Mean difference = -3.54,***p* < .001**, *g* = 0.982, 95% CI [-5.55–(-1.52)]
	Partially adjusted	9.55 [a]	10.42 [a]	6.06 [a]	9.55 [a]	No changes
	Fully adjusted	10.36 [b]	9.98 [b]	6.23 [b]	8.75 [b]	No changes
Tactile total	Unadjusted	9.79 (3.61)	11.18 (4.66)	5.87 (3.57)	9.94 (4.47)	**Autism only > REDs only:** Mean difference = 3.92,***p* < .001**, *g* = 1.093, 95% CI [1.93–5.91] **Autism+REDs > REDs only:** Mean difference = 5.31,***p* < .001**, *g* = 1.314, 95% CI [3.37–7.25] **REDs only < REDs high autistic traits:** Mean difference = -4.08,***p* < .001**, *g* = 1.049, 95% CI [-6.25–(-1.90)]
	Partially adjusted	9.68 [a]	11.20 [a]	5.91 [a]	9.97 [a]	No changes

	Fully adjusted	10.61 [b]	10.84 [b]	5.99 [b]	9.10 [b]	No changes
Visual total	Unadjusted	10.70 (4.20)	12.00 (4.70)	5.33 (3.23)	10.14 (4.26)	**Autism only > REDs only:** Mean difference = 5.37, ***p* < .001**, *g* = 1.480, 95% CI [3.39–7.36] **Autism+REDs > REDs only:** Mean difference = 6.67, ***p* < .001**, *g* = 1.717, 95% CI [4.73–8.61] **REDs only < REDs high autistic traits:** Mean difference = -4.81, ***p* < .001**, *g* = 1.340, 95% CI [-6.98–(-.2.64)]
	Partially adjusted	10.82 [a]	11.98 [a]	5.29 [a]	10.11 [a]	No changes
	Fully adjusted	12.03 [b]	11.46 [b]	5.39 [b]	9.04 [b]	**Additional significance:** **Autism only > REDs high autistic traits** Mean difference = 2.98, ***p* = .013**, 95% CI [.43–5.54] **Autism+REDs > REDs high autistic traits** Mean difference = 2.41, ***p* = .025**, 95% CI [.20–4.63]
Auditory total	Unadjusted	16.72 (3.41)	18.00 (3.44)	10.32 (4.34)	14.25 (3.97)	**Autism only > REDs only:** Mean difference = 6.41, ***p* < .001**, *g* = .467, 95% CI [4.49-8.32] **Autism only > REDs high autistic traits:**

						Mean difference = 2.47,***p* = .026**, *g* = .703, 95% CI [.19–4.76] **Autism+REDs > REDs only:** Mean difference = 7.68, ***p* < .001**, *g* = 1.889, 95% CI [5.82–9.55] **Autism+REDs > REDs high autistic traits:** Mean difference = 3.75, ***p* < .001**, *g* = 1.169, 95% CI [1.50–6.00] **REDs only < REDs high autistic traits :** Mean difference = -3.93,***p* < .001**, *g* = 0.814, 95% CI [-6.02–(-1.85)]
	Partially adjusted	16.92 [a]	17.96 [a]	10.24 [a]	14.21 [a]	No changes
	Fully adjusted†	18.03 [b]	17.51 [b]	10.32 [b]	13.23 [b]	No changes
Vestibular total	Unadjusted†	9.21 (4.62)	10.47 (4.91)	5.64 (3.17)	9.44 (4.09)	**Autism only > REDs only:** Mean difference = 3.57, ***p* < .001**, *g* = .943, 95% CI [1.52–5.61] **Autism+REDs > REDs only:** Mean difference = 4.83, ***p* < .001**, *g* = 1.220, 95% CI [2.83–6.82] **REDs only < REDs high autistic traits:** Mean difference = -3.80, ***p* < .001**, *g* = 1.089, 95% CI. [-6.03–(-1.57)]

	Partially adjusted†	9.51 [a]	10.41 [a]	5.53 [a]	9.37 [a]	No changes
	Fully adjusted	10.68 [b]	9.88 [b]	5.64 [b]	8.38 [b]	No changes
Proprioception total	Unadjusted†	8.74 (4.83)	10.00 (4.77)	4.97 (2.55)	7.61 (4.81)	**Autism only > REDs only:** Mean difference = 3.77, ***p* < .001**, *g* = 1.050, 95% CI [1.73–5.81] **Autism+REDs > REDs only:** Mean difference = 5.03, ***p* < .001**, *g* = 1.395, 95% CI [3.04–7.02] **REDs only < REDs high autistic traits:** Mean difference = -2.64, ***p* = .011**, *g* = 0.769, 95% CI. [-4.86–(-.41)]
	Partially adjusted†	8.66 [a]	10.02 [a]	5.01 [a]	7.63 [a]	No changes
	Fully adjusted†	9.59 [b]	9.55 [b]	5.14 [b]	6.80 [b]	**Additional significance:** **Autism only > REDs high autistic traits** Mean difference = 2.79, ***p* = .038**, 95% CI. [.10–5.47] **Autism+REDs > REDs high autistic traits** Mean difference = 2.75, ***p* = .011**, 95% CI. [.42–5.08]

Note. †Assumption of homogeneity of variance not met (see Table 1, Appendix 13).
[a] Covariate is evaluated at the following value: age (years) = 32.22.

[b] Covariates are evaluated at the following values: age (years) = 32.22, HADS depression = 9.62, HADS anxiety = 13.86, SPIN total = 40.16.

The ‘Autism only,’ ‘Autism+REDs,’ and ‘REDs high autistic traits’ groups scored significantly higher than the ‘REDs only’ group on all sensory modality subscales. The pattern of group differences was similar for the food-specific modalities (gustatory, olfactory, and tactile) and the other subscales (visual, vestibular, proprioception), apart from for the auditory subscale (see Table 26). ‘Autism only’ and ‘Autism+REDs’ reported significantly higher auditory sensitivity than ‘REDs high autistic traits,’ which could have resulted in the interaction effect. On all other subscales ‘Autism only,’ ‘Autism+REDs,’ and ‘REDs high autistic traits’ scored similarly. The majority of effect sizes for significant group differences were large, or very large, with some medium effect sizes (see Table 26).

Impact of Adjustments on Main Effects and Group Differences in Food-Specific and Other Sensory Modalities. As seen in Table 25, the main effects of group, subscale, and subscale by group were maintained in the partially and fully adjusted models. Estimated means for the adjusted models and changes for the adjusted models for each subscale are presented in Table 26. For all GSQ sensory modality subscale scores, the same pairwise comparisons reached significance in the partially adjusted and fully adjusted models. There were no changes to the pattern of group differences for any of the food-specific modalities (gustatory, olfactory, tactile) in the partially or fully adjusted model. For visual sensitivity and proprioception, there were additional significant differences between ‘Autism only’ and ‘REDs high autistic traits’ as well as between ‘Autism+REDs’ and ‘REDs high autistic traits’ in the fully adjusted model, with the estimated means for ‘REDs high autistic traits’ being significantly lower than for the other two groups.

Group Differences in Taste Identification Ability and Pleasantness Ratings for Sweet, Sour, Salty, and Bitter Tastes

Data for the taste test was available for a subset of participants in the 'Autism only' and 'Autism+REDs' groups (n = 25 and n = 12, respectively), due to a change in methodology in response to COVID-19. Demographics, clinical presentation scores, and self-reported GSQ general total and gustatory total scores of these participants, as well as group comparisons for these variables, are presented in Table 27. The subset of the 'Autism+REDs', who completed the taste test, was slightly older than the 'Autism+REDs' group overall. Levels of autistic traits, depression, anxiety, social anxiety, overall sensitivities and sensitivity to gustatory stimuli in the 'Autism only' and 'Autism+REDs' subset were representative of the wider 'Autism only' and 'Autism+REDs' sample.

Table 27

Demographics, clinical variables, and self-reported sensitivities of participants who completed the taste test

	'Autism Only' (n = 25)	**'Autism+REDs' (n = 12)**	**Group Comparison**
Age	37.89 (10.81)	36.56 (13.27)	*t*(35) = -.487, *p* = .629, 95% CI [-9.73–5.96], *g* = -.167
RAADS-14 total	32.79 (6.16)	37.17 (3.60)	*t*(34.69) = -2.50, ***p* = .017**, 95% CI [-.43–1.08], *g* = -.695
ADOS-2 social affect	8.17 (3.44) (n = 24)	11.00 (4.24)	*t*(34) = -2.16, ***p* = .038**, 95% CI [-5.50–(-.16)], *g* = -.746
ADOS-2 RRBs	3.17 (1.90) (n = 24)	3.67 (1.44)	*t*(34) = -.80, *p* = .439, 95% CI [-1.77–.66], *g* = -.277
ADOS-2 total	11.33 (4.62) (n = 24)	14.67 (4.85)	*t*(34) = -2.01, *p* = .053, 95% CI [-6.71–.04], *g* = -.694
EDE-Q global	1.54 (1.11)	3.37 (1.67)	*t*(15.09) = -2.38, ***p* = .031**, 95% CI [-2.34–(-.14)], *g* = -.964
SWEAA total	29.18 (11.24)	74.17 (54.65)	*t*(35) = -16.37, ***p* < .001**, 95% CI [-30.98–(-16.01], *g* = -2.190
HAADS depression	5.75 (4.49)	10.28 (5.32)	*t*(35) = -1.66, *p* = .106, 95% CI [-5.80–.59], *g* = -.570

HAADS anxiety	10.89 (4.18)	14.67 (5.15)	*t*(35) = 1.81, *p* = .079, 95% CI [-6.25–.64], *g* = -.621
SPIN	36.24 (13.07)	46.00 (8.70)	*t*(35) = -2.34, ***p* = .025**, 95% CI [-18.22–(-.30)], *g* = -.805
GSQ gustatory total	9.36 (4.62)	11.92 (3.99)	*t*(35) = -1.64, *p* = .109, 95% CI [-5.60–.48], *g* = -.565
GSQ total	71.36 (20.84)	81.92 (21.48)	*t*(35) = 1.43, *p* = .162, 95% CI [-25.56–4.45], *g* = -.491
Smoking	n = 3 (12%)	n = 1 (8.3%)	N/A

Note. RAADS-14 = Ritvo Autism Asperger Diagnostic Scale –14, ADOS-2 = Autism Diagnostic Observation Schedule, Second Edition; RRBs= Restricted and Repetitive Behaviours, EDE-Q = Eating Disorder Examination-Questionnaire, SWEAA = SWedish Eating Assessment for Autism spectrum disorders, HAADS = Hospital Anxiety and Depression Scale, SPIN = Social Phobia Inventory, GSQ = Glasgow Sensory Questionnaire.

The ‘Autism+REDs’ group had significantly higher RAADS-14 total, ADOS-2 social affect subscale, EDE-Q global, SWEAA total, and SPIN total scores than ‘Autism only’. Three ‘Autism only’ participants and one ‘Autism+REDs’ participant reported that they smoked. There were no significant differences between both groups in age or in ADOS-2 RRBs subscale, ADOS-2 total, HAADS depression, HAADS anxiety, GSQ gustatory total, and GSQ total scores. However, non-significant effects here and in the subsequent analysis should be interpreted with caution, as the analysis might have been underpowered due to small and unequal sample sizes.

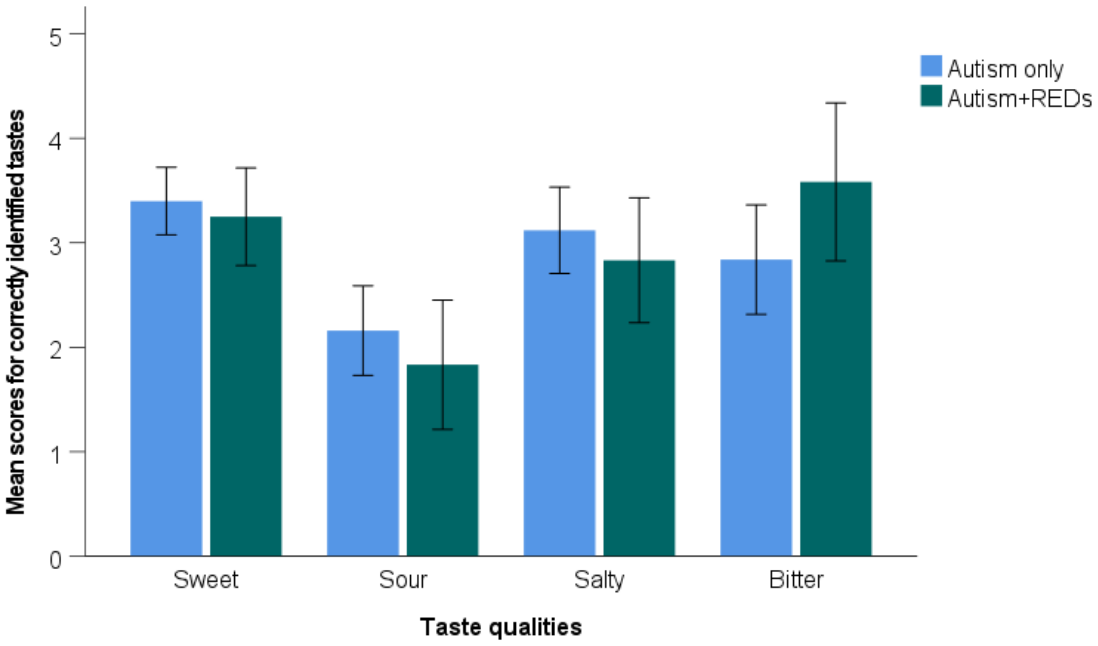
The average number of identified tastes, as well as the mean pleasantness rating overall and for each taste quality, were compared between groups to assess whether ‘Autism+REDs’ presented with better taste identification ability and whether they rated tastes as less pleasant than ‘Autism only.’ For correctly identified tastes, the assumption of equality of covariance was met, according to Box’s test (Box’s *M* = 20.90, *F*(10, 2251.40) = 1.77, *p* = .061). According to Levene’s test (see Table 1, Appendix 13), the assumption of equality of variance was met for all taste qualities

apart from bitter. Mauchly's test of sphericity indicated that the assumption of sphericity was met (χ^2 (5) = 6.41, p = .268).

The patterns of mean scores for correctly identified tastes across the different taste qualities (sweet, sour, salty, bitter) by group are presented in Figure 15.

Figure 15

Mean score for correctly identified sweet, sour, salty, and bitter tastes by group



Note. Error bars indicate 95% CI.

There was a significant main effect of taste quality (F(3, 105) = 16.38, ***p* < .001**, η_p^2 = .319), reflecting a tendency for participants across both groups to be less accurate at identifying sour tastes. There was no significant main effect of group (F(1, 35) < 0.00, p = .985, η_p^2 < .000). The main effect of group can be interpreted as a test of group difference on the total of correctly identified tastes, because it is the

sum of correctly identified tastes across the four taste qualities. The mean totals for the number of correctly identified tastes for each group are presented in Table 28.

Table 28

Mean totals of correctly identified tastes and accuracy scores for each group

	'Autism Only' (n = 25)	**'Autism+REDs' (n = 12)**
Mean (SD)	11.52 (3.33)	11.50 (2.20)
Accuracy (%)	72%	72.88%

There was a significant interaction effect between taste quality and group ($F(3, 105) = 2.85$, $p = .041$, $\eta_p^2 = .075$). Post-hoc pairwise comparisons between groups for each taste quality are presented in Table 29.

Table 29

Mean scores and SDs for correctly identified tastes and pleasantness ratings and pairwise comparisons between groups for each taste quality

	Taste Quality	**'Autism Only' (n = 25)**	**'Autism+ REDs' (n = 12)**	**Pairwise Comparisons With Bonferroni Adjustment for Multiple Comparison**
Correctly identified tastes	Sweet	3.40 (.71)	3.25 (.97)	Mean difference = .15, $p = .596$, $g = .187$, 95% CI [-.91–4.84]
	Sour	2.16 (.99)	1.82 (1.19)	Mean difference = .33, $p = .384$, $g = .346$, 95% CI [.-.43–1.08]
	Salty	3.12 (1.09)	2.83 (.84)	Mean difference = .29, $p = .428$, $g = .285$, 95% CI [-1.01–.44]
	Bitter	2.84 (1.49)	3.58 (.67)	Mean difference = -.74, $p = .110$, $g = .574$, 95% CI [-1.66–.18]
Pleasantness	Sweet	3.68 (.88)	3.83 (.74)	Mean difference = -.15, $p = .605$, $g = .179$, 95% CI [-.75–.44]
	Sour	2.83 (.83)	2.02 (.61)	Mean difference = .81, $\mathbf{p = .005}$, $g = 1.055$, 95% CI [.26–1.36]
	Salty	3.23 (.78)	2.38 (.75)	Mean difference = .86, $\mathbf{p = .003}$, $g = 1.103$, 95% CI [.31–1.41]

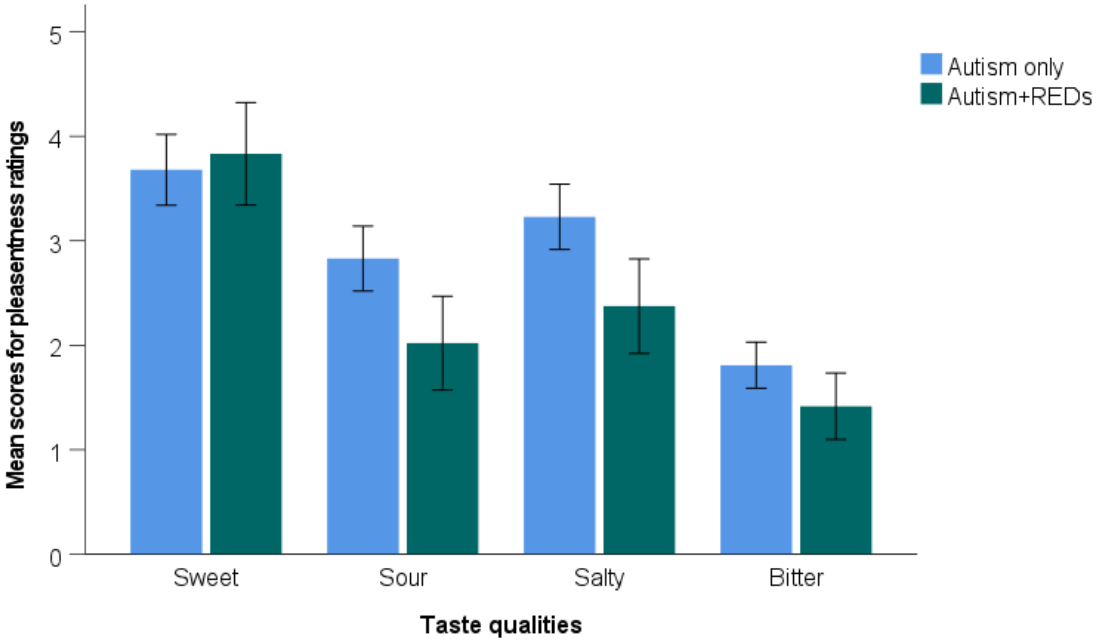
Bitter	1.81 (.62)	1.42 (.31)	Mean difference = .39, ***p* = .047**, *g* = .720, 95% CI [.01–.78]

There were no significant differences in the groups' abilities to correctly identify tastes for any of the taste qualities. The interaction effect could be driven by differences in the pattern of difference between taste qualities within groups. Specifically, although both groups identified significantly more sweet and bitter tastes correctly than sour tastes, the difference between salty and sour was significant for 'Autism only' (mean difference of .96, p = .006, 95% CI [.21–1.71]), but not for 'Autism+REDs' (p = .085). All effect sizes for group differences in correctly identified taste qualities were in the small or medium range (see Table 29).

For participants' ratings of how pleasant the tastes were, according to Box's test, the assumption of equality of covariance was met (Box's *M* = 13.13, *F*(10, 2251.40) = 1.11, *p* = .349). According to Levene's test (see Table 1, Appendix 13), the assumption of equality of variance was met for pleasantness ratings for all taste qualities. Mauchly's test of sphericity indicated that the assumption of sphericity was violated (χ^2 (5) = 14.72, *p* = .012); therefore, Huynh-Feldt corrections were applied (*ε* = .88). The patterns of mean scores for pleasantness ratings of tastes across the different taste qualities by group are presented in Figure 16.

Figure 16

Mean scores for pleasantness ratings of sweet, sour, salty, and bitter tastes by group



Note. Error bars indicate 95% CI.

There was a significant main effect of taste quality ($F(2.64, 92.37) = 46.83$, $p < .001$, $\eta^2 = .572$), a significant effect of group ($F(1, 35) = 13.82$, $p = .001$, $\eta^2 = .283$), and a significant interaction effect between taste quality and group ($F(2.64, 92.37) = 3.24$, $p = .031$, $\eta^2 = .085$). This indicates that there were differences in pleasantness ratings of tastes in each taste quality across groups, in pleasantness ratings across taste qualities between groups, and in the pattern of pleasantness ratings for each taste quality between groups.

Post-hoc pairwise comparisons between groups for each taste quality are presented in Table 29. 'Autism+REDs' rated sour, salty, and bitter (but not sweet) tastes as significantly less pleasant than 'Autism only.' All effect sizes for significant group differences were large (see Table 29).

Discussion

Patterns of Group Differences for General Hyper- and Hyposensitivity and Sensitivities Affecting Food-Specific Modalities

In the current chapter, we compared levels of general hyper- and hyposensitivity and of sensitivities affecting food-specific and other sensory modalities between (1) autistic women without REDs ('Autism only'), (2) autistic women with REDs ('Autism+REDs'), (3) non-autistic women with REDs ('REDs only'), and (4) women with REDs and high autistic traits ('REDs high autistic traits'). We repeated each analysis, controlling for age (partially adjusted model) and controlling for age and levels of co-occurring mental health difficulties (fully adjusted model) to determine whether group differences in these variables affected group differences in sensitivities.

'Autism only,' 'Autism+REDs,' and 'REDs high autistic traits' presented with higher levels of general and food-specific sensitivities compared to 'REDs only.' However, the levels of sensitivities among these groups were similar. Further, there was no evidence that the patterns of hyper- and hyposensitivities or of sensitivities affecting food-specific and other sensory modalities were different for 'Autism+REDs' and 'REDs high autistic traits' compared to the other two groups. There were no significant differences between 'Autism+REDs' and 'REDs high autistic traits' , appart from for general hypersensitivity, for which the 'REDs high autistic traits' group scored significantly lower than 'Autism+REDs'.

Across all analyses, age had very little impact on sensitivities in any of the groups. This is in line with other studies, which have found no significant correlation between age and self-reported levels of sensitivities in autistic adults and healthy controls (e.g. Crane et al., 2009). A meta-analysis of studies on sensitivities in autistic individuals reported that sensitivities are mostly stable throughout adulthood (Ben-Sasson et al., 2019), but is more susceptible to change in early development and late adulthood (Boyce & Shone, 2006; Pohl et al., 2003).

Controlling for differences in co-occurring mental health difficulties changed the pattern of group differences for a few GSQ subscales. In particular, 'REDs high autistic traits' presented with significantly lower scores on these subscales than 'Autism only' and 'Autism+REDs.' However, overall patterns of group differences were maintained, and levels of sensitivities in 'REDs high autistic traits' remained significantly higher than 'REDs only' for all general and food-specific subscales.

What Do These Findings Mean in Terms of the Role Sensory Sensitivities Might Play for REDs in Autistic Individuals?

The current study is the first to demonstrate that autistic women with REDs and women with REDs and high autistic traits present with significantly higher levels of general and food-specific sensitivities compared to other women with REDs. However, the similarities in sensitivities in autistic women with and without REDs does not support the idea that high levels of general and/or food-specific sensitivities could put some autistic women at risk of developing REDs. Instead, high levels of sensitivities in autistic individuals with REDs appear to be part of being autistic. Indeed, the observed patterns of group difference are similar to those of autistic traits, which were also lowest in 'REDs only,' similar in 'Autism only' and 'Autism+REDs,' and slightly lower in 'REDs high autistic traits' (see Chapter 4). Autistic traits might be driving hypersensitivity more so than hyposensitivity, which could explain a significant difference between 'Autism_REDs' and 'REDs high autistic traits' on one subscale, but not the other. They may also link to other co-occurring mental health difficulties, such as anxiety, particularly in 'REDs high autistic traits'.

This appears to contradict the findings of our qualitative study (Figure 12; see Chapter 2; Brede et al., 2020), which suggested a causal link between high levels of

sensitivities and restrictive eating difficulties in autistic individuals, and other evidence, such as the meta-analysis by Page et al. (2021), which identified sensitivities as one of the few factors that is consistently correlated with picky eating in autistic children. Further, the lack of elevated levels of food-specific sensitivities in autistic individuals with REDs contradicts findings from Chapter 4, where 'Autism+REDs' and 'REDs high autistic traits' presented with higher levels of autism-specific eating behaviours, as measured by the SWEAA (Karlsson et al., 2013), including the SWEAA perception subscale, which describes unusual eating behaviours resulting from sensitivities.

However, based on the current findings, we cannot reject the possibility that general or food-specific sensitivities contribute to REDs in autistic individuals. There are several potential explanations for our finding of no significant difference in levels of sensitivities between autistic women with and without REDs.

Methodological Limitations. First, we must consider the possibility that the measures used did not accurately capture the hyper- and hyposensitivity that affect individual sensory modalities. Even though the GSQ has good psychometric properties (see Chapter 3 for more details; Robertson &Simmons, 2013; Holder 2014), validation studies only considered the GSQ total score. Each GSQ item is meant to capture either hyper- or hyposensitivity for a specific sensory modality; however, some items have questionable face validity, in that it is not clear why they contribute to hyper- as opposed to hyposensitivity. For example, item (7) ("Do you smell your food before you eat it?") is counted toward olfactory hyposensitivity, even though this behaviour could equally result from olfactory hypersensitivity or sensory seeking differences. Similarly, some of the GSQ items counted toward one sensory modality could equally relate to another modality. For example, item (23) ("Do you

hate the feel or texture of certain foods in your mouth?") is counted toward gustatory sensitivity. However, in the context of the current study, it could be considered a sign of (oral) tactile sensitivity, as it describes a reaction to the mouthfeel of food textures. Principal component analysis of the GSQ, which was conducted as part of the as original measure development, suggested that a single-factor model was most appropriate when interpreting this measure (Roberston et al., 2012). Thus, individual GSQ subscales might not be as distinct as assumed in the current study, and they might not have accurately captured differences in levels of hyper- and hyposensitivity or in levels of sensitivities affecting different sensory modalities.

The interpretation of our finding that autistic women with REDs do not present with heightened levels of food-specific sensitivities is further complicated by the fact that the current study made assumptions about GSQ olfactory and tactile sensitivity subscale scores being indicative of sensitivity to the smell and texture of food, even though few items contributing to these subscales were food-specific. All items in the gustatory subscale related to food and eating. However, for the olfactory subscale, only two of the six items related to eating (e.g., (24) "Do you avoid going to restaurants because you can smell a certain odour?"), with the other items relating to olfactory sensations more generally (e.g., (17) "Are you ever told by others that you wear too much perfume/after-shave?"). For the tactile subscale, none of the items focused on food texture and the mouthfeel of food; rather, all items related to general tactile sensations (e.g., (22) "Do you cut the labels out of your clothes?"). Our qualitative study (Chapter 2, Brede et al., 2020) and other previous research led us to believe that sensory aversion to food textures could be important for food-specific sensitivities, but the GSQ tactile sensitivity subscale did not actually capture this. Instead, the subscale encompasses items referencing a broad range of sensory

experiences, including pain sensation, skin response to physical touch, and sensitivity to temperature. The relationship of these items to oral tactile sensitivity and the mouthfeel of food is uncertain. Even if there is a link between these broader tactile experiences and restrictive eating, different forms of tactile sensitivities could relate to REDs in different ways. While our qualitative data suggested a link between oral tactile sensitivity and aversion in response to food textures (Brede et al., 2020), see Chapter 2), other research found that women with AN experience affective touch as less pleasant and more intense compared to healthy controls, and proposes that this could contribute to distorted body representation in AN (Bischoff-Grethe et al., 2018; Crucianelli et al., 2016). A clear distinction between oral and other tactile sensitivities would have been desirable to disentangle potential differences in presentation between groups.

To the author's knowledge, no other existing self-report measures for sensitivities distinguish between food-specific and non-food-related tactile sensitivities (see DuBois et al., 2017 for an overview). This indicates a need for the development of a new measure that separates sensory response related to food and other stimuli across different modalities. This would allow for exploration of self-reported sensitivities to taste, smell, and texture of foods alongside general sensitives, and of the different ways these might contribute to REDs in autistic individuals.

Theoretical Explanations. Despite the possibility that the GSQ is not able to adequately distinguish between subscales and is not fully equipped to measure food-specific sensitivities, the pattern of total scores nonetheless suggests that sensitivities in autistic women with REDs are similar to those in autistic women

without REDs. There are a number of theoretical considerations that might explain the lack of difference in sensitivities between autistic women with and without REDs.

Firstly, it is possible that the presence of an RED modulates the sensory experience of autistic women with REDs. In line with our model (Figure 12), autistic women with REDs could have had higher levels of sensitives prior to the onset of their RED, and restricting their eating could have "reduced" their sensitives to similar levels as experienced by other autistic individuals. However, the fact that general sensitivities were not correlated with BMI in any of the group makes this unlikely. Longitudinal studies assessing sensitivities prior to and after the onset of REDs in autistic individuals would be needed to further explore this possibility.

Secondly, it is possible that high levels of sensitivities in autistic individuals on their own contribute to restrictive eating and unusual eating behaviours, but not disordered restrictive eating of a clinically concerning level. Indeed, autistic women without REDs in our study also reported eating and feeding difficulties and unusual eating behaviours in childhood, often driven by sensitivities, and presented with similar levels of supposedly autism-specific unusual eating behaviours to non-autistic women with REDs (see Chapter 4). Picky eating in response to sensory aversion is extremely common in autistic individuals, particularly when younger (Hubbard et al., 2014; Mayes & Zickgraf, 2019). Yet not all of these individuals develop an ED later in life. Emerging research on how autistic adults who experienced picky eating related to sensitivities in their youth have overcome their eating difficulties (Folta et al., 2020), as well as research on how autistic adults who continue to experience eating difficulties at a subclinical level cope in their day-to-day lives (Kinnaird, Norton, Pimblett, et al., 2019) could be of value for informing preventative approaches and helping autistic individuals in recovery from their REDs to manage their eating.

Finally, it might be that other factors, in combination with high levels of sensitivities, result in the development of REDs for some autistic individuals, but not others. Such interaction effects could involve shared risk factors with other non-autistic women within REDs. For example, in individuals with AN, sensitivities have been linked to emotional regulation difficulties (Merwin et al., 2013), self-disgust (Bell et al., 2017), and body image disturbances (Zucker et al., 2013), all of which are considered to play a causal role in traditional eating disorder presentations. Alternatively, there could be autism-specific pathways that link sensitivities with REDs in autistic individuals, for example, high levels of intolerance of uncertainty. Intolerance of uncertainty is characterised by a negative appraisal of and maladaptive response to situations that are ambiguous, unexpected, or unpredictable (Buhr & Dugas, 2009; South & Rodgers, 2017), and is heighted in autistic individuals (Vasa et al., 2018). Intolerance of uncertainty has been linked to sensory reactivity differences in autistic individuals, and the combination of both has been proposed to contribute to anxiety in autistic individuals (Hwang et al., 2020; Neil et al., 2016). Based on their qualitative investigation of autistic adults' sensory experiences, MacLennan et al. (2021) suggested that control and predictability of a sensory stimulus may be a conditional influence on whether the stimulus is experienced as pleasant or aversive. Thus, autistic individuals with higher levels of intolerance of uncertainty might feel a stronger need to control sensory stimuli to make them bearable, and might use restrictive eating behaviours as a strategy to reduce adverse sensory experiences. A need for control and predictability was mentioned by autistic women with AN in our qualitative investigation, and intolerance of uncertainty forms part of our proposed model of mechanisms underlying restrictive eating behaviours in autistic individuals (see Chapter 2). While high levels of

intolerance of uncertainty are also common in individuals with REDs, particularly AN (Brown et al., 2017; Sternheim et al., 2011), the link with sensitivities could be specific to autistic individuals with REDs. Future research should explore of other potential causal and maintaining factors, such as intolerance of uncertainty, in combination with sensitivities in both autistic and non-autistic women with REDs, before conclusions about the role of sensitivities in autistic individuals can be drawn.

The Potential Overlap of REDs in Autistic Individuals With ARFID

The fact that the 'Autism+REDs' group presented with higher levels of sensitivities than other women with REDs could suggest that autistic women's REDs might resemble ARFID, even though these women might have received a diagnostic label of AN or another RED. However, the current study also raised doubt about the direct link between heightened sensitivities and REDs in autistic individuals, as levels of sensitivities in autistic individuals with and without REDs were similar. It should be noted that our REDs groups predominantly included individuals with REDs diagnosis other than ARFID, and that findings may well be different in ARFID populations, for which sensory sensitivities play a more integral role (Bourne et al., 2020).The findings of the current chapter suggest that autistic women with other RED diangoses, such as AN, are unlikely to simply represent (misdiagnosed) autistic women with ARFID whose restriction is driven by sensitivities.

Nonetheless, the potential overlap between ARFID and other REDs in autistic individuals seems worth investigating further, as there could be superficial similarities in presentation of sensitivities, even though these might not be driving restrictive eating in all cases. Further, there is substantial heterogeneity in ARFID presentations and in the main drivers of food avoidance and restriction (Norris et al., 2018; Reilly et

al., 2019). Sensitivities are only one of several potential driving factors in ARFID that could be relevant for RED presentation in autistic individuals.

Similarities in Presentation of Autistic Women and Those With High Autistic Traits

It is noteworthy that, overall, sensitivities in the 'REDs high autistic traits' group were similar to those of 'Autism+REDs' and 'Autism only,' and that these three groups had the same pattern of group differences to 'REDs only'. This provides further evidence for the suggestion from Chapter 4 that the 'REDs high autistic traits' group may include undiagnosed autistic women. Where there were differences to 'Autism+REDs' and/or 'Autism only,' this was because 'REDs high autistic traits' scored somewhat lower than one or both of these groups. These differences became more apparent when controlling for differences in co-occurring mental health difficulties. However, if we assume that sensitivities are largely driven by autistic traits, lower levels of sensitivities in the 'REDs high autistic traits' group could be due to somewhat lower, but still clinically meaningful, levels of autistic traits in this group compared to 'Autism only' and 'Autism+REDs' (see Chapter 4).

Relationship of Sensory Sensitivities to BMI and Autistic Traits

The current chapter also tested whether general sensitivities were associated with BMI and autistic traits in each group. The lack of correlation with BMI suggests that sensitives in individuals with REDs do not merely present as a side effect of starvation (Slankster et al., 2020). This is in line with research that shows that higher sensitivities in individuals with AN persist after weight recovery (Zucker et al., 2013). As far as we are aware, this is the first study to assess the correlation between self-reported sensitivities and BMI in individuals with REDs.

The correlation with autistic traits across all groups further supports the suggestion that sensitivities are connected to autistic traits (although we cannot establish the direction of the relationship in this cross-sectional study). This is also in line with the pattern of group differences reported above, with groups with higher autistic traits ('Autism only,' 'Autism+REDs,' 'REDs high autistic traits') reporting significantly greater general sensitivities. The finding that correlations between sensitivities and autistic traits were also present in the 'REDs only' group suggests that this link extends to those with sub-clinical levels of autistic traits, and that autistic traits might still influence general sensory experiences in non-autistic individuals with REDs. These findings support the validity of the GSQ (Robertson & Simmons, 2013) as a measure of sensitivities typically seen in autistic individuals. These findings are also in line with studies that demonstrate a link between sensitivities and autistic traits in autistic people and the general population (Horder et al., 2014; Tavassoli et al., 2013). However, the findings are in contrast to studies with AN samples, which have either found no correlation between sensitivities and autistic traits (Bentz, Guldberg, et al., 2017; Kinnaird, Stewart, et al., 2020b) or have reported effects in the opposite direction, as in the case of Tonacci et al. (2019), who found that adolescents with AN with higher autistic traits presented with worse olfactory function. Studies with AN samples assessed associations between autistic traits and performance on psychophysical measures for specific sensory modalities, whereas our study and others (Horder et al., 2014; Tavassoli et al., 2013) used self-report measures of general sensitivities. Thus, it might be that differences in sensory reactivity and subjective experience of sensitivities, more so than differences in underlying sensory processing ability, are associated with autistic traits. Research

that uses a combination of self-report and psychophysical measures, as we initially intended in the current study, is still needed.

Taste Identification Ability and Pleasantness Ratings

The current chapter also compared more objective psychophysical assessments of taste identification ability (an aspect of gustatory sensitivity), as well as pleasantness ratings for different tastes, for a subset of 'Autism only' and 'Autism+REDs.' Findings were not supportive of a difference in taste ability between autistic individuals with and without REDs; this was true across the individual taste qualities (sweet, sour, salty, bitter) and for overall taste ability. However, the findings do suggest that autistic individuals with REDs might experience certain tastes as less pleasant than autistic individuals without REDs. Our hypothesis that 'Autism+REDs' would present with better taste identification ability than other autistic women was not supported. However, our hypothesis that 'Autism+REDs' would rate tastes as less pleasant than other autistic women was supported. Given the small number of participants in each group ('Autism only': n = 25; 'Autism+REDs': n = 12), which meant the analysis was underpowered (see Chapter 3), the lack of a group difference for correctly identified tastes should be interpreted cautiously. We cannot be certain that there is truly no difference between 'Autism only' and 'Autism+REDs' in terms of their ability to identify different tastes. However, these findings are in line with the lack of difference in self-reported total and gustatory sensitivities in this subset of participants and in the full sample.

Interestingly, the fact that autistic women with REDs rated sour, salty, and bitter tastes as less pleasant could suggest that it is not differences in the processing of gustatory stimuli, but the hedonic response and valence placed on those sensations, that result in restrictive eating behaviours. Autistic individuals who

develop REDs might be as sensitive to food-specific sensations as other autistic individuals, but might experience them as particularly unpleasant. Alternatively, they might find tastes less pleasant because of their RED. Studies suggest that individuals with AN present with altered reward processing of illness-related stimuli, including sensory characteristics of food, such as taste (Keating et al., 2012), although it is not clear whether inhibited reward response and adverse reactions to tastes precede the development of REDs or constitute a subsequent symptom (Kaye et al., 2013). Regardless, without a comparison group of non-autistic women with REDs, we cannot rule out the possibility that greater aversion to tastes in 'Autism+REDs' is merely part of RED presentation. This should be considered for future research. In addition, longitudinal designs should be employed to tease apart cause and effect.

Another issue with the present analysis is that the two groups differed in their levels of social anxiety and autistic traits (specifically, in their expression of social affect), which we did not control for so as not to further compromise the already limited power of the analysis. We also included a small number of individuals who smoked (n = 4), which might affect taste ability, although findings in previous studies did not tend to change after excluding participants who smoked (Kinnaird, Stewart, et al., 2020b). Future research that compares taste identification ability and pleasantness ratings in autistic women with REDs to other groups should account for differences in levels of autistic traits (if comparing to another group of autistic participants), differences in co-occurring conditions, and the effect of smoking.

Despite the lack of firm conclusions about taste identification, the inclusion of the taste test was valuable as proof of concept, in that it supports the feasibility of using the taste test to assess taste identification ability in autistic women with REDs.

It was accepted by autistic women with REDs, who could conceivably have refused the taste test administration, and generated valid data. Thus, it could be a useful tool for future research.

Treatment Implications for Autistic Women With REDs

The current study is the first to demonstrate that autistic women with REDs and those with high autistic traits present with significantly higher levels of general and food-specific sensitivities compared to other women with REDs. Regardless of whether sensitivities are contributing to the presentation of REDs in autistic women, high levels of sensitivities in autistic women and those with high levels of autistic traits warrant attention in ED services, as these features are likely to affect their treatment experience (Babb et al., 2021; Kinnaird, Norton, Stewart, et al., 2019).

It could be of value to routinely screen for sensitivities in individuals accessing treatment for REDs in order to identify individuals with specific sensory needs and inform treatment adaptations. Our results suggest that individuals with REDs who are autistic or have high autistic traits are likely to present with heighted sensitivities. In fact, sensory profiles might be a way to identify potentially undiagnosed autistic individuals. Further, even though the ‘REDs only’ group presented with lower sensitivities than the other groups, other studies have found that the levels of sensitivities in this group are still elevated compared to healthy controls (Bell et al., 2017; Zucker et al., 2013). Thus, women with REDs, regardless of their levels of autistic traits, might benefit from interventions targeting sensory wellbeing (Tchanturia, Baillie, et al., 2021).

Assessments of sensory needs could be of value for all individuals in ED service settings, although this seems to be particularly important in those with high autistic traits. Kinnaird, Dandil, et al. (2020) developed and piloted a brief pragmatic

sensory screener for use in ED settings. Although the psychometric properties of this tool have not yet been assessed, initial feedback from clinicians and patients was positive, and the screener appeared to be a useful starting point for discussions about individuals' sensory experiences (Kinnaird, Dandil, et al., 2020). Schaaf and Lane (2015) reviewed the literature on sensory assessments that have been validated for use with autistic individuals and provided recommendations for best practices. Their recommendations include using a combination of self-report and direct, observational measures; employing a comprehensive approach that assesses sensory reactivity, perception, and integration across different modalities; and involving multi-disciplinary teams, including occupational therapists (Schaaf & Lane, 2015). While this would require more time and resources, which might not always be available, such an approach could be employed by ED services following positive findings in initial screening and/or in individuals with a known (or suspected) autism diagnosis to get a full picture of their sensory needs.

Given high sensitives experienced by autistic individuals with REDs across various modalities, adapting the sensory environment in which treatment is provided might improve the accessibility of ED services. As will be discussed in more detail in Chapter 6, multiple qualitative studies have highlighted the perceived impact adverse sensory environments have on autistic adults' ability to access services and engage with treatment in ED and other mental health service settings (Brede et al., 2021). Aversive sensory stimuli have been found to affect autistic adults' ability to tolerate certain spaces and have been suggested to be a barrier for their engagement with these environments (Amos et al., 2019). This likely also applies to ED service settings, especially ward environments. Further, sensitivities might affect autistic individuals' social and communication skills and functioning during therapy sessions

(Cosbey et al., 2010). Accommodating sensitivities by adapting the service environment could be an essential step toward improving service experience for these individuals.

Further, once mechanisms of how sensitivities might relate to REDs in autistic individuals are explored, they could be considered as a target for treatment. Our finding that autistic women with and without REDs have similar levels of sensitivities suggests that sensitivities in autistic women with REDs should not necessarily be expected to reduce once these individuals are in recovery. If sensitivities are indeed part of being autistic, as the current study suggests, it might be difficult to teach autistic individuals with REDs to attenuate sensation. However, it could be useful to support autistic individuals with REDs to change their response to sensory experiences and to develop more adaptive coping mechanisms (Zucker et al., 2013). Longitudinal studies could provide a better understanding of how sensitivities in autistic individuals change (if at all) after RED recovery, and could be shed light on their potential as a target for treatment.

Finally, our findings suggest that high levels of co-occurring mental health difficulties might have some effect on the experience of sensitivities. Controlling for differences in levels of co-occurring mental health difficulties predominantly affects group differences involving the ‘REDs high autistic traits’ group. However, we only tested whether differences in co-occurring mental health difficulties impacted group differences in sensitivities, not how much they influenced levels of sensitivities overall. The changes to the estimated mean when moving from the unadjusted model to the fully adjusted model suggest that co-occurring mental health difficulties affected sensitivities in all groups. A link between sensitivities and co-occurring mental health difficulties, particularly anxiety, in autistic individuals is well established

(Green & Ben-Sasson, 2010; Hwang et al., 2020). Several theories to explain this link have been proposed. For example, there might be a bidirectional relationship, where high levels of sensitivities increase anxiety, which in turn increases sensitivities (Green et al., 2012; Mazurek et al., 2013). If a causal link between sensitivities and mental health difficulties in (autistic) individuals with REDs was to be confirmed, and the direction of that effect established, co-occurring mental health presentations should be considered when supporting women who struggle with sensitivities in ED settings. Depending on the direction of such a link, different adaptations could be possible. For example, adapting the treatment environment in ED settings to meet the sensory needs of those with high autistic traits could help to address other co-occurring mental health difficulties, which could in turn increase efficacy of treatment targeting RED symptoms (Hughes, 2012; Kezelman et al., 2015). Conversely, addressing co-occurring anxiety and/or depression in autistic women with REDs might reduce their adverse experiences of sensory stimuli, which in turn could ease their RED presentation.

Conclusion

The current study is the first to explore sensitivities in autistic women with REDs. In addition, it lays the groundwork for future research by bringing to light methodological and theoretical considerations associated with sensory sensitivities in autistic and RED populations.

We demonstrated that autistic women and women with high autistic traits present with higher levels of general and food-specific sensitivities compared to non-autistic women with REDs, regardless of RED status. However, even though autistic women told us they felt sensory sensitivities were implicated in the development and maintenance of their REDs (see Chapter 2), the current study is not supportive of a

direct causal link between high levels of sensitivities and REDs in autistic individuals. Levels of sensitivities in autistic women with and without REDs were similar. This also applied to women with REDs and high autistic traits. Further, there was no clear evidence that sensitivities in autistic women with REDs and women with REDs and high autistic traits are driven by higher levels of hypersensitivity or food-specific sensitivities relative to the other groups. Instead, high levels of sensitivities appear be primarily linked to being autistic.

The finding of similar levels of food-specific sensitivities in autistic women with and without REDs could be explained by a failure to appropriately capture sensitivities affecting different food-specific modalities. There is potential for the development of a new measure that separates sensory response related to food and other stimuli across different modalities.

Future research should continue to explore sensitivities in both autistic and non-autistic individuals with REDs, particularly in combination with other potential contributing factors. Further, there might be difference in the subjective experience of sensitivities and underlying sensory processing ability. Research using a combination of self-report and psychophysical measures, as we initially intended, is still needed.

Regardless of whether sensitivities are contributing to REDs in autistic individuals, services should be aware of high levels of sensitivities in autistic individuals with REDs and those with high autistic traits, as these sensitivities are likely to affect their treatment experience. Thereby, it will be important to consider interactions with other co-occurring mental health difficulties.

Chapter 6: "*We Have to Try to Find a Way, a Clinical Bridge*" - Autistic Adults' Experience of Accessing and Receiving Support for Mental Health Difficulties: a Systematic Review and Thematic Meta-Synthesis

This chapter is a version of a manuscript currently under review at *Clinical Psychology Review* (Brede et al., 2021). The full reference for this submitted manuscript is:

Brede, J., Cage, E., Trott, J, Palmer, L., Smith, A., Serpell, L., Mandy, L., Russell, A. (2021). "We Have to Try to Find a Way, a Clinical Bridge" - Autistic Adults' Experience of Accessing and Receiving Support for Mental Health Difficulties: a Systematic Review and Thematic Meta-Synthesis. *Under review: Clinical Psychology Review.*

Introduction

The current chapter presents Study 3 of this thesis, which consists of a systematic review and meta-synthesis of qualitative research on autistic adults' experiences of accessing mental health services. This study is taking a broader approach, considering the experience of autistic adults in mental health services more generally, rather than looking at ED services specifically, as this allows to draw on a more extensive evidence base, and autistic adult's experience in other mental health settings and proposed adaptations are likely to be relevant in the context of supporting autistic women with REDs. The purpose of this study was to establish perceived barriers and ways to overcome them for autistic adults accessing and engaging with support for mental health difficulties, with a view for these findings to be of relevance for to improving ED services for autistic people.

Autistic adults are at high risk of having co-occurring mental health difficulties, and existing service provision is not currently meeting their resultant support needs

(Joshi et al., 2013). Several studies have explored autistic adults' experiences in mental health services, reporting on the perspectives of autistic adults themselves, family members and professionals working in mental health care settings, and there is a need to synthesise these perspectives to inform efforts to improve service provision for this population. The current chapter presents a systematic review and meta-synthesis of studies utilising qualitative methodologies to investigate autistic adults' experiences of accessing and receiving support for mental health difficulties.

Recently, there has been increased interest in understanding the presentation, experiences and support needs of autistic adults (Murphy et al., 2016; Wise, 2020). This reflects a growing recognition in clinical practice and research that autism occurs across the lifespan, not just in childhood. Those diagnosed in childhood become adults, and increasingly many autistic individuals are diagnosed in adulthood, due to changes in diagnostic criteria (Bent et al., 2017), growing awareness of variation in autistic presentations (Dillenburger et al., 2013), and increased screening (Gernsbacher et al., 2005).

Autistic adults experience elevated rates of co-occurring mental health conditions compared to the general population (Croen et al., 2015; Joshi et al., 2013; Lai et al., 2019). The presence of co-occurring mental health problems affects quality of life and wellbeing of affected individuals (Mason, Mackintosh, et al., 2019) and their families (Herrema et al., 2017), and can contribute to premature mortality (Hirvikoski et al., 2016). Despite this, service provision for autistic adults with co-occurring mental health difficulties is insufficient: Autistic adults report higher levels of unmet mental health needs compared to non-autistic adults (Nicolaidis et al., 2013) and children on the spectrum (Turcotte et al., 2016), and autistic adults with

mental health difficulties report being less satisfied with services than those seeking support for physical health difficulties (Vogan et al., 2017).

Both policy and the autism community view mental health care for autistic individuals, and specifically adults, as a priority. For example, the World Health Organization (WHO, 2013) has recognized unmet needs of autistic adults as a public health concern and highlighted the importance of a life-course perspective for autistic people. In England, the Autism Act (2009) was put into place to ensure that the needs of autistic adults and their family members are met, and updates to the Act emphasised the need for greater autism awareness in adult mental health services (Department of Health, 2015). In addition, the National Health Services (NHS) long-term plan published in 2019 makes improving the health and wellbeing of autistic individuals a priority for healthcare developments in the next ten years (NHS, 2019). In line with this, an online survey of UK stakeholders identified 'How can public services best meet the needs of autistic people?' as one of the top autism research priorities across stakeholders (N=1624), including autistic adults, family members, practitioners and researchers (Pellicano et al., 2014). Another survey with 255 autistic adults and 143 representatives of adults with high support needs in the US found 'improving public services', 'health care access', and 'public acceptance' to be key priority research areas (Gotham, Marvin, et al., 2015). A UK community priority exercise recognised identifying suitable interventions and adapting existing treatments and services to better meet the needs and improve the mental health of autistic individuals among autistic people's top ten research priorities (Cusack & Sterry, 2016).

To inform efforts to improve the accessibility and effectiveness of mental health services, including ED services, for autistic adults, a critical first step is to

generate a better understanding of their experiences in existing mental health services. Qualitative research in particular has the potential to document the complexity and variety of experiences (Lachal et al., 2017) and to suggest explanations for why specific factors might promote or hinder successful service provision (Hannes et al., 2013). There have been various studies investigating different aspects of autistic adults' experience in general and mental health services. However, on their own, qualitative studies are rarely used to inform services provision (Lachal et al., 2017). Recently, systematic reviews have attempted to bring together different studies on autistic individuals' healthcare experience, including both qualitative and quantitative studies. Existing reviews focused on physical health care for autistic adults (Calleja et al., 2019; Mason, Ingham, et al., 2019) and on barriers and facilitators to accessing psychological treatment, but reporting these combined for both autistic children and adults (Adams & Young, 2020).

The current study adds to existing insights by synthesizing qualitative studies to explore the broader experience of accessing and engaging with support for mental health difficulties, focusing on autistic adults specifically. This review is also distinct in that it combines the perspectives of autistic adults themselves with those of parents/carers and healthcare professionals, who may support autistic adults in accessing and engaging with services. Different stakeholder groups will experience issues related to service provision for autistic individuals in different ways (Shattuck et al., 2020). Triangulating perspectives can enrich our understanding of available support, as well as giving insight whether others involved in autistic adults' care understand their experience (Carter et al., 2014). Additionally, we employed a meta-synthesis approach to combine study findings. Meta-syntheses offer an in-depth, systematic approach to combine perspectives from qualitative studies and bring

together a broad range of participants' perspectives (Lachal et al., 2017). By identifying patterns and developing an overarching interpretation of studies included in the synthesis, we can generate new insights beyond the findings of individual studies (Barnett-Page & Thomas, 2009). Accordingly, meta-syntheses are particularly well suited to identifying research gaps and providing evidence for the development, implementation, and evaluation of healthcare interventions and policies (Lachal et al., 2017; Tong et al., 2016). Therefore, the aim of the current study was to systematically review and meta-synthesize qualitative studies on autistic adult's experiences of accessing and engaging with support for mental health difficulties, from the perspectives of autistic adults, their parents/carers and healthcare professionals.

Methods

We conducted a systematic review of existing literature and used thematic meta-synthesis (Thomas & Harden, 2008) to combine the findings of identified studies, using qualitative methodology to elucidate autistic adults' experiences of accessing and receiving mental health support. Thematic meta-synthesis (Thomas & Harden, 2008) is a method of reviewing qualitative research to address questions about people's perspectives and experiences in a systematic way. It is one of multiple meta-synthesis/ethnography approaches (Barnett-Page & Thomas, 2009). It was developed and is primarily used in the context of reviewing research to inform health promotion and public health programmes (Lachal et al., 2017; Thomas & Harden, 2008), and was therefore thought to be well suited for the current study.

The study was the product of a larger review exercise initiated by the 'Autistica mental health study group', an interest group bringing together autistic people, parents, researchers and professionals to co-develop strategic initiatives to

facilitate high-quality research on mental health in autism (Autistica, 2018). A subset of this group joined the team for this research project, actively contributing to the systematic review and meta-synthesis process. The systematic review protocol was pre-specified and pre-registered (PROSPERO ID: 163706), and findings are reported in line with PRISMA guidelines (Moher et al., 2009).

Eligibility Criteria

This review focused on empirical peer-reviewed qualitative and mixed-method studies (including unpublished doctoral dissertations). Participants had to include autistic adults (with or without co-occurring intellectual disability (ID), aged 16 years or older), and/or their parents/carers, and/or healthcare professionals working with autistic adults in a field related to mental health care provision, including gatekeepers, such as family doctors. Studies had to explore autistic adults' experiences of accessing and receiving support for mental health difficulties. Research on physical healthcare provision, experiences of accessing other support services or experiences in adulthood more generally were only included if they made direct reference to mental health care. They had to either ask specific questions about mental health services experiences, or report on this because participants had brought this up in response to general questioning. Only publications in English were included due to lack of resources for translation.

Information Sources

We conducted electronic database searches in three bibliographic databases (MEDLINE, PsycINFO and Embase) within the Ovid interface in December 2019, which was repeated in December 2020 to identify any additional publications[2].

[2]The original protocol specified additional searches on NICE evidence search, British Library EthOS and Google scholar. However, since the other elements of the search strategy produced more extensive results than anticipated, this was deemed no longer necessary.

Reference lists of included studies, relevant position pieces and existing systematic reviews on related topics were manually scanned for additional studies. Experts in the field were contacted to obtain any missed studies.

Search

The search strategy was developed with the help of a subject librarian. Similar search terms and operators were used for all database searches. The searches combined text words and MeSh terms, or equivalent subject headings, related to the concepts of ‘autism’, ‘mental health’, ‘service provision’ and ‘experience’. No restrictions for date of publication were applied. The full search strategy is available in Appendix 14.

Study Selection

Screening was conducted in two stages. First, the title and abstract of all identified studies were screened against the pre-established inclusion and exclusion criteria. Second, the full texts of potentially relevant studies or those where more information was required were assessed for eligibility. At this stage a rationale for excluding any paper was recorded.

Two reviewers (JB and EC) conducted inter-rater checks to ensure inclusion and exclusion criteria were applied consistently across all papers. One reviewer screened all papers at both stages of the screening process. The second reviewer blindly screened 11% of randomly selected papers at stage one, with 99% agreement, and 25% at stage two, with 85% agreement. Any disagreements were resolved by discussion. Two other members of the research team (WM and AR) were consulted to confirm these decisions. After discussing any points of uncertainty, they agreed with the other two reviewer’s ratings and rationale for exclusion. The

second reviewer then checked the first reviewer's decisions for the remaining papers at stage two to confirm the final set of included studies.

Data Collection Process

We developed a list of study characteristics of interest in collaboration with the Autistica mental health study group and refined it through discussion with the research team. One reviewer (JT) extracted key characteristics from included studies and a second reviewer (JB) checked the extracted data.

Risk of Bias in Individual Studies (Quality Assessment)

Quality assessment was performed using the Mixed Methods Appraisal Tool (MMAT- Version 18, Hong et al., 2019). The MMAT has good validity and reliability (Hong et al., 2019). It was chosen because it is designed to appraise the methodological quality of studies with diverse designs, including studies using qualitative and mixed methodologies, and thus allowed us to appraise all studies utilising the same tool. We used the 2018 version of the MMAT (Hong et al., 2019), which consisted of 2 screening questions, followed by five items specific to the study design. Mixed method studies were rated on a total of 15 items; five items for each for the qualitative and quantitative element of the study, as well as five additional items to determine the integration of these elements. Total methodological quality scores were calculated based on the percentage of criteria met. Only qualitative elements of the mixed-method study were included in the synthesis, but the methodology scores are reported for the whole study as it was published.

Two reviewers (JB and EC) conducted the appraisal process to confirm eligibility and determine overall quality scores for each study. They independently rated 10% of the studies (82% agreement) and discussed any discrepancies until agreement was reached. One reviewer then rated all papers and the other reviewer

reviewed these ratings. Any disagreements were discussed until resolved. No studies failed to meet the two screening criteria, and thus all studies were included irrespective of their methodological quality scores. While the researchers were mindful of quality scores, they also considered other study characteristics, including the specificity of overall study aim to autistic adults' mental health service experience, when conducting the meta-synthesis.

Synthesis of Results

A meta-synthesis of qualitative data was conducted following guidelines for thematic synthesis (Lachal et al., 2017; Thomas & Harden, 2008). Thematic synthesis has three interlinked stages: the coding of text 'line-by-line'; the development of 'descriptive themes'; and the generation of 'analytical themes' (Thomas & Harden, 2008). NVivo software (NVivo, 2018) was used to aid the analysis, using electronic copies of the articles as primary documents. First, all papers were read and re-read to stimulate consideration of potential codes and themes. Second, we conducted line-by-line coding of the results section of each paper, applying codes to all sections relevant to autistic adults' mental health service experiences. Codes were created inductively to capture the meaning and content of each sentence, sometimes applying multiple codes to one section. Third, codes across articles were grouped and categorised to construct descriptive themes. At this stage codes and initial themes were extracted to Excel (Microsoft Corporation, 2018), to aid exploration of relationships between codes and themes. Finally, through further interpretation of the descriptive themes in relation to the research aim and discussion within the research team, analytical themes were created. While the descriptive themes had remained 'close' to the original studies (Lachal et al., 2017), this stage 'moved beyond' these, generating new interpretive constructs (Thomas &

Harden, 2008). The researchers moved back and forward between these steps until the final set of analytical themes was felt to sufficiently describe and/or explain the initial descriptive themes. The resulting meta-synthesis is a third-order account of autistic adults' experience of mental health services, as it is the researchers' interpretation of other authors' interpretation of participants' reports.

We employed a collaborative approach, with all members of the research team contributing to the analytic process. The research team consisted of a diverse group of researchers, clinicians and autistic adults, some of whom had personal experience with mental health care and/or had supported autistic individuals with accessing services. This approach was considered to be important, as each researcher were likely to view themes in light of their own experience and knowledge, which would influence their judgment about the relevance of a theme and how to describe it (Braun & Clarke, 2019; Toye et al., 2014). Bringing together different perspectives not only enriched the final interpretation, but also allowed us to challenge individual assumptions.

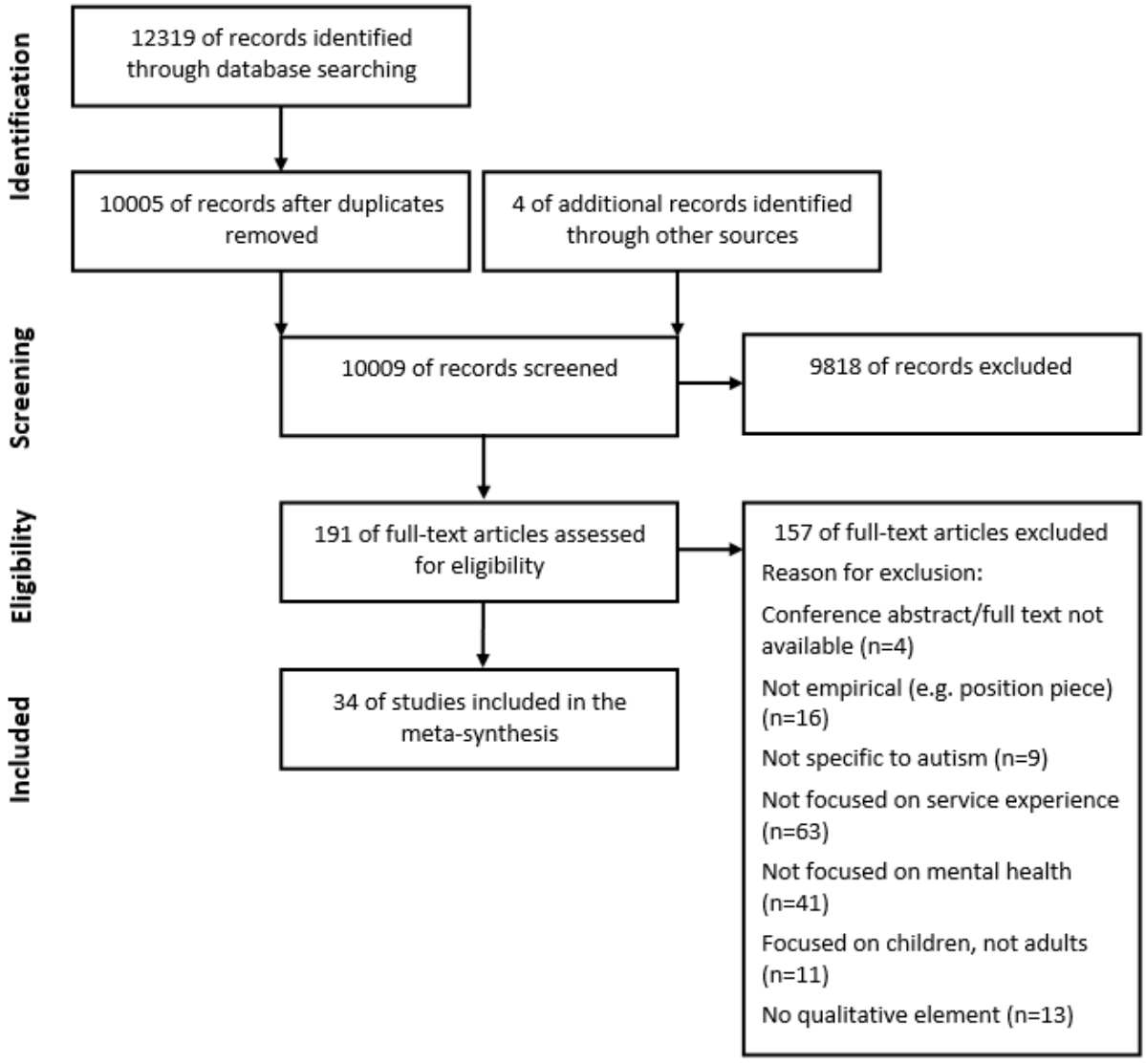
Results

Study selection

The flow of information through each stage of the systematic review is presented in Figure 17. The combined database searches identified 12,319 records, reduced to 10,005 after duplicate removal. Four additional papers were identified by screening reference lists of included papers and asking experts in the field. The title and abstract of 10,009 records was screened. Full text screen was conducted for 191 references. This procedure identified 34 relevant studies - details of exclusions are noted in Figure 17.

Figure 17

PRISMA diagram showing flow of information through the different phases of a systematic review



Study Characteristics

Key characteristics of each study are presented in Table 30.

There were 26 qualitative studies and eight mixed-method studies. All included studies (n=34) were published from 2012 onwards, with the majority (N=27) published after 2015. Twenty-three studies were conducted in the UK, seven in the US, three in Canada and one in Belgium. Twenty-two studies included first person

accounts from autistic adults, eight from family members and eleven from professionals; seven included multiple participant groups. In total, 807 autistic adults, 118 family members and 875 professionals were included as participants. Eight studies reported using a participatory approach, with members of the autism community actively involved in shaping and/or conducting the research.

Nineteen studies directly focused on autistic adults' experience in mental health services. Ten of these focused on a specific mental health difficulty (three on eating disorders, two on anxiety, two on depression, one on social anxiety, one on ADHD, one on suicidality and self-harm). Six focused on a specific treatment approach or setting (two on guided self-help/CBT, one on medication use, on inpatient care, one on high secure psychiatric hospital and one on general practice). The remaining studies explored experiences in non-specialist healthcare, in other support settings, and of the life of autistic adults more generally, but all included mention of mental health care. Thirteen studies focused on specific groups of autistic adults (eight on young adults, three on autistic women, one on students in higher education and one on older adults).

Twenty-two studies reported on whether autistic adults themselves, parents' children or professionals' clients presented with co-occurring ID. Thirteen focused exclusively on the experience of autistic adults without ID, whereas eight, predominantly those using parental report, looked at the experience of autistic adults of whom some (N=6) or most (N=2) had co-occurring ID.

Twenty-seven studies included autistic individuals and/or their parents, all of which reported autistic adults' gender. Two studies had an all-female sample, and one study included all females apart from two participants identifying as non-binary. Most remaining studies included more males than females, but the proportion of

male participants ranged from 38.5-89%. Two studies reported including participants identifying as non-binary or transgender.

Two studies included possibly autistic adults (without a formal autism diagnosis). Sixteen of the 27 studies reported the age at which autistic adults had received their autism diagnosis. Six of these, often with a focus on young adults, reported mostly on the experience of adults who had been diagnosed in childhood. Five studies included participants for whom age of diagnosis ranged widely, covering both child- and adulthood, and five included participants who had predominately or exclusively received their autism diagnosis in adulthood.

Thirteen studies of the 27 studies reported the ethnicity of autistic adults. For two studies all participants identified as White. For seven studies more than 90%, for 11 studies more than 80% and for one study 73% of participants were described to be White. Only one study had a more diverse sample with 50% (n=4) of participants reporting to be of Asian or Latino heritage. Five out of 11 studies that included professionals reported on their ethnicity. The majority of professionals were White (min 69.9%; see Table 30 for other ethnicities included).

Risk of Bias Within Studies (Quality Assessment)

Total methodological quality scores based on the MMAT (Hong et al., 2019) are reported in Table 30. Detailed ratings on each item can be found in Appendix 15. Overall, the quality of included studies was high. For the qualitative studies, 23/27 studies met 100% of quality criteria and one study met 80%, because the study did not state the analytic approach used. For the mixed method studies, five met over 80%, two met 66.6% and one met 40% of the quality criteria. The main issues were the samples' limited representativeness of the target population (e.g. high proportion

of females, majority of participants being highly educated) and lack of explicit integration of findings from the qualitative and quantitative elements of the studies.

Table 30

Overview of identified studies, methodological quality scores and key study characteristics

Study ID	Authors	Year	Quality score (MMAT)	Location	Main focus	Method	Participant group(s)	Participants ethnicity	Autism diagnoses; Age at diagnosis (yrs)	Co-occurring ID	Age of autistic adults (yrs)	Gender of autistic adults	Co-occurring mental health difficulties
1	Adamson, Kinnaird, Glennon, Oakley & Tchanturia	2020	5/5; 100%	UK (n=9), USA participants (n=1)	Carers perspectives on their autistic daughters' experience of AN, including treatments	Qualitative: Semi-structured interviews. Thematic analysis	Parents/carers of autistic adult daughters with AN (n=10)	Not specified	Autism diagnoses not specified; Mean, range = 15, 9-23	Not specified	Range = 16-25	All female (n=10)	AN and at least one co-occurring diagnosis, most commonly OCD and GAD
2	Ainsworth, Robertson, Welsh, Day, Watt, Barry, Stanfield & Melville	2020	5/5; 100%	UK, Scotland	Practitioners perspectives on presentation and treatment of anxiety in autistic adults	Qualitative: Semi-structured interviews. Thematic analysis	Practitioners current/past experience working with autistic individuals with anxiety (n=8)	Not specified	Not specified	Not specified	Adults, not further specified	Not specified	Anxiety
3	Anderson & Butt	2018	5/5; 100%	US	Parents' perspective on general service provision & transitions for young autistic adults, some mention of access to mental health services	Qualitative: Unstructured interviews .Analysis used constant comparative method	Parents of autistic young adults (n=35)	83% White (n=30), 11% Black/African American (n=4), 6% Other (n=2)	31% Autism (n=11), 36% Asperger's syndrome (n=13), 33% PDD-NOS/other ASD (n=12); 36% aged 0-3(n=13), 17% aged 4-7 (n=6), 47% aged 8 or above (n=17)	39% ID, details on severity level/support required provided	Mean, range = 23.2, 19-31	19% Female (n=7), 81% Male (n=29)	67% Anxiety disorder (n=24), 47% Mood disorder (n=17), 28% OCD (n=10), 8% Psychosis (n=3), 19% Seizures (n=7)
4	Anderson, Lupfer & Shattuck	2018	5/5; 100%	US, Maryland and the District of Columbia	Parents perspective on transition experiences of young autistic adults, some mention of support for co-occurring mental health difficulties	Qualitative: Unstructured interviews. Analysis used constant comparative method (grounded theory)	Parents of offspring diagnosed with ASD (n=20)	90% White (n=18), 100% non-Hispanic (n=20)	35% Autism (n=7), 30% Asperger's syndrome (n=6), 15% PDD-NOS (n=3) 20% Other ASD (n=4); 50% aged 0-3(n=10), 15% aged 4-7 (n=3), 40% aged 8 or above (n=8)	40% ID (n=8)	Mean = 24.0	25% Female (n=5), 75% Male (n=15)	Not specified

Study ID	Authors	Year	Quality score (MMAT)	Location	Main focus	Method	Participant group(s)	Participants ethnicity	Autism diagnoses; Age at diagnosis (yrs)	Co-occurring ID	Age of autistic adults (yrs)	Gender of autistic adults	Co-occurring mental health difficulties
5	Au-Yeung, Bradley, Robertson, Shaw, Baron-Cohen & Cassidy	2019	14/15; 93%	UK	Autistic adults experience of mental health diagnoses and perceived misdiagnosis	Mixed: Online survey including open-ended questions. Thematic analysis. Participatory approach: Study developed in partnership with a steering group	Autistic (n=208), possibly autistic (n=71), non-autistic (n=141) adults	Not specified	Autism diagnoses not specified; Mean (SD), range= 34.5 (12.2), 4–59	Not specified	Mean (SD), range = 38.6 (11.4), 18-67	Autistic participants: 34.6% males (n=72)	88% reported co-occurring mental health difficulties. % for individual conditions provided (depression, anxiety, OCD, personality disorder, feeding or eating disorders, bipolar, psychotic disorders, trauma, gender dysphoria, dissociative disorders, substance abuse)
6	Camm-Crosbie, Bradley, Shaw, Baron-Cohen & Cassidy	2019	5/5; 100%	UK	Autistic adults experience of treatment and support for mental health problems, self-injury and suicidality	Mixed: Online survey including open-ended questions. Thematic analysis. Participatory approach: Study developed in partnership with a steering group	Autistic adults (n=200)	Not specified	% of diagnoses reported by gender (Asperger's syndrome/high functioning autism, autism, PDD, other); Mean, range = 34.1, 2-59, some participants diagnosed in childhood.	None	Mean, range = 38.9, 18-67	61% Female (n=122), 38.5% Male (n=77), 0.5% unreported (n=1)	90.4% reported a mental health diagnosis, most commonly depression and anxiety. % for individual conditions provided.
7	Cheak-Zamora & Teti	2015	5/5; 100%	US	Young autistic adults and their caregivers experience of health care transition, some mention of mental health services	Qualitative: Semi-structured focus groups. Thematic analysis	Autistic youth (n=13), caregivers (n=19)	Not specified	Not specified	Yes, details on ability level provided	Range = 15-22	25% Female (n=2), 85% Male (n=11)	Not specified
8	Coleman-Fountain, Buckley & Beresford	2020	5/5; 100%	UK	Young autistic adults experience of managing mental health problems through primary care	Qualitative: Semi-structured interviews. Thematic analysis. Participatory approach: Two supporting advisory panels	Autistic young adults (n=19)	All but one white British'	Autism diagnoses not specified; 'Most received diagnosis before 8 years'	None	Range = 23-24	11% Female (n=2), 89% Male (n=17)	All had experience of mental health problems. Screening for anxiety depression and OCD reported, but not formal diagnoses

Study ID	Authors	Year	Quality score (MMAT)	Location	Main focus	Method	Participant group(s)	Participants ethnicity	Autism diagnoses; Age at diagnosis (yrs)	Co-occurring ID	Age of autistic adults (yrs)	Gender of autistic adults	Co-occurring mental health difficulties
9	Cooper, Loades & Russell	2018	12/15; 80%	UK	Practitioners (therapists) experience of working psychologically with autistic adults	Mixed: Survey including open-ended questions. Content analysis	Psychological therapists (n=54) attending workshop on CBT for autistic clients	Not specified	Not specified	Not specified	Not specified	Not specified	Not specified
10	Coxon	2016	5/5; 100% (both studies)	UK	Autistic adults and practitioners experience of psychological therapies (two separate chapters)	Qualitative: Practitioners: Interviews. Interpretative phenomenological analysis Autistic adults: Semi-structured interviews. Grounded theory approach	Practitioners (n=6), autistic adults (n=7)	Practitioners: All white British. Autistic adults: 6/7 Caucasian British, one Caucasian/Asian	'High-functioning autism disorder'; mean, range = 7.7, 2-33; individual ages provided	None	Range = 21-38	43% Female (n=3), 57% Males (n=4)	Not specified
11	Crane, Adams, Harper, Welch & Pellicano	2019	13/15; 87%	UK; % from different regions provided	Young autistic adults mental health experience, including support needs and experience of service provision	Mixed: Online survey and semi-structured interviews with separate participant group (only interview data included in meta-analysis). Thematic analysis. Community-Based Participatory Research (CBPR) approach	Young autistic adults: (n=21)	95.2% White (n=20), 4.8% Mixed (n=1)	28.6% Asperger's syndrome (n=6), 9.5% Autism (n=2), 42.9% ASD/C (n=9), 9.5% Pervasive developmental disorder (n=2); Mean, range=14.68, 4-22	None	Mean, range = 20.90, 16-25	47.6% Female (including transgender female) (n=10), 42.9% Male (including transgender male) (n=9), 9.5% Non-Binary (n=2)	% with co-occurring conditions provided (anxiety, ADHD, bipolar disorder, depression, developmental coordination disorder, dyslexia, epilepsy, fragile X, OCD, PTSD, schizophrenia, Tourette's)
12	Crane, Davidson, Prosser & Pellicano	2019	12/15; 80%	UK; % of psychiatrists practicing in different regions provided	Psychiatrists autism knowledge, attitudes and experiences of working with autistic individuals,	Mixed: Online survey including open-ended questions. Thematic analysis	Psychiatrists (n=172)	69.8% White (n=120), 2.3% Black (n=4), 19.2% Asian (n=33), 3.5% Mixed (n=6), 1.2% Other (n=2),	Not specified	Not specified	Not specified	Not specified	Not specified

Study ID	Authors	Year	Quality score (MMAT)	Location	Main focus	Method	Participant group(s)	Participants ethnicity	Autism diagnoses; Age at diagnosis (yrs)	Co-occurring ID	Age of autistic adults (yrs)	Gender of autistic adults	Co-occurring mental health difficulties
					some mention of mental health support for autistic adults			4.1% Prefer not to say (n=7)					
13	Elichaoff	2015	5/5, 100%	UK	Autistic adults experience of growing older, experience with mental health professionals as a subtheme	Qualitative: Semi-structured interviews. Thematic analysis	Autistic adults (n=4)	All White British (n=4)	Asperger's syndrome/ASD; Age not specified	None	Range= 58-63	50% Female (n=2), 50% Male (n=2)	Depression
14	Griffith, Totsika, Nash & Hastings	2012	5/5; 100%	UK, Wales	Autistic adults general support experience and needs, some mention of mental health service experience	Qualitative: Semi-structured interviews. Interpretative phenomenological analysis	Autistic adults (n=11)	Not specified	Asperger's syndrome; Mean, range = 37.89, 19-50; Two participants were seeking diagnostic assessment at time of study	None	Mean, range = 46.36, 37-57	36% Female (n=4), 64% Male (n=7)	'Many participants suffer from anxiety and/or depression'
15	Henry	2014	5/5; 100%	US	Autistic adults and family members' perceptions of barriers to support services in employment and health care, some mention of mental health	Qualitative: Phenomenological approach to interviews. Narrative analysis	Autistic adults (n=5), relatives (n=3)	Caucasian (n=4), Asian (n=2), Latino (n=2)	Autism, Asperger's syndrome; One person was diagnosed in adulthood, no further details provided	1/5 had ID	23,27,24, 23,55	20% Female (n=1), 80% Male (n=4)	3/5 experienced co-occurring mental health difficulties, including social anxiety, depression, oppositional defiance disorder
16	Jordan, Marczak & Knibbs,	2020	5/5; 100%	UK	Autistic adults experiences of low mood and depression, some mention of experience interacting with services	Qualitative: Semi-structured interviews, supported by a mood diary and feeling wheel visual aid. Interpretive Phenomenological Analysis. Participatory approach: Autistic adults commented	Autistic adults (n=8)	Not specified	Asperger's syndrome (N=8); Childhood (N=2), adulthood (N=6); Age not further specified	None	Mean (SD), range = 31.75 (12.7), 19-51	12.5% Female (N=1), 87.5% Male (N=7)	Depression (n=6), the two remaining participants experienced low mood

Study ID	Authors	Year	Quality score (MMAT)	Location	Main focus	Method	Participant group(s)	Participants ethnicity	Autism diagnoses; Age at diagnosis (yrs)	Co-occurring ID	Age of autistic adults (yrs)	Gender of autistic adults	Co-occurring mental health difficulties
						on study design and co-developed themes in analysis							
17	Joseph-Kent	2018	4/5; 80%	US	Autistic adults with ID and their family members experience of barriers to access and helpfulness of different health care services, including mental health services	Qualitative: Explorative interviews. No details on analytic approach provided	Family members (n=12), autistic adults (n=4)	White (all participants)	ASD/ID; Range=1-42; Two individuals were diagnosed in adulthood, all others before the age of 10 years	mid-moderate ID (n=5), severe ID (n=5)	Mean = 41.5	17% Female (n=2), 83% Male (n=10)	7/12 experienced co-occurring mental health difficulties
18	Kinnaird, Norton, Stewart & Tchanturia	2019	5/5; 100%	UK; Participants had received treatment in various locations across the UK, the US, and Western European countries	Autistic women's experience of eating disorder treatment	Qualitative: Semi-structured interviews. Thematic analysis	Women with formal autism diagnosis (n=9), or high levels of autistic traits (n=4)	Not specified	'Formal diagnosis of autism' (n=9), 'high levels of autistic traits' (n=4); Age not specified	Not specified	All participant: Mean = 28.46; Participants with formal autism diagnosis: Mean = 23.56	84% Female (n=11), 16% Non-binary (n=2)	AN and 92% (n=12) had additional co-occurring diagnoses, including depression (n=8), anxiety (n=8), OCD (n=6), bipolar disorder (n=2), PTSD (n=2), Tourette's (n=1). Two were diagnosed with borderline personality disorder, but disputed the diagnosis
19	Kinnaird, Norton & Tchanturia	2017	5/5; 100%	UK, London	Clinicians perspective on working with AN and autism comorbidity	Qualitative: Semi-structured interviews. Thematic analysis	Mental health clinicians/therapists (n=9)	Not specified	Not specified	Not specified	Not specified	Not specified	AN and at least one additional co-occurring diagnosis, most commonly OCD and GAD
20	Lake, Milovanov, Sawyer & Lunsky	2015	5/5; 100%	Canada, Toronto	Parents views on autistic children and young adults' use of psychotropic medication and healthcare services	Qualitative: Focus group, 'thematic approach'	Mothers of autistic youth (n=7)	Caucasian (n=6), South Asian (n=1).	Asperger's syndrome (n=3), PDD-NOS (n=4); Age not specified	Normal intelligence (n=2), Mild ID (n=3), Moderate ID (n=1, N/A (n=1).	24, 21, 12, 21, 21, 28, 28	43% Female (n=3), 57% Male (n=4).	Anxiety (n= 3), OCD (n= 3), ADHD (n= 3), borderline personality disorder (n= 1), bipolar (n= 1)

Study ID	Authors	Year	Quality score (MMAT)	Location	Main focus	Method	Participant group(s)	Participants ethnicity	Autism diagnoses; Age at diagnosis (yrs)	Co-occurring ID	Age of autistic adults (yrs)	Gender of autistic adults	Co-occurring mental health difficulties
21	Mack	2020	5/5; 100%	US	Counsellors' experience of providing counselling to autistic adults	Qualitative: Two rounds of semi-structured interviews. Transcendental phenomenology approach	Counsellors (n=11)	White (n=10), Black/African American (n=1)	Not specified	Not specified	Not specified	Not specified	Not specified
22	Maddox, Crabbe, Beidas, Brookman-Frazee, Cannuscio, Miller, Nicolaidis & Mandell	2019	5/5; 100%	US	Autistic adults, clinicians and agency leaders perspectives on improving mental health services for autistic adults	Qualitative: Semi-structured interviews with autistic adults. Clinicians and agency leaders participated in either an individual interview or a focus group. Thematic analysis	Autistic adults (n=22), Community health clinicians (n=44), Mental health agency leaders (n=11)	Autistic Adults: 81.8% White, 9.1% Asian, 4.5% Black, 4.5% mixed, 4.5% Hispanic/Latino Clinicians: 79.5% White, 18.2% Black, Hispanic/Latino18.2% Hispanic/Latino, 2.3% more than one race Agency leaders: 90.9% White, 9.1% Black	ASD; 59.1% had received their diagnosis in adulthood	Not specified	Mean = 34.4	22.7% Female, 77.3% Male	21/22 had accessed mental health services during adulthood. No further details provided
23	Maloret & Scott	2018	5/5; 100%	UK, East England	Autistic adults experience of acute inpatient psychiatric services	Qualitative: In-depth interviews. Interpretative phenomenological analysis. Participatory approach: Consultation of member of the local autism community. Coding framework	Autistic adults (n=20)	Not specified	ASC (including Asperger's syndrome or high functioning autism); At least one participant was diagnosed in late adulthood	None	Mean = 35.5	40% Female (n=8), 60% Male (n=12)	35% anxiety disorder, 27% psychotic disorder, 25% mood disorder, 10 depression, 5% eating disorder, 4.5% substance abuse

Study ID	Authors	Year	Quality score (MMAT)	Location	Main focus	Method	Participant group(s)	Participants ethnicity	Autism diagnoses; Age at diagnosis (yrs)	Co-occurring ID	Age of autistic adults (yrs)	Gender of autistic adults	Co-occurring mental health difficulties
						confirmed with participants							
24	McMorris, Baraskewich, Ames, Shaikh, Ncube & Bebko	2018	6/15; 40%	Canada	Young autistic adults (college students) experience of accessing services for mental health issues	Qualitative: Interview. Analytic approach not specified. Participatory approach: Peer mentors conducted the interviews	Autistic adults (n=45)	73% European-Canadian (n=29)	Not specified	22% ID (n=10)	Mean = 21.03	18% Female (n=8), 82% Male (n=37)	56% (n=25) had at least one mental health diagnosis, 29% (n=13) had at least two mental health diagnosis, % for individual disorders provided (anxiety, depression, learning disorder, ADHD, other)
25	Merrick, King, McConachie, Parr, Le Couteur & Transition Collaborative Group	2020	10/15, 66,6%	UK	Young autistic people's experience of transition from child to adult mental health services	Mixed: Qualitative notes from discussion with young person, guided by questionnaire responses, and from the clinical records. Framework analysis	Autistic young people (n=118), parents/carers (n=113)	'98.3% described themselves as White British'	ASD; Age not specified	None	Mean (SD), range = 19.1 (1.4), 16.1–21.9	31% Female (n=36), 69% Male (n=82)	ADHD/ADD (n=35), mood (n=27), anxiety (n=27), ODD/challenging behaviour (n=8), sleep disorders (n=17), other (n=8), self-harm (n=8)
26	Murphy & McMorrow	2015	10/15, 66,6%	UK	High secure psychiatric hospitals staff's views on autism	Mixed: Survey including open-ended question. Analytic approach not specified	Staff working in high-secure psychiatric care with patients with specific needs (n=206)	Not specified	Not specified	Not specified	Not specified	Not specified	Not specified
27	Newlove-Delgado, Ford, Stein & Garside	2018	5/5; 100%	UK, Southwest England	Young people's experiences of transition from child to adult care for ADHD, including subset of participants with co-occurring autism	Qualitative: Semi-structured interviews. Thematic analysis	Young adults (n=7), three of whom were diagnosed with ASD	Not specified	ASD; Age not specified	None	Range= 17-18	Gender of participants with ASD - 33% Female (n=1), 67% Male (n=2)	ADHD
28	Robertson Stanfield, Watt, Barry,	2018	5/5; 100%	UK, Scotland	Autistic adults and family members	Qualitative: Semi-structured	Autistic adults (n=10), supporters of	Not specified	Asperger's Syndrome (n=7),	None	Mean, range=	50% Female (n=5),	Anxiety

Study ID	Authors	Year	Quality score (MMAT)	Location	Main focus	Method	Participant group(s)	Participants ethnicity	Autism diagnoses; Age at diagnosis (yrs)	Co-occurring ID	Age of autistic adults (yrs)	Gender of autistic adults	Co-occurring mental health difficulties
	Day, Cormack & Melville				experiences of anxiety, including barriers to support	interviews. Thematic analysis	autistic adults(n=7)		Autism (n=3); Age not specified		40, 19 – 60	50% male (n=5)	
29	Rodgers, Herrema, Garland, Osborne, Cooper, Heslop & Freeston	2018	5/5; 100%	UK, England, Scotland	Autistic adults worries regarding their futures, some mention of mental health services	Qualitative: Focus groups. Thematic analysis	Autistic adults (n=23)	Not specified	Autism (n=2), Asperger's syndrome (n=16), ASD (n=6); Mean (SD), range = 16 (13), 2.5 - 62	Not specified	Mean, range = 36, 18 - 64.	48% Female (n=11), 52% Male (n=12)	Multiple participants reported experiencing depression and anxiety in findings. No further details provided
30	Russell, Gaunt, Cooper, Horwood, Barton, Ensum, Ingham, Parr, Metcalfe, Rai, Kessler & Wiles	2019	5/5; 100%	UK, Bristol, Newcastle	Autistic adults and therapists experiences of a trial of autism-specific guided self-help (GSH) for depression	Qualitative: In-depth interviews. Thematic analysis. Participatory approach	Autistic adults GSH arm (n=14), autistic adults treatment as usual arm (n=7), therapists (n=5)	Not specified	Autism diagnoses not specified; 'Eighteen participants had received an ASD diagnosis in the previous 6 years and nine had received it in the previous year'	Not specified	Range = 21-60	19% Female (n=4), 81% Male (n=17)	Depression
31	Spain, Rumball, O'Neill, Sin, Prunty & Happe	2017	5/5; 100%	UK, London	Multidisciplinary professionals views on working with autistic individuals with social anxiety	Qualitative: Focus groups. Thematic analysis	Professionals (n=22)	Not specified	Not specified	With and without ID	Not specified	Not specified	Social anxiety
32	Tint & Weiss	2018	5/5; 100%	Canada	Autistic women's experiences of service needs and barriers to care, some mention of mental health service experience	Qualitative: Focus groups. Inductive, semantic-level analysis conducted	Autistic women (n=20)	90% White	Autism diagnoses not specified; Mean, range = 26.25, 2-65	None	Mean, range = 35.45,19 - 69	All female	Not specified
33	Unigwe, Buckley, Crane,	2017	13/15; 87%	UK; % from different	Family doctors experience of managing their	Mixed: Online survey including open-ended	Family doctors (n=304)	79.6% White (n=242), 3.0% Black	Autism; Age not specified	Not specified	Not specified	Not specified	Not specified

Study ID	Authors	Year	Quality score (MMAT)	Location	Main focus	Method	Participant group(s)	Participants ethnicity	Autism diagnoses; Age at diagnosis (yrs)	Co-occurring ID	Age of autistic adults (yrs)	Gender of autistic adults	Co-occurring mental health difficulties
	Kenny, Remington & Pellicano			regions provided	patients on the autism spectrum, some mention of co-occurring mental health difficulties	questions. Thematic analysis		(n=9), 11.2% Asian (n=34), 2.6% mixed (n=8), 1.6% other (n=5), 2.0% prefer not to say (n=6).					
34	Van Hees, Moyson & Roeyers	2015	5/5; 100%	Belgium, Flanders	Autistic students experience in higher education, some mention of managing mental health difficulties	Qualitative: Semi-structured interviews. Grounded Theory analysis.	Autistic university/college students (n=23)	Not specified	ASD, Asperger's syndrome, PDD-NOS; Age not specified	None	Range = 18 - 25	26% Female (n=6), 74% Male (n=17)	Anxiety (n=22), stress (n=23), fatigue (n=21, feeling overwhelmed (n=21), loneliness (n=20), depression (n=16)

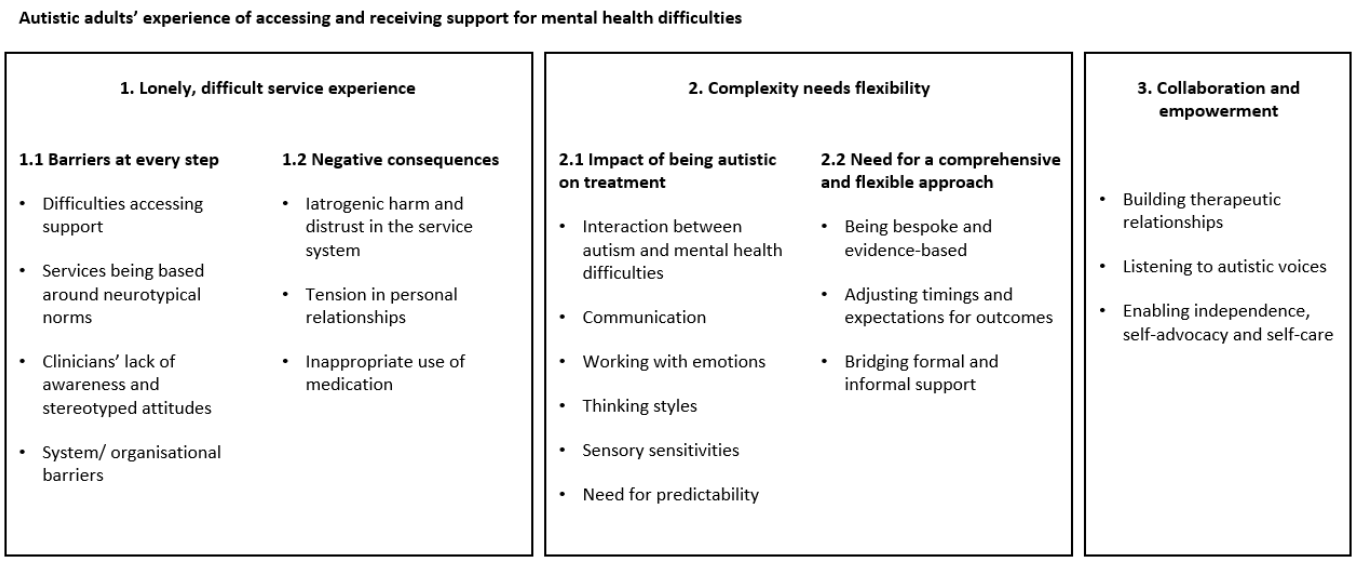
Note. Abbreviations: AN= Anorexia Nervosa, ADHD = Attention Deficit Hyperactivity Disorder, ASD/C = Autism Spectrum Disorder/Condition, GAD = General Anxiety Disorder, ID = Intellectual Disability, MMAT = Mixed Methods Appraisal Tool- Version 18 (Hong et al., 2018), OCD = Obsessive–Compulsive Disorder, ODD = Oppositional Defiant Disorder, PDD-NOS = Pervasive Developmental Disorder-Not Otherwise Specified

Thematic Meta-Synthesis

We generated three superordinate analytical themes “Lonely, difficult service experience”, “Complexity needs flexibility” and “Collaboration and empowerment”, each with several subthemes. An overview of all analytical themes and subthemes is provided in Figure 18.

Figure 18

Overview of analytical themes and subthemes from the thematic meta-synthesis.



In the following description of each theme, first-order accounts (participants' direct quotes) are presented in quotation marks and italics, whereas second-order accounts (the original authors' interpretations) are referred to in quotation marks with no italics. For both, study IDs (see Table 30) are used to link them to the original paper. Additional first-order quotes illustrating each of the themes are provided in Appendix 16.

1. Lonely, difficult service experience. This theme encapsulated a sense of lonely, frustrating and difficult service experiences that the majority of autistic

participants had encountered. Existing services were perceived to be unsuitable, inaccessible and at times unwilling to meet autistic adults' needs. This experience had negative effects on autistic adults' wellbeing, motivation for future help-seeking and family relationships. For some, this experience was also thought to have resulted in inappropriate reliance on medication.

> *'People might feel like they want to kill themselves […] It is terrible when you have to wait a year, because a lot of people have gone and done it. It is just sad when that happens, it really is, especially when you can do something about it; someone can help you and you can resolve the problem.'* (Autistic adult, M, UK)[10]

Several subthemes were identified within this theme:

1.1 Barriers at every step. Potential barriers were reported at almost every step towards service engagement, resulting in many autistic adults not receiving the support they needed or encountering various obstacles along the way:

Difficulties accessing support. Both autistic individuals themselves and those involved in their care, such as family or doctors, struggled with recognising symptoms of mental health difficulties, often assuming presenting difficulties were part of being autistic.

> *'I recognise that I often don't realise just how bad things have become. In the last year I have started thinking about suicide, even though I don't want to die, and that has been the thing that's made me realise how bad things might be.'* (Autistic adult, F, UK)[6]

Some parents worried about their adult child recognising their own need for mental health support, and expressed frustration about not being able to initiate care

on their child's behalf since they had entered adult services. Some autistic adults expressed a sense of being '*used to doing things [their own] way'*[8]*,* feeling like *'someone's trying to interfere*'[8], when others expressed concern or offered help, even though '*it's probably for the best'*[8].

Autistic adults also reported that asking for support could be daunting, with 'the steps to accessing services being too overwhelming'[24]. Some found it difficult to judge '*what the boundaries are concerning emotional things'*[16], resulting in hesitancy to talk to others about their difficulties. For others, their hesitancy stemmed from previous experiences of not being believed. Many also seemed put off from approaching services because of uncertainty about what the therapy process might entail and a perceived lack of transparency. Additionally, autistic adults and their parents reported being rejected by services because of co-occurring autism diagnosis, which 'made them *'too complicated'*, and ineligible for services'[6] without alternative services being available. Practitioners also stated that many mental health services were *'reluctant to work with autistic individuals'*[12].

The existing service system was perceived to be complex and confusing. Participants had experienced disjointed services systems, particularly between different services, such as mental health and autism diagnostic or learning disability services. This incoherence resulted in help-seeking individuals being 'batted back and forth between agencies'[3], with a risk of 'slip[ping] through the net'[6] of available services. Further, there were physical barriers to services - for example, travel to and from services and the service setting itself prevented some autistic adults from accessing or engaging with treatment, due to social or sensory overload on public transport, in waiting areas, on inpatient wards, or in group settings.

Services being based around neurotypical[3] norms. Participants felt that available services were often inappropriate and '*not fit for purpose*'[6], with autistic individuals *'being a square peg in a round hole'*[32].

> *'They are all set up for what I would call, and I don't know what your typical patient with anorexia is like, but it is not our daughter; she has got complex needs and none of them, you know none of the workshops we attended addressed those extra needs.'* (Family member, UK)[1]

In some cases, their perceived difficulty to engage led to early discharge or they were actively discouraged from approaching available services, as they were deemed unsuitable to meet their needs. Clinicians commented on rigid service structures, which they felt prohibited flexibility to meet heterogeneous needs. They also criticized reliance on self-report measures, developed based on non-autistic presentations, to assess mental health difficulties and track outcomes, which were often required for service commissioning purposes. This was deemed especially problematic, when access to services was being denied based on low scores on such measures. Clinicians argued that atypical presentation of mental health difficulties, use of compensatory strategies, and difficulties with introspection may confound self-report, making them less valid for autistic individuals.

Autistic adults and their parents commented on services being inconsiderate of autistic individuals' developmental stage. For example, some young adults felt they had not reached the level of independence expected of them when they transferred to adult services. Similarly, parents of adult children with co-occurring intellectual disability struggled to find settings that were developmentally appropriate.

[3] 'Neurotypical' refers to individuals, whose cognition, perception or behaviours are not affected by living with a neurodevelopmental condition.

While some questioned whether it was appropriate for their adult children to be treated in paediatric settings, others recounted *'horror stories'*[17] of their offspring being admitted to general adult psychiatric provisions, pressing the need for specialist provision.

Clinicians' lack of awareness and stereotyped attitudes. Participants across groups reported varied, yet overall low, levels of confidence and competence among professionals involved in mental health care for autistic adults. Participants felt that many professionals lacked an in-depth 'understanding of the unique challenges'[11] associated with being autistic and living with mental health difficulties. Several papers discussed 'stereotypical and homogenizing attitudes towards autism'[29] among professionals, which was particularly problematic for autistic individuals who tend to present differently from the traditional autistic norm, such as autistic women.

> *'In this field it's really frustrating because people want to take a cookie cutter approach and that's impossible because what one person with ASD is capable of doing another person with ASD is not capable of doing or vice versa."* (Counsellor, F,US)[21]

Autistic adults also described encountering harmful assumptions, for example, about being 'high-functioning'[6] and therefore able to cope, when in fact they were struggling, or being labelled as potentially violent, without any indication that this was the case. Others reported incidences of clinicians challenging or refusing to acknowledge autism diagnoses. In cases where autism was recognized, autistic adults felt they were not listened to or that being autistic was used as a reason to not take them seriously.

Although some autistic adults described clinicians as *'well-meaning'*[6], many perceived the clinicians they had encountered as insensitive and unaccommodating, 'unable or unwilling to shift'[32] stereotyped views or to adapt their approach to meet the needs of autistic individuals. Several autistic adults described experiences of being blamed for lack of treatment success. Even among professionals, who expressed an awareness of the variability and complexity of presentation in autistic adults, many admitted having 'low confidence'[21], feeling they did not have the skills to provide adequate support or reported little practical experience of applying their theoretical knowledge to individuals' specific circumstances. It was suggested that 'fear of failure'[10] might lead to them rejecting autistic adults in need.

***System/organisational barriers*.** Several papers discussed service barriers on a systemic and organisational level that were preventing autistic adults accessing support for mental health difficulties. The cost of accessing treatment presented a significant barrier for some. In the US, frustration was expressed about seemingly arbitrary insurance coverage for mental health issues in autistic adults. Even in the UK, where mental health care is free at point of access, funding was often withdrawn on short notice, funded services were not appropriate, or autistic individuals encountered long waiting times for services. Those who had recently transitioned from child and adolescent to adult services reported a 'sudden decrease in the amount of help and support available'[11]. These circumstances often left autistic individuals no choice but to pay for private treatment, which not everyone could afford. Clinicians also expressed frustration about limited funding, which they felt was preventing them from offering more tailored services. They described a disconnection between clinical reality and service funding, which they perceived to

be fuelled by misconceptions about the value of providing mental health treatments to autistic individuals.

Further, clinicians commented on a lack of evidence, training and support to guide working with autistic adults. Clinicians explained that adaptations to treatment delivery and content were often made 'ad-hoc'[2], requiring them to *'learn on their feet'*[2]. Providing adequate support was described to be challenging as there are 'no hard or fast rules'[31] about the best approach and little evidence to inform adaptations. Additionally, they criticised the lack of support within their services and connection with other specialist provisions, resulting in '*feeling isolated'*[21] and leaving them 'to their own resourcefulness'[2]. Participants across groups also highlighted the lack of training and continued support for mental health professionals and gatekeepers who are likely to engage with autistic adults in their work.

1.2 Negative consequences. Having to navigate this complex service system and being held back by various barriers to care had negative effects on autistic adults:

Iatrogenic harm and distrust in the service system. Attempting to gain access to and/or engaging with treatment was described to be exhausting, frustrating and anxiety-provoking. Several papers highlighted the 'harmful'[10] effect of seeking support for mental difficulties, whereby professionals, who are supposed to help, at times had an 'adverse effect'[10]. The lack of appropriate services resulted in unsupported individuals remaining in distress and gave them and their family members the impression that autistic adults' mental health was less valued than that of non-autistic individuals. Experiences of not being believed and being blamed resulted in autistic adults not feeling *'worthy of support'*[6] and doubting themselves. This experience caused individuals in need of support to feel desperate, hopeless

and isolated. For some, accumulative experiences eventually led 'to *'loss of trust'* towards professionals and services'[6] and affected confidence in and motivation towards future help-seeking.

> *'I dread having to come into contact with any sort of medical thing to do with autism... or mental health because they're just a nightmare, they just make you much worse.'* (Autistic adult, UK)[29]

Tension in personal relationships. Lack of services meant that responsibility for care often fell on families and friends, putting those who did not have a strong support network at disadvantage. It also created pressures for families who were able to provide support, and took away from their capacity to take on other roles in their autistic family member's life. Several autistic adults mentioned feeling conflicted about being dependent on family and friends, aware of the impact caring responsibilities had on other's well-being, and frequently chose to suffer in silence to minimise the burden on others. Family member's involvement in autistic adult's care also caused tension due to power imbalances and disparity in family's and autistic adults' expectations and desired outcomes. Further, some commented that relying on the support of family and friends might reduce autistic adult's potential for developing independence.

Inappropriate use of medication. Lack of options often resulted in long-term medication use, which was perceived by some participants to be inappropriate and ineffective. Several participants, particularly parents, praised immediate effects and emphasised that 'medication has made a great deal of difference'[14]. Yet, for most autistic adults 'the balancing act of the right medications and the right dosage is something that is a lifelong challenge'[17]. Participants across groups raised concerns about medication being used due to lack of alternatives, not because it was effective,

and without much consideration of the complexity of the individual's presentation, thus making little difference to their mental health.

> *'The answer was often medication of some sort and for some that was appropriate and suited them, but I think for many the medication was given just because we didn't have anything else to do'* (Therapist, M, UK)[10]

2 Complexity needs flexibility. Across papers, participants emphasised the impact being autistic had on mental health presentation, as well as on the skills, abilities and needs they brought to treatment. Participants felt that the resulting variability of presentation and complexity of needs should be accounted for in treatment.

2.1 Impact of being autistic on treatment.

Interaction between autism and mental health difficulties. Participants felt that autistic traits and autism-related difficulties played a significant role in the development, maintenance and presentation of mental health difficulties, and it was important to acknowledge this interaction and to modify treatment accordingly.

Autistic adults' experiences of mental health difficulties were described to be fundamentally shaped by being autistic, with some even perceiving 'their mental health difficulties to [be] resultant of ASC'[5]. For example, depression and anxiety were described as *'a reaction to stress associated with having autism'*[6] and a 'repercussion of masking or compensating for social communication difficulties'[32]. Further, some autistic traits were described to mimic symptoms of mental health conditions, for example, sensory issues presenting as eating issues, resulting in potential misdiagnosis or diagnostic overshadowing. It was also noted that mental health difficulties could affect the presentation of autistic traits, which in turn could intensify the manifestation of their mental health difficulty or impact on their ability to

cope. For example, sensory sensitivities might be amplified when an autistic individual experiences high levels of anxiety.

Participants across groups felt that healthcare professionals often gave priority to treating mental health conditions, leaving underlying autistic needs and other psychosocial needs unmet. Some autistic adults emphasised that clinicians should 'focus on treating the co-occurring conditions, not on changing core autistic traits'[22]. However, several autistic adults reported having received their autism diagnosis when seeking support for mental health difficulties and felt that this had positively affected their mental health and the treatment they had received, allowing them to 'make sense of the diagnosis as part of the therapeutic work'[10]. Yet, one clinician pointed out that not all potentially autistic individuals benefit from receiving a diagnosis, and that this, as well as the timing of diagnosis, should be considered on an individual basis and in the context of the therapy they are receiving.

Communication. Almost all papers commented on communication difficulties and needs affecting autistic adults' treatment experiences. Both sides of the service user/clinician dyad saw the reason for this in themselves as well as in their communication partner. Autistic adults explained how they sometimes struggled to express themselves, especially when talking about emotional states or when in crisis. In addition, some reported being overwhelmed by too much verbal input and may '*zone out*'[1], not processing what is being said.

> *'I could keep up with the nurse for one or two sentences at the most and then I felt that my brain could take no more, I would stop trying to follow what she was saying and simply close down. I remember hearing nothing, but still see her mouth going up and down.'* (Autistic adult, UK)[23]

However, autistic adults felt communication difficulties also persisted due to *'practitioner's inability to try to understand their lived experience and about different ways of communicating'*[10]. Clinicians noted that less experienced colleagues might misunderstand some autistic people's communication style as being disinterested, but that communication difficulties could prove challenging for any clinician as it can be '*really hard to get communication going*'[19] and *'to find a way to communicate more abstract concepts in a way that was understandable to [autistic clients]'*[9].

Participants suggested several strategies to facilitate communication. Clinicians felt that adapting a 'clear and concrete'[21] communication style was beneficial in that it led them to being 'more honest and genuine with their clients'[21]. Autistic adults generally preferred direct questioning but warned about the risk of making assumptions and '*putting words in [the client's] mouth'*[16]. Instead, they felt it was important to '*give them time to fully express themselves*'[16]. Clinicians emphasised periodically checking in with clients to ensure they understood the concepts discussed, even though this may sometimes feel 'patronising'[32]. This seems to be a balancing act, with some autistic adults noting that some communication they had received felt 'too simplistic and childlike'[10].

Working with emotions. Difficulties with identifying, understanding, communicating and/or regulating emotions were widely discussed as a potential interference with therapy.

> *'They'd ask me questions, how you feel about this, how you feel about that, and the harder I thought about it, the more I couldn't figure out what I was feeling like . . . That was kind of useless.'* (Autistic adult, US)[22]

Further, since autistic individuals might express distress differently, clinicians suggested it was important to 'look beyond initial presentations'[31] when assessing

autistic adults for mental health difficulties, and to enquire about different *'cognitive and physiological symptoms'*[31], rather than just asking how people were feeling. Relatedly, clinicians emphasised the need to pay increased attention to suicidal ideation, as 'flat affect might hide contemplations'[21]. Several clinicians and autistic adults reported finding it helpful to engage in preparatory emotional literacy work prior to the start of therapy. Others suggested that it was helpful to turn the focus away from emotions and take a more pragmatic approach.

Thinking styles. A few papers, mainly those representing the views of clinicians, noted how differences in thinking style 'can interfere with traditional therapy'[22] and could 'potentially hinder engagement in, and the success of, psychological treatments'[31]. These may include 'rigid thought patterns associated with autism'[18], 'concrete thinking', 'difficulties perspective-taking ... ToM [Theory of Mind] impairments'[31], with 'executive function'[21], '*with a very fixed world view'* and *'not always generalising experience'*[9].

Sensory sensitivities. Often treatment environments, especially in-patient settings, were described as 'not autism-friendly'[1], resulting in sensory overload and discomfort that 'distracted or distressed autistic individuals during therapy sessions'[23]. It was noted that sensory sensitivities may be heightened and self-regulation more difficult in novel situations and when individuals are overwhelmed or distressed. Triggering stimuli included excessively bright lighting, overpowering smells of other people's perfume or strong cleaning products, loud air conditioning systems, noise from other people, and the taste, smell and texture of the hospital food. Although many of these sensory aversions could be accommodated, autistic adults reported that this possibility was often not considered. For some, their requests for sensory sensitivities to be accommodated were interpreted as part of

their pathology, such as requests for specific food textures to be avoided being viewed as symptoms of an eating disorder, rather than stemming form their autism.

Need for predictability. Change and uncertainty were repeatedly discussed as a source of concern for autistic individuals, for example, in relation to the prospect of starting a new treatment, transition between services, changes in staff, or being discharged. Participants across groups noted the importance of structure, predictability and transparency of treatments and during individual sessions to make 'the encounter less anxiety-provoking'[10]. Examples of how to implement this included keeping a 'routine with appointment times and location'[19], 'setting clear expectations'[27] before starting a new treatment, and 'following a similar structure for each session'[22]. Autistic adults in inpatient settings described how building new routines and engaging in regular activities helped them to manage anxieties related to being in an unfamiliar environment. Clinicians suggested that the notion of change should be discussed 'in a tentative and considered manner'[31] and that changes may need to be introduced gradually.

2.2 Need for a comprehensive and flexible approach*.* Participants voiced the need for flexibility in treatment provision to better suit autistic adults. They argued that this requires services to move away from their rules and regulations, and to *'be as flexible as [they] can be'*[10] to give everyone the opportunity to engage with the treatments they are offering:

Being bespoke and evidence-based. Participants emphasised that adaptations should be tailored towards the individual as well as evidence-based.

> *'Just know who you're talking to. Know that a lot of people with autism are very smart and a lot of them have great skills and a lot of them have great potential, and just figure out how can you specifically tailor to this specific*

person's needs and interests. And how can you make it relatable and memorable.' (Autistic adult, US)[22]

However, there was much variation in what adaptations they considered to be effective, with the heterogeneity of autism acknowledged. Therefore, rather than following standard adaptations and recommendations for 'a generic group of autistic people'[11], participants emphasised that adaptations should be considered and implemented based on 'individual client's unique profile of strengths, weaknesses, and interests'[22]. It was noted that if time was taken to assess an individual's needs, clinicians could still draw on pre-existing adaptations to appropriately support the individual, with one clinician suggesting it would be helpful to have *'some kind of tool-kit of interventions that can be customised to a particular patient'*[31]. Participants highlighted the need for research to find out what worked for whom and why, to inform the development of evidence-based treatments and adaptations for this group.

Adjusting timings and expectations for outcomes. Participants advocated for the need to consider more preventative approaches to mental health care, to adjust the timing of treatment, and to re-evaluate desired outcomes. Existing service systems were critiqued for their reactive approach, only responding when individuals were in crisis. This approach was viewed to be problematic, as participants felt the severity of autistic individual's difficulties was often underestimated. Participants thought it was necessary to consider the presence of co-occurring mental health difficulties more routinely and to ensure that support was more readily available, particularly for sub-groups exposed to high levels of stress, such as autistic students in Higher Education.

Autistic adults felt that standard treatment provision was often not long or frequent enough to '*make yourself well*'[6]. They reported to be *'struggling to make progress within the typical time frames for treatment'*[18] and felt they were *'being asked to do things that they did not feel ready for'*[30]. Participants suggested that therapy sessions for autistic adults need to be longer and at 'a slower pace'[2] or 'shorter [and] more frequent'[9].

Criticising 'the limited nature of services'[11], participants suggested that it might be necessary to 'continue support after psychological therapy to ensure on-going [mental health] management'[2]. Autistic adults described taking care of their mental health as 'a constant battle'[16]. Further, clinicians reported frequent regression and suggested it might be more difficult for some autistic adults to maintain progress under changing circumstances.

Several participants discussed how expectations for recovery and outcomes should be re-evaluated for some autistic individuals.

> *What a change looks like in their mind, it might be 'I have to be 100% better and nothing's better until I've reached that point' but actually our whole job is pointing out the shades of grey ...'* (Therapist, F, UK)[31]

For example, autistic women who have had treatment for eating disorders and considered themselves recovered, described still having certain behaviours around food, such as a need for control, which they viewed as 'stemming from their autism rather than from Anorexia Nervosa'[18]. Clinicians suggested that it might not be helpful to eliminate all behaviours associated with the mental health difficulty, even if they superficially look like they might be maintaining the problems, as they might also represent autism-related coping strategies. For example, for someone recovered from an eating disorder it might still be important to follow rigid routines at

mealtime as a means of introducing structure to their day. Participants felt that it was more important to consider 'the extent to which symptoms impact on functioning or cause distress'[31] and to '*work towards a good quality of life*'[19].

Bridging formal and informal support. Participants emphasised a need for greater collaboration between social, educational, and health services and between formal and informal support sources to provide more comprehensive and holistic support. Several papers discussed the benefit of informal support, but also acknowledged challenges (see 'tension in personal relationships' above). Friends and family members were a valuable resource to ensure continued support after psychological therapy or to help with implementation between sessions. Clinicians highlighted that this should be considered when planning treatment and might require additional resources to manage dynamics within a therapy context and to teach supporters necessary skills.

Autistic adults valued autistic peer support, appreciating the 'common connection'[16] with others who identified as autistic and commenting that 'shared experience of the world'[16] made it easier for them to express themselves and feel understood. Yet, autistic adults emphasised that peer support needed to be specific to the individual's needs, 'rather than simply providing access to a generic group of autistic people' and expressed a desire for such support to be 'formal [and] facilitated by specially trained autistic people'[11].

3. Collaboration and empowerment. Autistic adults with positive experiences of receiving support for their mental health difficulties reported the relationship with their clinician to be pivotal, and empowerment was a central element of the treatment process as well as an overarching goal for treatment outcomes:

Building therapeutic relationships. Participants across groups viewed therapeutic relationships to be 'the most important aspect of therapy'[10] and 'essential to ensure positive experiences of mental health support'[11]. Participants felt it was fundamentally important to foster 'strong and trusting relationships'[11] 'before expecting [autistic adults] to do any difficult psychological work'[1]. Clinicians noted that it might take some autistic adults a little longer to develop trust but emphasised that this could be *'true of everybody'*[10] and that autistic adults were capable of building and utilising therapeutic relationships. As such, they saw a need to prioritise working on this and highlighted their responsibility to assist with finding another therapist if unable to establish a connection themselves. Autistic adults agreed that they could sometimes struggle to build an *'immediate connection'*[6] and that it can take them *'ages to develop good rapport'*[6]. For this reason, they highly valued 'continuity of care'[6] that allowed them to build trust.

> *'… you make progress … but then that psychologist tries to leave, passes on everything to someone else, and then it all gets lost and forgotten about.' (*Autistic adult, UK)[8]

Autistic adults who were satisfied with the relationship with their clinician experienced these relationships to be 'reciprocal and responsive to [their] needs'[27] and were appreciative of the support they had received. Clinicians described 'being humbled'[21] and feeling a 'sense of fulfilment'[21] from successfully establishing such relationships.

Listening to autistic voices. Participants felt it was important to engage autistic individuals in treatment decisions, treating them as experts on their own experience. Clinicians reported that they encouraged autistic adults to be 'active participants'[31] in the therapy process and asked them about 'their views on the pace

and content of the clinical work'[31]. Clinicians noted that autistic individuals 'may have had limited opportunities to develop assertiveness skills to express their views'[31] and that 'an implicit element of the therapeutic relationship and process should involve encouraging patients to feel confident to say what they think'[31]. Thereby, they thought it was important for clinicians to clearly communicate their willingness to 'understand [the autistic adults'] experience to the best of [their] ability'[21]. To empower their autistic client to partake in treatment, clinicians needed to 'step into [their] client's worldview'[10] and 'speak the same language'[19]. Relatedly, clinicians felt it was important to demonstrate understanding if autistic adults were sceptical due to previous experiences of *'being failed by various systems [and] society not recognising their needs'*[30], showing 'empathy and 'patience'[21]. Those autistic adults who felt their insights were 'taken into consideration'[11] described 'better treatment experiences and outcomes'[18]. Clinicians spoke about this being a learning experience, and that listening to autistic adults gave them new insight into the diversity of human experiences and improved their skills as a therapist, making them '*more empathic and less judgmental'*[21].

Despite the importance of listening to them, autistic individuals and their families were adamant that professionals should not rely on them to teach them about autism and it was the clinician's responsibility to acquire sufficient knowledge prior to offering treatment. However, several papers discussed the potential benefits of involving autistic adults in creating and delivering training for staff in mental health settings.

Enabling independence, self-advocacy and self-care. It was considered of high import to help autistic adults to develop independence and autonomy in managing their mental health outside of therapy. Even though most participants

seem to have been disappointed by the care they received, those who were satisfied felt it had provided them with the opportunity to increase their 'self-awareness' and *'compassion for [themselves] as a human being'*[6]. They reported that among the most valuable things they had taken from treatment were *'self-management techniques'*[11] and 'strategies to raise [their] mood'[30], with some reporting they 'routinely employed the techniques [they] had been taught'[28]. They also realised that they did not have to 'do it all by [them]selves'[6] and felt more able to ask for help if needed in the future. Autistic adults described how appropriate tailored support and treatment 'empowered them, gave them autonomy, facilitated their inclusion in social networks and wider society and gave them hope for a future'[6].

Discussion

The current study systematically reviewed and synthesised qualitative research on autistic adults' experience of accessing and receiving mental health support, triangulating perspectives of autistic adults, professionals and family members, to generate an evidence-based understanding of autistic adults' experiences in mental health care. We identified 34 studies related to autistic adults' experiences of accessing support for mental health difficulties. The thematic synthesis highlighted that autistic adults' experience in current service systems is predominantly negative, with autistic adults facing several barriers when accessing and engaging with support for mental health difficulties. There is a clear need for a more flexible, comprehensive and holistic approach, which takes account of how being autistic affects the individual's mental health presentation and engagement with treatment. Building trusting relationships, including autistic adults as active participants in the treatment process, and empowering them to take agency are important steps for more effective and inclusive mental health care provision.

Overall, the views of participants from the different stakeholder groups were consistent with each other. This is encouraging as it grants the possibility of working together towards a common goal of improving service provision for this group. Professionals and family members also reported frustrating and lonely experiences, which were impacting on their ability and motivation to support autistic adults. Working towards better mental health care provision for autistic adults should not only result in more positive outcomes for this group, but also make the roles for parents and clinicians more enjoyable and rewarding.

However, participants' accounts also suggested that conflicting perceptions and stereotyped views of autistic individuals held by clinicians may interfere with successful service provision for autistic adults. Clinicians participating in included studies commented on lacking confidence when working with autistic adults. This is in line with larger scale surveys of different professional groups autistic adults might encounter in the mental health care system, suggesting that, while they tend to have good basic knowledge of autism, many lack formal training and/or do not feel adequately supported to work with autistic individuals (Crane, Davidson, et al., 2019; Murphy et al., 2016; Unigwe et al., 2017). Further, a few of the perceived issues raised by clinicians in the current study, such as presumed difficulties with 'Theory of Mind' (ToM), have recently been challenged (Gernsbacher & Yergeau, 2019). Gernsbacher and Yergeau (2019) discuss how there have been numerous failed attempts at demonstrating ToM 'deficits' in autistic individuals in terms of replication, specificity, universality and validity. Thereby, they emphasise the potentially damaging and dehumanising narrative that is perpetuated by ToM discourse - the belief that autistic people lack insight into the thoughts of themselves and others, which is allegedly part of 'being human' (Gernsbacher & Yergeau, 2019). Such

narratives may influence the stereotyped views held by care providers. However, if we consider the Double Empathy Problem (Milton, 2012), it is vital that the communicative role of *both* interaction partners are taken into account, and we must also consider how the clinician's own difficulties in understanding and reading autistic minds may impact on mental health care. Indeed, Mitchell et al. (2021) discuss how misunderstandings and misperceptions from non-autistic people can serve to isolate autistic people and worsen their mental health. Critically, our meta-synthesis highlighted collaboration and empowerment as key themes - and we argue that these are not achievable unless autistic people are truly listened to and understood.

Another important and concerning finding in our meta-synthesis was that services seem to be not only ineffective in supporting autistic people with co-occurring mental health problems, but can also pose a risk of worsening the individual's condition through iatrogenic harm. While some of this harm seems to be due to lack of knowledge and stereotyped beliefs about autistic adults' ability to benefit from treatment, even motivated and experienced clinicians encountered challenges and constraints, feeling unable to offer more appropriate support in what was perceived to be a rigid and tightly commissioned service system. Thus, the current systems appear to be potentially causing more harm than good. With 'avoiding harm' being a key principle of psychological practice (APA, 2017; British Psychological Society, 2017), a clinician's initial response could be to withdraw and be even more hesitant with offering support to autistic people. Instead, there is a need to actively work towards changing the status quo. Further, given how frequently autistic adults report negative service experiences and iatrogenic harm, it could be

sensible to routinely ask new autistic services users about previous experiences of care and consider this in formulation and subsequent care provision.

Apart from social responsibility, there are also potential economic reasons to work hard to improve the mental health support offered to autistic individuals. Currently, autistic adults have to repeatedly engage with services that are poorly equipped to meet their needs, which has been demonstrated to be expensive for individuals, their families and society as a whole (Buescher et al., 2014). In addition, the impact of persistent mental health difficulties on autistic adults' daily living and independence (Chiang & Gau, 2016; Hendricks, 2010) means they are more likely to require further support and are less likely to be able to work. Indeed, autistic adults' medical costs exceed those of children, and during adulthood access to supportive living and productivity loss are among the factors contributing the highest cost for autistic individuals (Buescher et al., 2014). Working towards removing barriers to access and investing into the development of more effective, proactive, tailored services may be among the most efficient ways to reduce this cost, while simultaneously improving individual's productivity and ability to work (Iemmi et al., 2017). Improved support across the healthcare system may also reduce the burden on individual clinicians. Thus, both for autistic adult's wellbeing (Mason, Mackintosh, et al., 2019) and for societal/economic benefits (Buescher et al., 2014) it is desirable to continue to work towards offering appropriate and effective help to autistic adults seeking support for mental health difficulties. The current review demonstrated the benefits of successful service provision and, importantly, offered insights into how to achieve this.

The meta-synthesis provided clear suggestions for changes and adaptations to current service provision to improve accessibility. First, autistic adults encounter

barriers to accessing the support needed, and these barriers could be addressed by raising awareness of diversity in mental health presentations among gatekeepers and assisting autistic adults with navigating the service system. Second, within services, simple adaptations, such as tailoring communication, addressing sensory stressors, and including autistic adults in decision making processes, can be implemented without many additional resources. More complex adaptations, such as adapting the timings and number of therapy sessions, tailoring treatment approaches, and developing new interventions specifically for autistic people, will require higher levels of expertise, facilitated by clinician training and continuous support for staff, as well as changes on a service/commissioning level, including additional funding and greater flexibility within services.

Although these suggestions were identified via an exploration of autistic adults' experiences, they seem helpful to inform improvements of mental healthcare more generally. Principles of Universal Design, which outline how deliberately designing products and services to serve all can reduce the need for later adaptation, have been applied to education, conceptualising the inclusive classroom as able to flexibly accommodate all learners (e.g. Burgstahler & Russo-Gleicher, 2015; Milton et al., 2016). Extending these principles to the design of mental health services, emphasising bespoke individualised and person-centred care from the very outset, could improve the experience and effectiveness of service provision for all service users, not just autistic people.

The steps to improve mental health provision for autistic adults that were highlighted by the current study align with others' suggestions. For example, Green (2019) discussed the need for a strategic, developmentally-informed approach to services for autistic individuals, including management of co-occurring mental health

difficulties, to optimise long-term outcomes for autistic individuals. This suggestion is consistent with our meta-synthesis, arguing for a more comprehensive long-term approach and for empowering autistic individuals through facilitating self-care. Further, Green (2019) argued that in the absence of autism-specific evidence for mental health intervention, already evidenced interventions for specific conditions should be used with appropriate adaptation, but also highlighted the need to develop an evidence base specific to autistic individuals. This argument aligns with conclusions drawn from the meta-synthesis, that research to inform the development of new treatments and adaptations, and to evaluate their implementation, will be vital for improving mental health care provision for autistic adults.

While there is emerging evidence for the effectiveness of some approaches and adaptations for treating mental health difficulties in autistic adults (A. Russell et al., 2019; Russell et al., 2013; Sizoo & Kuiper, 2017), there is a need to continue this work with high-quality studies and focus on translation into practice (Lounds Taylor et al., 2012; Spain et al., 2015; White et al., 2018). Thereby, it will be important to collaborate with autistic adults to ensure acceptability of potential interventions (Benevides et al., 2020). Further, with the high use of psychotropic medication in autistic adults (Nylander et al., 2018), there is a specific need for more research exploring the effectiveness and experiences of medication use in this population (Esbensen et al., 2009; Lake et al., 2015). It is possible that an over-reliance on medication stems from a false belief amongst clinicians that autistic individuals are unable to engage in or benefit from talking therapies and/or lack of effective treatment models in this group. Our synthesis also highlighted the need for autism-specific outcome measures (Gotham et al., 2014) and the potential value of ‘toolboxes’ to support autistic adults accessing mental health support as well as

professionals providing care to this population, similar to those developed to aid communication in physical health settings (Nicolaidis et al., 2019) and the ‘Know your Normal’ toolkit for young autistic adults (Crane et al., 2017).

Strengths and Limitations

Overall, this study identified a larger number of papers than previous reviews on similar topics (Adams & Young, 2020; Calleja et al., 2020; Mason, Ingham, et al., 2019), presumably due to the broader scope of looking at autistic adults’ experience of accessing and engaging with services for mental health difficulties in general, rather than focusing on barriers and facilitators to access specifically. In addition, this topic seems to be a growing area of research, with several included papers being published since the searches of previous reviews were conducted. Thus, the current review provides a more up-to-date overview of the existing literature.

The included studies were rated high in quality, strengthening the validity of this review. However, the MMAT (Hong et al., 2019) is one of several possible frameworks for appraising study quality and offers a less detailed evaluation of qualitative studies than some other appraisal tools developed exclusively for qualitative studies, which might have resulted in a more generous rating.

Although a relatively large number of qualitative papers were identified, the detail in which they covered autistic adults’ experience of support for mental health difficulties varied (see Table 30), and consequently they contributed to the meta-synthesis to different degrees. In terms of the breadth of experiences included, there is still scope for more focused explorations of specific aspects of autistic adults' experience in mental health settings, such as specific therapeutic approaches or treatment for specific co-occurring conditions, as have started to emerge for EDs (Adamson et al., 2020; Babb et al., 2021; Kinnaird, Norton, Stewart, et al., 2019;

Kinnaird et al., 2017). Such in-depth qualitative explorations could be used together with larger scale quantitative studies to inform and evaluate adaptations to treatment specific to those conditions and settings. In addition, most studies highlight barriers and challenges individuals experienced when accessing services and draw conclusions about what could have been done differently to make these experiences more positive, but there is less focus on what aspects of mental health care are experienced as helpful. It could be valuable to ask autistic adults who have had good experiences about what worked for them and why, highlighting examples of good practice.

The meta-synthesis combined the views of participants from a wide range of studies, yet it is still likely to present a limited set of voices. All studies were conducted in Western countries, with the majority conducted in the UK. Due to differences in the healthcare system, experiences are likely to vary across countries. Additionally, certain groups of autistic adults, such as those with co-occurring ID or those from non-White ethnic groups, were underrepresented. The experience of autistic adults with ID might be different to those without, for example because they tend to access support via learning disability teams, rather than general adult mental health (Bhaumik et al., 2008). There also seems to be unique challenges experienced by adults with ID, such as the developmental appropriateness of services, highlighted in our findings. Similarly, Black, Asian and Minority Ethnic (BAME) groups are disproportionately affected by health care inequalities (Bignall et al., 2019) and likely to face additional and different challenges (Memon et al., 2016), which must be considered by service providers and clinicians. The underrepresentation of these groups in has been noted by others and systemic

change in autism research is needed to better represent those with co-occurring ID and non-White autistic people (Jones & Mandell, 2020; G. Russell et al., 2019).

Conclusions

The current systematic review and meta-synthesis provided a comprehensive overview of qualitative research on autistic adults' experience of accessing and engaging with support for mental health difficulties. Based on the included studies, current mental health service provision does not adequately support autistic adults with co-occurring mental health difficulties. There is a need for a more flexible, comprehensive and holistic approach, considering how being autistic affects the individual's mental health presentation and engagement. Building trusting relationships, listening to autistic adults, and empowering them to take agency, are fundamental steps towards more successful mental health care provision. Improvements to mental health care informed by autistic adults' unique experiences will likely also benefit other services users as well as improving conditions for professionals providing treatment. There is a need to further explore autistic adults' experience of specific treatment approaches, as well as the experiences of currently underrepresented groups of autistic adults, including those with co-occurring ID and from BAME backgrounds. Qualitative insights should be combined with larger scale quantitative studies to inform the development of new treatments and adaptations, and to evaluate their implementation in mental health service settings.

Chapter 7: General Discussion

Previous research has established that autistic women are overrepresented in RED populations (Huke et al., 2013; Westwood et al., 2017) and that commonly available eating disorder treatments appear to lack efficacy in this client group (Nazar et al., 2018; Stewart et al., 2017; Tchanturia et al., 2016). The current thesis aimed to contribute to an evidence base that can inform the improvement of ED services for autistic women. Specifically, this thesis employed a mixed-method approach to generate a better understanding of (1) autistic women's experiences of REDs, (2) the mechanisms that might link autism and REDs, and (3) the ways in which mental health services, including ED services, function for their autistic clients. The current chapter will discuss the findings of this thesis in relation to these aims, highlight limitations of the studies conducted, and consider the implications for future research and clinical practice.

A first step toward an evidence base to guide service improvements for autistic women seeking support for REDs is to gain a better understanding of how REDs develop and persist in autistic women, and the role autism-specific factors might play. Chapter 2 presents the findings from qualitative interviews with autistic women who have experience of AN, parents of such women, and healthcare professionals. The chapter then proposes a theoretical model of autism-specific mechanisms that might contribute to the development and maintenance of restrictive eating difficulties in autistic individuals (Study 1). Chapters 4 and 5 test some elements of this model, using quantitative methods, and provide initial insights into the clinical presentation of autistic women with REDs (Study 2).

Another step toward improving ED service provision for autistic women is to learn about the barriers autistic adults face in mental health services more generally,

and the ways these barriers might be overcome. Chapter 6 contributes to this goal by conducting a systematic review and meta-synthesis to gain insight into autistic adults' experiences of accessing and engaging with support for co-occurring mental health difficulties (Study 3).

The knowledge gained from these studies can be used by ED services to improve the way these services engage with autistic individuals. It could also, can inform treatment adaptations and, eventually, the development of new autism-specific ED treatments and interventions to prevent REDs in autistic individuals.

Evaluation of the Theoretical Model of Restrictive Eating Difficulties in Autistic Individuals

Based on a thematic analysis of in-depth interviews with autistic women, parents, and healthcare professionals about perceived causal and maintaining factors of AN in autistic individuals, we developed a theoretical model of the mechanisms that may underlie restrictive eating difficulties in autistic individuals (Chapter 2). Our model proposes that restrictive eating behaviours in autistic individuals can stem directly from their autism, reflecting, for example, sensory aversions to foods. Eating difficulties may also arise as an attempt to cope with the indirect challenges related to being autistic, such as feelings of being overwhelmed or issues around identity. Restrictive eating behaviours and the effect of starvation are hypothesised to numb or resolve emotional and sensory overload, and controlling food intake may counter the anxiety that arises from being in an unpredictable environment.

In Chapters 4 and 5, elements of this model were tested via a group comparison of autistic women without REDs ('Autism only'), autistic women with REDs ('Autism+REDs'), and non-autistic women with REDS ('REDs only'). This

study also included a fourth participant group, women with REDs and high autistic traits ('REDs high autistic traits'), who, overall, presented similarly to formally diagnosed autistic women with REDs, but did not have an autism diagnosis. The rationale for employing a group comparison approach was that the factors which present to a stronger degree in autistic women with REDs than in the other two main groups might be implicated in the development and maintenance of REDs in autistic individuals. The findings of the group comparison were supportive of some elements of the model, but not of others. Some elements of the model have also been included in investigations by the other researchers who contributed to this project and are not presented in the current thesis, and yet some other elements have not yet been explored further, but they pose promising candidates for future research. In the following, I will evaluate the model proposed in Study 1 based on findings from Study 2, whilst also drawing on the wider scientific literature.

The Role of Weight and Shape Concerns

Weight and shape concerns did not form part of the model of autism-specific mechanisms underlying restrictive eating difficulties, as our qualitative findings suggested that these might be less relevant for REDs in autistic women (Chapter 2). Indeed, our quantitative findings in Chapter 4 demonstrated that autistic women with REDs present with fewer shape concerns. Further, their weight concerns were lower than in non-autistic women with REDs, after controlling for co-occurring mental health difficulties in autistic women with REDs (Chapter 4). However, it is also important to note that, compared to autistic women without REDs, weight and shape concerns were still elevated in autistic women with REDs. Even though weight and shape concerns are often viewed as interlinked, in that they are both a response to body image issues (Gowers & Shore, 2018; Taylor, 2015), they might be related to

different underlying drivers in autistic women. For example, our qualitative data suggest that weight concerns could reflect certain obsessive thinking styles, e.g. wanting the numbers on the scales to follow a pattern, or a need for control (Chapter 2). Future research should explore different constructs associated with weight and shape concerns in autistic women with REDs using independent, more detailed measures. Further, our qualitative research suggests that, if present, body image issues in autistic women may be interlinked with autism-related factors, such as camouflaging behaviours and women's sense of self (Chapter 2). This is another potential avenue for future research.

In combination, the findings of Studies 1 and 2 suggest that clinicians should not categorically expect a lack of weight and shape concerns in autistic individuals, but should not assume them either. In addition, when supporting autistic women with REDs, it appears important to consider other factors that are likely to contribute to restrictive and rigid eating in this population and that might make change more difficult. Common treatments, such as Enhanced Cognitive Behavioural Therapy for Eating Disorders (CBT-E; Fairburn et al., 2003), view weight and shape concerns as central to ED psychopathology and target these as a primary mechanism (Fairburn et al., 2003). However, the danger of assuming a singly causal mechanism and reducing AN complexity to body image issues has repeatedly been highlighted (e.g., Zanker, 2009). Our quantitative findings in Study 2 demonstrated that autistic women's RED presentations tend to be particularly complex, with both traditional ED symptoms and additional autism-specific eating behaviours (see Chapter 4). Therefore, a narrow focus on traditional ED symptomatology, including weight and shape concerns, in assessment and treatment risks underestimating the complexity of autistic women's REDs, and could hinder progress toward recovery.

Exploration of Autism-Specific Contributing Factors

Our qualitative findings suggest that autistic women's experience of autism and their REDs are closely intertwined. Our theoretical model proposes a number of autism-specific factors that are hypothesised to directly or indirectly contribute to restrictive eating difficulties in autistic individuals (Chapter 2).

In Chapter 4, we compared the four groups' presentation of core autism diagnostic characteristics (characteristics inherent to being autistic), as captured by general measures of autistic traits, as well as camouflaging behaviours, which are often part of women' s autism presentation (Cook, Hull, et al., 2021; Hull et al., 2020). We also included the SWEAA (Karlsson et al., 2013) as a measure of autism-specific unusual eating behaviours; this assessment has multiple subscales related to constructs more widely associated with autism, providing an initial sense of other autism-related difficulties that might be driving REDs in autistic women. The similarities between autistic women with and without REDs in terms of core autistic traits and levels of camouflaging behaviours do not suggest that these autism characteristics or a female-specific autism presentation are directly implicated in REDs in autistic women. However, comparing autism-specific unusual eating behaviours between groups provided preliminary evidence that other factors could be of relevance to REDs in autistic women (Chapter 4). Autistic women with REDs presented with higher overall autism-specific unusual eating behaviours than both autistic women without REDs and non-autistic women with REDs, and scored higher than both groups on a number of subscales related to specific autism characteristics, namely, sensory sensitivities, intolerance of uncertainty, and social difficulties. These

characteristics could therefore be considered as possible autism-specific RED contributors (Chapter 4).

Sensory Sensitivities. In Chapter 5, we explored one of these factors, sensory sensitivities, which was also a central element of the theoretical model in Chapter 2, in more depth. Our theoretical model proposes that sensory sensitivities experienced by autistic individuals could lead to restrictive eating behaviours either via a direct pathway (e.g., restriction in response to a sensory aversion to food characteristics) or an indirect pathway (e.g., general sensitivities acting as a stressor, and restrictive eating serving as a way to modulate this stress by numbing emotional distress and sensory experiences). One of the SWEAA subscales assessed preference and avoidance of food with certain sensory properties. Autistic women with REDs scored significantly higher than autistic women without REDs and non-autistic women with REDs on this subscale (Chapter 4). However, our more in-depth exploration of sensory sensitivities in Chapter 5 did not support the suggestion that sensitivities are directly linked to REDs in autistic women. Even though autistic women presented with significantly higher sensitivities than non-autistic women with REDs, neither general sensitivities nor sensitivities affecting food-specific modalities distinguished between autistic women with and without REDs. This questions the relevance of sensory sensitivities for the development and maintenance of REDs in autistic women, and thus, their inclusion in the theoretical model of autism-specific mechanisms. Additional research is required to evaluate the role sensory sensitivities and inform revisions of the model.

It should be noted that our RED groups predominantly included individuals with ED diagnoses other than ARFID, and that findings may be different in ARFID populations, for whom sensory sensitivities play a more integral role (APA, 2013;

Bourne et al., 2020). Nonetheless, taken together, the findings of the current thesis suggest that the general sensitivities experienced by autistic women with AN (Chapter 2) appear to be a feature of life as an autistic person, rather being a direct causal and maintaining factor of their REDs (Chapter 5). Further exploration of sensory sensitivities still seems worthwhile, in part because the lack of significant difference between autistic women with and without REDs, particularly with regard to food-specific sensitivities, could be explained by a failure to appropriately capture food-specific sensitivities affecting different modalities. There appears to be potential for the development of a new bespoke measure that separates sensory response related to food and other stimuli across different modalities.

In addition to including a self-report measure of sensory sensitivities, we initially intended to measure food-related sensory processing directly by including a psychophysical assessment of taste identification ability. However, due to COVID-19, we were only able to collect this data for a subset of the two autism groups, which meant our findings were inconclusive (Chapter 5). Future research should explore possible discrepancies between self-reported sensory sensitivities and performance on measures of sensory processing ability (Schaaf & Lane, 2015).

Other Potential Contributing Factors to REDs in Autistic Individuals. The theoretical model from Study 1 and subsequent evaluation in Study 2 shed light on a number of other factors that could be implicated in REDs in autistic individuals. These factors warrant further investigation.

Apart from sensory sensitivities, other factors that appeared to be driving high levels of autism-specific unusual eating behaviours in autistic women with REDs were intolerance of uncertainty and social difficulties (Chapter 4). Both of these factors are also elements of the theoretical model of autism-specific mechanisms

(Chapter 2). The SWEAA findings from Chapter 4 can be seen as initial evidence supporting the inclusion of these elements in the model, as these factors are elevated in autistic women with REDs and those with high autistic traits relative to autistic women without REDs and non-autistic women with REDs. Other research also supports the suggestion that these factors could play a causal or maintaining role in REDs in autistic individuals For example, Kerr-Gaffney, Halls, et al. (2020) examined the relationships between ED symptoms and autistic traits in individuals with a lifetime history of AN using network analysis. In line with our suggestion that social difficulties play a contributing role, their findings indicate that interpersonal problems may mediate the relationship between ED symptoms and autistic traits in those with AN (Kerr-Gaffney, Halls, et al., 2020).

The SWEAA also included a subscale assessing sensitivity to hunger and satiety sensations, which are elements of interoception. Interoceptive difficulties were also part of the theoretical model (Chapter 2). However, in contrast to our qualitative findings (Chapter 2), there were no significant differences between groups for this subscale (Chapter 4), calling into question whether differences in sensitivity to hunger and satiety sensations are directly linked to REDs in autistic individuals. However, the subscale only included two items, which could have reduced variability in the responses. In addition, the subscale does not take into account other issues related to interoception that were raised by participants in Study 1, such as heightened sensitivity to internal sensations, resulting in discomfort related to digestion, and emotional confusion as a consequence of lack of insight into bodily responses (Chapter 2). Interoceptive difficulties are common among autistic individuals (DuBois et al., 2016) and have also been identified in those with AN (Jenkinson et al., 2018). Thus, relevance of interoception for REDs in autistic women

still remains an important avenue for future research and should be explored with more detailed measures.

The theoretical model (Chapter 2) includes other factors that were not further explored in Study 2, but could be of relevance for REDs in autistic women. These include difficulties with emotional regulation and the presence of certain cognitive styles. The potential role of all of these factors for restrictive eating difficulties in autistic individuals should be investigated further. These factors could be directly linked to restrictive eating behaviours, or could interact with one another and with other factors, such as sensory sensitivities (Chapter 5).

Future research should also start to distinguish between causal and/or maintaining factors to better understand autism-specific risks for RED development and factors that might interfere with recovery. This could be achieved by employing longitudinal approaches and tracking changes in symptom presentation over time. These insights will help to inform preventative approaches as well as treatment adaptations.

Other avenues for Future Research

A number of other questions emerged and remain to be explored in relation to potential causal and maintaining factors of restrictive eating difficulties in autistic individuals. These questions not only represent avenues for future research, but also bring to light potential opportunities to improve treatment and services for autistic individuals with REDs.

Firstly, the specificity of the theoretical model to REDs and the role of other mental health difficulties needs to be further examined. The model proposes that autism-related difficulties are linked to restrictive eating behaviours via a direct and indirect pathway (Chapter 2). In the indirect pathway, autism-related difficulties are

hypothesised to lead to distress, which may result in the person experiencing mental health difficulties, which they then cope with by restricting their eating (Chapter 2). Autistic women with REDs and those with high autistic traits who participated in Study 2 presented with significantly higher co-occurring mental health difficulties (symptoms of depression, anxiety, and social anxiety) than participants in the other groups (Chapter 4). At times, these mental health difficulties appeared to interact with their presentation of autistic traits, including sensory sensitivities, as well as their disordered eating-related symptoms, as indicated by changes in group differences after controlling for differences in co-occurring mental health difficulties (Chapters 4 and 5). This is supportive of the indirect pathway proposed in the model. It also suggests that the factors contributing to REDs in autistic individuals may also affect their mental health more generally. Future research should first aim to replicate the findings of the current study. If heightened co-occurring mental health difficulties are confirmed to be part of the clinical presentation of autistic individuals with REDs, then potential interactions with disordered eating-related symptoms should be explored. Further, future research should explore whether the autism-related difficulties hypothesised to be implicated in the development and maintenance of REDs contribute directly to restrictive eating difficulties or to mental health difficulties more generally. This could inform treatment and approaches aimed at preventing REDs in autistic individuals.

Secondly, future research should explore the specificity of the proposed model to REDs (as opposed to non-restrictive EDs). The model was developed based on qualitative interviews about autistic women's experience of AN, but was extended to be applicable to restrictive eating difficulties more generally, as our findings did not necessarily suggest that the proposed autism-specific mechanisms

were limited to a specific diagnostic category (Chapter 2). Study 2 included individuals with different RED diagnoses (AN, atypical AN, and ARFID) (Chapter 3). However, the relevance of the model to non-restrictive EDs has not yet been explored. Some elements of the model might result in disordered eating that is not necessarily restrictive in nature. For example, difficulties with sensory sensitivities, interoception, or emotional regulation in autistic individuals could also contribute to bulimia nervosa or binge eating, as has been anecdotally reported in qualitative research (Kinnaird, Norton, Pimblett, et al., 2019; MacLennan et al., 2021). Although most research on the co-occurrence between autism and EDs has focused on AN (Nickel et al., 2019), there is some evidence that high levels of autistic traits are also common in non-restrictive EDs (Dell'Osso et al., 2018; Vagni et al., 2016). In addition, autistic adults have been found to be more likely than non-autistic adults to present with extreme BMIs, both in the underweight and overweight/obese range (Sedgewick et al., 2019; Weir et al., 2021). In line with this, in Study 2, participants in the 'Autism only' group presented with a wide range of BMIs (Chapter 4). Thus, it might well be that autistic individuals are also overrepresented among individuals with non-restrictive EDs, including those that may lead to high BMIs, such as binge eating disorder. Autistic adults' vulnerability to non-restrictive EDs and potential autism-specific mechanisms should be explored further.

Finally, future research should explore whether the model and findings of the subsequent chapters can be generalised to males and individuals with other gender identities. The model was developed based on qualitative findings on the AN experience of autistic women (Chapter 2), and Study 2 also primarily included women, although some participants in the autism groups identified outside the binary gender norm (Chapters 3 and 4). Given the gender differences in the presentation of

autism (Hull et al., 2020) and in the causes, presentation, and needs of males and females with EDs (Stanford & Lemberg, 2012), the relevance of this model to individuals with non-female gender identities—and the presentation of REDs in these individuals—should be explored. The additional stressors that might affect the mental health of gender diverse individuals (Bennett & Goodall, 2016; Hartman-Munick et al., 2021) provide another compelling reason to explore the generalisability of the model.

The Current Understanding of REDs in Autistic Women and Implications for Clinical Practice

The findings of the current thesis suggest that autistic women with AN experience their autism and AN as closely intertwined, and that there might be autism-specific drivers of REDs in autistic individuals, such as intolerance of uncertainty, social difficulties, and possibly food-related sensory sensitivities, resulting in particularly complex RED presentations. Autistic women with REDs tend to present with fewer traditional ED symptoms; however, these symptoms do still exist for many of these women. In addition, autistic women with REDs are likely to present with high levels of autism-specific unusual eating behaviours. The theoretical model developed in this thesis (Chapter 2) provides an initial guide to considering potential autism-specific factors that could be implicated in REDs in autistic women, although the role of sensory sensitivities was not supported by our subsequent study (Chapter 5), and other elements warrant further exploration. Following further testing, a revised version of the model could be of value for clinical formulation and to inform treatment adaptations or the development of new ED treatments that address autism-specific mechanisms.

There are a number of existing psychological therapy approaches and ED treatments that might be particularly well suited to address autism-specific causal and maintaining factors when treating REDs in autistic individuals. For example, individual psychotherapy in the form of the Maudsley model of AN treatment for adults (MANTRA; Schmidt et al., 2014), which identifies and addresses drivers specific to the individual, could incorporate autism-specific factors. Therapies that target specific mechanisms assumed to be underlying AN, which are likely to be particularly pronounced in autistic individuals, could also be of value. Anecdotal evidence from qualitative research (Babb et al., 2021) suggests that dialectical behaviour therapy (DBT; Linehan, 1993), a version of which has been developed for AN (radically open dialectical behaviour therapy (RO-DBT); Isaksson et al., 2021; Lynch et al., 2013), might be beneficial for autistic individuals with REDs. These therapies aim to address difficulties with emotional regulation and control. Similarly, groups aiming to increase intolerance of uncertainty (Sternheim & Harrison, 2018) and sensory wellbeing workshops (Tchanturia, Baillie, et al., 2021) could be of value for autistic individuals with REDs. Further, treatment enhancers, such as cognitive remediation therapy (CRT; Tchanturia & Lock, 2011) and cognitive remediation and emotion skills training (CREST; Tchanturia et al., 2015) , which aim to improve retention of other therapies by addressing factors associated with ED symptoms, such as cognitive rigidity, detail focus, and emotional processing difficulties (Tchanturia et al., 2015; Tchanturia et al., 2014), could be helpful for autistic individuals. Preliminary evidence supports the feasibility of these treatment enhancers in this group (Dandil et al., 2020). These therapies, as well as any bespoke new treatment approaches focusing on autism-specific mechanisms, need to be tested for effectiveness in autistic individuals with REDs.

Reducing Barriers for Autistic People in ED Services

In addition to understanding and addressing the autism-specific mechanisms underlying restrictive eating difficulties, ED services must also become more accessible for and accommodating of autistic people in order to improve service provision for this client group. A wealth of previous research has explored autistic adults' experiences in mental health services, reporting on the perspectives of autistic adults themselves, their family members, and mental health professionals. These insights highlight barriers that autistic individuals attempting to access support may experience and suggest ways to overcome these barriers. Chapter 6 presented a systematic review and meta-synthesis of qualitative studies investigating autistic adults' experiences of accessing and receiving support for mental health difficulties (Study 3). It identified 34 studies, three of which focused on the service experience of autistic adults in ED settings. In the following section, I will summarise findings of the meta-syntheses that are particularly relevant to ED settings and relate them to findings from previous chapters and other research.

Ineffective Service Provision and Risk of Iatrogenic Harm

The meta-synthesis in Chapter 6 highlighted that current mental health care provision is not fit for the purpose of supporting autistic people with co-occurring mental health difficulties, and can even pose a risk of worsening the individual's condition through iatrogenic harm (Chapter 6). It has repeatedly been found that commonly available ED treatments are less effective in autistic individuals or those with high autistic traits than in other women with REDs (Nazar et al., 2018; Nielsen et al., 2015; Stewart et al., 2017; Tchanturia et al., 2016). This was one of the motivations for the current thesis. The longer illness duration observed in the 'Autism+REDs' group relative to the 'REDs only' group in Study 2 (Chapter 4) also

indicates that ED services might not be as effective for autistic women. Harm might arise if ED services assume the presence of weight and shape concerns in individuals who do not feel these are relevant to their presentation (Chapter 2, Brede et al., 2020; Zanker, 2009), or if these services refuse to acknowledge and accommodate other autism-related difficulties, such as sensory sensitivities (Babb et al., 2021; Kinnaird, Norton, Stewart, et al., 2019). The current thesis increased understanding of the clinical presentations of autistic women with REDs, and these insights can be used by ED services to improve their accessibility and acceptability for this client group.

Need for Flexible and Individualised Treatment Approaches

Participants in the studies included in the meta-synthesis (Chapter 6) advocated for a more flexible, comprehensive, and holistic approach—one that considers how being autistic affects an individual's mental health presentation and ability to engage with treatment offered. Our qualitative findings suggest that RED presentations in autistic individuals are diverse, with a multitude of potential contributing factors (Chapter 2), and our quantitative findings highlight the complexity of autistic women's REDs, which exhibit both traditional ED symptoms and autism-specific unusual eating behaviours (Chapter 4). Further, autistic traits (Chapter 4), including high levels of sensory sensitivities (Chapter 5), are likely to affect the skills and abilities autistic women with REDs bring to treatment. Therefore, in line with the findings of the meta-synthesis, a flexible approach, taking into account the complexity and variability of autistic individuals' presentations, appears essential to improving ED service provision for this client group.

The meta-synthesis in Chapter 6 highlights various factors that should be considered for treatment adaptations. These treatment adaptations should take into

account the specific needs of autistic women with REDs, including their communication preferences, sensory sensitivities, need for predictability, and expectations for treatment outcomes. However, there are likely to be ED specific challenges that were not captured in the meta-synthesis, such as nutritional rehabilitation, food exposure, and meal planning. These challenges warrant the development and testing of adaptations of ED treatments for autistic individuals. The Pathway for Eating Disorders and Autism Developed From Clinical Experience (PEACE pathway; https://www.peacepathway.org/), which was recently implemented as part of the South London and Maudsley NHS Trust Eating Disorders Services, provides one of the first systematic attempts toward treatment adaptations (Tchanturia, Dandil, et al., 2021). In this pathway, specialist training is provided to help ED staff recognise and accommodate autistic traits in therapy. In addition, the ward environment was adapted to be more autism friendly, e.g., by reducing sources of noise and visual distraction. The pathway also offers a specialised food menu that takes into account common sensory aversions to food characteristics, as well as sensory workshops for patients to learn about their sensory needs and self-soothing techniques (Tchanturia, Baillie, et al., 2021). Evaluations of PEACE are ongoing (Tchanturia, Dandil, et al., 2021). While long-term outcomes are yet to be established, initial findings suggest that these autism-informed adaptations to ED treatment are feasible and well-received (Tchanturia, Dandil, et al., 2021). If deemed effective, this approach could inform future autism-specific ED treatment guidelines, and other ED services could implement this approach (or elements of it) to increase accessibility for autistic individuals.

Better Identification of Autistic Women in ED Services

One step toward improving ED service provision for autistic women is improving the identification of women who could benefit from autism-specific adaptations. The meta-synthesis highlights the value of collaborating with autistic adults, empowering them, and respecting their agency, and considers this to be a fundamental step toward more successful mental health care provision (Chapter 6). In addition, the theme of 'self and identity' in our thematic analysis (Chapter 2) suggests that helping autistic women to better understand of themselves and their autism could be an integral component of their recovery (Chapter 2). However, this can only happen if autistic women and the people around them are aware of their autism.

Several autistic adults who participated in studies included in the meta-synthesis (Chapter 6) reported that they did not receive their autism diagnosis until a decline in their mental health brought them into contact with clinical services. This path seems particularly common for autistic women in ED services. Most autistic women with REDs who participated in Study 1 or 2 received their autism diagnosis in adulthood, often long after the onset of their RED (Chapter 2 and 4). In addition, Study 2 demonstrated that a significant proportion of women with REDs without a formal autism diagnosis have very high autistic traits and present with similar autism characteristics, disordered eating-related symptoms, and additional co-occurring mental health difficulties to formally diagnosed autistic women with REDs (Chapters 4 and 5). This suggests that a significant proportion of women with REDs could represent undiagnosed autistic women, who are likely to have autism-specific RED presentations and other needs.

The similarity in presentations between formally diagnosed autistic women with REDs and those with high autistic traits (Chapter 4) also suggests that

confirming the presence of high autistic traits might be sufficient for identifying individuals who could benefit from autism-informed treatment adaptations. In other words, it might not be necessary for individuals to meet full diagnostic criteria. In the UK, ED services are primarily designed to treat people with EDs, whereas separate autism services diagnose (and support) autistic adults. ED teams tend not to have the training or commissioning to recognise or diagnose autistic people. However, adult autism diagnostic services have long waiting times (Leedham et al., 2019). In addition, even if these waiting times were shorter, it is not advisable to conduct full diagnostic assessments while a person is experiencing an acute episode of a mental health difficulty, such as an ED (NICE, 2012). This means that undiagnosed autistic women in ED services may be missed or face considerable delay before obtaining a formal autism diagnosis, which could provide them with access to additional support (Mandy & Tchanturia, 2015; Westwood et al., 2017b). If ED services were given appropriate training and resources to recognise high autistic traits in their clients and to adapt support according to their needs, a greater proportion of individuals would receive the support they need and deserve.

Screening for Autistic Traits. The current thesis provides new insights that may ultimately improve the screening process for identifying autistic individuals in RED populations. Study 2 of this thesis was the first to use the RADS-14 (Eriksson et al., 2013) in individuals with REDs (Chapter 3 and 4), and it provides initial evidence for the clinical utility of this measure in ED settings and its validity in ED populations. All formally diagnosed autistic women with REDs scored above the standard cut-off (≥14; Erikson et al., 2013) used to confirm the presence of autistic traits (Chapter 3). The use of a more conservative cut-off (≥ 23; Erikson et al., 2016) identified a subgroup of potentially undiagnosed autistic women with REDs (‘REDs

high autistic traits'—see Chapters 3 and 4). This group was similar in proportion to the percentage of potentially undiagnosed women identified in other studies using more rigours assessment tools (Westwood et al., 2017b). The conservative cut-off also retained an 'REDs only' group who exhibited similar levels of autistic traits to individuals with RED in other studies (Westwood, Eisler, et al., 2016). The similarity of 'REDs high autistic traits' to the two autism groups, but not to 'REDs only,' on the RAADS childhood ratio, which was first conceptualised in this thesis (Chapter 4), further supports the potential value of the RAADs-14 as a screening measure in ED settings, because of additional insights gained regarding the developmental presentation of autistic traits. Recently, other research has started to explore the utility of other adult autism screening measures, such as the social responsiveness scale (SRS-2, Constantino & Gruber, 2012), in REDs samples, with promising initial findings (Kerr-Gaffney, Harrison, et al., 2020b). However, another study suggests that the SRS-2 might not be able to differentiate between autistic females and those with AN (Kerr-Gaffney et al., 2021).The psychometric properties of the RAADS-14 and other autism screening measures in ED populations should be further explored to inform the identification of autistic women in ED settings.

In addition, the group differences on the SWEAA (Karlsson et al., 2013) and sensory measures (Chapters 4 and 5) suggest that a combination of screening tools to assess core autistic traits and associated factors could be used to increase accuracy of identification. Further, in clinical practice, the screening process should be informed by clinical judgement (Wigham et al., 2018). Our experience providing training for ED clinicians on the presentation of autism in females and potential deviations in autistic women's RED presentations (in preparation for in-person recruitment for Study 2; see Chapter 3 for more detail) suggests that clinical

judgement of ED staff could be of value in identifying undiagnosed autistic women. Tools, such as Kinnaird and Tchanturia's (2020) framework of clinical features associated with both autism and AN and potential differences in their presentation, could be utilised to support clinicians with this process.

Differentiating Autism and Other Co-Occurring Conditions in REDs. The identification of autistic women in ED settings will be further complicated by the co-occurrence of other conditions with REDs, such as OCD and personality disorders, which may resemble autism in females (Steinhausen et al., 2021). In AN samples, 16.8% present with co-occurring OCD (Salbach-Andrae et al., 2008) and 24.8% meet the criteria for personality disorder, most commonly of avoidant, emotionally unstable, or obsessive-compulsive nature (Gaudio & Di Ciommo, 2011; Sansone et al., 2004). Similar to autistic women with REDs (Nazar et al., 2018; Stewart et al., 2017), women with AN and these co-occurring conditions have particularly complex presentations. These groups tend to require more intense care and have lower recovery and higher relapse rates than women without these conditions (Carrot et al., 2017; Gaudio & Di Ciommo, 2011). Further, research on the presentation of women with AN and personality disorders focuses on constructs that overlap with autism characteristics, such as inhibited mentalising ability (i.e., the understanding oneself and others in terms of mental states; (Bateman & Fonagy, 2012; Cortés-García et al., 2021). Similarly, research on women with AN and OCD focuses on restricted and repetitive behaviours, which also overlap with autism characteristics (Zucker & Losh, 2008). Thus, it is possible that some women with REDs who are considered to present with personality disorders or OCD would meet criteria for autism. At the same time, some women who are considered to be autistic in the growing field of research on the co-occurrence of autism and REDs (including the

current thesis) might be wrongly categorised. Therefore, not only autistic traits, but also presentations of characteristics indicative of other conditions, should be considered in a clinical setting when assessing whether an individual with an RED could be autistic. There is a need to explore the similarities, differences, and potential overlap of the presentation of autism and other co-occurring conditions in women with REDs in future research, as these groups might present with different needs in treatment (Acikel & Cikili, 2020; Kelly & Davies, 2019).

Strengths of the Thesis

One key strength of the current thesis is its rigorous methodological approach: the studies in the thesis employed methodologies that yielded generalizable insights of direct relevance for clinical practice, while remaining grounded in individuals' lived experience.

The mixed-method approach employed across Studies 1 and 2 (Chapters 2, 4, and 5) generated new ideas about the potential causal and maintaining factors of REDs in autistic individuals. These ideas and insights were informed by in-depth interviews with autistic women and those who support them, and were then tested deductively using a quantitative approach. While some of the insights from Study 1 were supported by Study 2, others, although plausible, did not bear out. This highlights the value of combining qualitative and quantitative research to create a solid evidence base that can be used to inform clinical practice.

This thesis also employed thematic meta-synthesis (in Study 3; Chapter 6), a methodology that generates evidence informing the development, implementation, and evaluation of healthcare provision (Lachal et al., 2017; Thomas & Harden, 2008) based on the accounts of those with lived experience. Thematic meta-synthesis works by identifying patterns and developing overarching interpretations across

existing qualitative studies (Barnett-Page & Thomas, 2009), which capture the complexity and variety of individuals' experiences. On their own, qualitative studies are rarely used to inform service provision (Lachal et al., 2017). Therefore, the use of this methodology represented an important step towards incorporating client-centred perspectives in service improvement.

In addition, we employed a participatory approach (Cornwall & Jewkes, 1995; Fletcher-Watson et al., 2019), collaborating with different autistic individuals with relevant lived experience throughout the research process. Autistic women contributed to the conceptualisation of the research ideas, study design, and interpretation (and dissemination) of all three studies conducted as part of this thesis. This ensured that the research was informed by the values of its community and contextualised within real-world settings, which will enhance the translation of its findings into practice.

Another strength of this thesis is that it addresses multiple research areas, which are a priority for both autism community and policy. The World Health Organisation and NHS long-term plan both recognise mental health care for autistic adults as a key priority for the near future (WHO, 2013; NHS, 2019). Understanding, treating and preventing mental health difficulties in autistic individuals has also been identified as a research area that warrants greater attention in various autism community priority setting exercises (Cusack & Sterry, 2016; Gotham, Marvin, et al., 2015; Pellicano et al., 2014). Improving mental health service provision for autistic adults, specifically for autistic women with REDs, was the primary motivation for the research conducted in this thesis. Other key research areas, identified by community priory setting exercises, are research increasing our understanding of sensory processing differences and improving the recognition and diagnosis of autism in

adults (Cusack & Sherry, 2016). The current thesis contributes new insights related to both of these areas. Another important issue, which the current thesis addresses, is high mortality in autistic individuals, who on average die 16 years earlier than non-autistic people (Hwang et al., 2019), with suicide rates being nine times higher (Hirvikoski et al., 2016). Anorexia Nervosa has the highest mortality rate of all mental disorders, mostly due to high levels of medical complications in underweight individuals and suicide (Arcelus et al., 2011; Chesney et al., 2014). Thus, by promoting the development of better ED treatments for autistic individuals, this research also contributes towards countering avoidable death in autism.

Finally, the current thesis benefits from a large sample sizes. Study 1 analysed data from total of 44 interviews with autistic women, parents and healthcare professionals. Study 2 presents one of the largest studies on the co-occurrence of autism and REDs to date. Importantly, it is the first study to include a group of formally diagnosed autistic women with REDs. Although, we exceeded our target sample size for the main three groups (‘Auitsm only’, ‘Auitsm+REDS’. ‘REDs only’), it should be noted that Study 2 was still only powered to detect group differences with a medium-large effect size (Chapter 3). This means we might have missed more subtle group differences that could still be clinically meaningful. Thus, caution is warranted when drawing conclusions about cases where differences were expected but not supported by the data. For example, the data showed that autistic women with and without REDs had similar levels of camouflaging behaviours and sensory sensitivities (Chapters 4 and 5). Replication of this finding with larger samples is desirable.

Limitations of the Thesis

The studies conducted as part of this thesis are not without limitations. For Study 1 (Chapter 2) we used Thematic Analysis (Braun & Clarke, 2006, 2019) to analyse qualitative data generated by the interviews conducted. This approach was chosen because of its flexibility, which suited both the aim of capturing the phenomenon of interest (AN in autistic women), as well as the more theory-generating aim of developing a model of restrictive eating difficulties in autistic individuals. There were also practical reasons; its structured yet flexible approach allowed the two researchers, who jointly conducted the analysis, to work closely together, and made the analysis process accessible to our (non-academic) autistic advisors. However, other approaches to qualitative analysis might also have been suitable for the aims of the study. For example, Interpretative Phenomenological Analysis (IPA; Smith et al., 2009) could have been used to explore the lived experience of autistic women with AN, or a Grounded Theory approach (Bryant, 2017; Glaser & Strauss, 1967) could have been used to inform the development of the theoretical model. Further, Study 1 focused on AN in autistic women, rather than REDs more generally, and only included those with experience of AN in the participant group of autistic women. The findings of our qualitative analysis suggested that perceived causal and maintaining factors of AN in autistic women could also be of relevance in REDs other than AN. We sought to reflect this by extending the theoretical model to propose autism-specific mechanisms for REDs more generally. However, the model is still primarily based on data about AN. Inclusion of individuals with other REDs, such as ARFID, from the onset, might have impacted the results. Finally, Study 1 might have benefited from more reflection by the research team about their own attitudes toward the research topic and

expectations for possible findings, for example, by using a bracketing approach (Tufford & Newman, 2010).

In Study 2 (Chapter 3, 4, 5), the cross-sectional nature of the group comparison limits the conclusions we can draw about cause and effect of potential contributing factors to REDs in autistic individuals. We cannot be certain that the factors which differentiated autistic women with REDs from autistic women without REDs and non-autistic women with REDs, such as intolerance of uncertainty and social difficulties (as measured by SWEAA subscales; Chapter 4), are casually implicated in the development of REDs in autistic women. For example, high levels of intolerance of uncertainty and social difficulties during mealtimes experienced by autistic women with REDs could equally be a consequence of their RED. Longitudinal research is needed to establish whether the group differences identified by the current study were present before the onset of women's REDs, and thus whether they may have played a causal role.

Study 2 did not include a non-autistic control group without REDs, which is unusual, particularly in the field of ED research. This design decision was made because the research question is primarily interested the presentation of autistic women with REDs compared to other autistic women without REDs and non-autistic women with REDs, rather than in establishing whether certain factors were elevated compared to a normative compassion group. Further, the additional recruitment efforts, which would have been required to include an additional control group, were beyond the scope of this project. The lack of a normative comparison group limits possible insights gained, for example with regard to whether the level of sensory sensitivities was still elevated in 'REDs only' compared to non-autistic women without REDs.

Moving data collection online in response to COVID-19 (see Chapter 3) affected our recruitment strategy. Recruiting predominantly via online pathways, instead of through NHS services as had been originally planned, might have introduced biases to the sample. Although we were able to extend the reach of our recruitment geographically (see Chapter 3), participants recruited online might be less representative of autism and ED populations. For example, a large proportion of autistic women in the sample had been diagnosed in adulthood, and the majority of ED participants presented with illness durations that could be considered chronic or enduring (Chapter 4). These groups might differ in important ways from those diagnosed in childhood and those with more recent ED onsets (Bargiela et al., 2016; Davis et al., 2020).

Moving data collection online might have created a barrier to participation for individuals who struggle with technology or completing long surveys independently, which can be the case for some autistic people (Cascio et al., 2020). The online survey took around one hour to complete. Participants were encouraged to take breaks and were given two weeks in total. We also emphasised that we would be available for any questions or queries (Chapter 3). Nonetheless, for some individuals, this might have been an inaccessible form of research participation, which could have affected the representativeness of our sample.

Further, moving the study online meant that we were unable to test potential mechanisms using direct experimental and observational measures (see Chapters 3 and 5). The exclusive use of questionnaires might have affected the quality of the data. Self-report measures are prone to social desirability bias, which could be problematic with sensitive topics such as EDs (Lavender & Anderson, 2009) or when assessing individuals with high levels of camouflaging. In addition, self-report

measures require insight into one's presentation and behaviours, which some autistic individuals or those who are currently unwell with EDs might struggle with (Keith et al., 2019; Konstantakopoulos et al., 2011; Mazefsky et al., 2011).

Moving the study online also meant that we relied on self-reported autism and ED diagnoses and current ED status. Although we asked for diagnostic details as part of the screening process, it would have been desirable to confirm participants' autism status, for example by using the ADOS-2 (Lord et al., 2012), as was part of the original pre-COVID-19 research plan. This would have also given further clarity as to whether women in the 'REDs high autistic traits' group were likely to constitute undiagnosed autistic women. Similarly, for the REDs groups, we did not include an independent measure of ED severity, giving rise to the possibility that differences in traditional disordered eating symptoms between RED groups (Chapter 4) could be due to differences in ED severity overall. Although we ensured that all RED participants included in the final sample presented with current disordered eating symptoms (see Chapter 3), there may have been variation in the severity of these symptoms and the extent to which the participants' REDs affect them in their day-to-day lives.

Several groups were underrepresented or excluded from our Study 2 sample, which affects the generalisability our findings. As mentioned above, we excluded males from our Study 2 sample. In addition, the majority of our participants were White, and we did not include those with co-occurring intellectual disability (ID). The underlying drivers and presentation of REDs in individuals from underrepresented ethnic groups might be different (Rodgers et al., 2018), and these individuals are likely to face additional challenges when engaging with services (Becker et al., 2003). Similarly, people with ID may have difficulties around food that are different

than those seen our sample of autistic women with REDs, including pica and difficulties with physical coordination, chewing, and swallowing (Gravestock, 2000). This means that our findings may lack applicability for individuals from underrepresented ethnic groups and those with co-occurring ID. As highlighted by the systematic review (Chapter 6), lack of inclusion of unrepresented ethnic groups and of individuals with co-occurring ID, is unfortunately common for both autism and ED research (Gravestock, 2000; Jones & Mandell, 2020; Rodgers et al., 2018; G. Russell et al., 2019).

In Study 3, the systematic review and meta-synthesis (Chapter 6), one limitation was its exclusive focus on the qualitative elements of the studies considered. The review included mixed-method studies, but did not consider the quantitative elements of their findings, and excluded quantitative studies altogether. Quantitative studies might also capture relevant information about autistic adults' experiences of mental health services, for example by using Likert scales in surveys about their satisfaction with specific aspects of the support they received. Including quantitative studies was beyond the scope of the review, but could be considered for future reviews.

Further, although the meta-synthesis generated new insights by combining studies focusing on autistic adults' support experience across different mental health settings, a narrower focus could have generated more specific guidance for ED services. The systematic search, which was conducted in December 2020, identified three qualitative studies related to supporting autistic individuals in ED settings. Since then, several more have been published, including by our research group (e.g., Babb et al., 2021). Thus, future research could consider a meta-synthesis specific to autistic individuals' experience in ED settings in order to identify barriers

and facilitators specific to ED service provision that may have been missed by the current review.

Concluding Remarks

The current thesis makes a novel contribution by exploring perceived causal and maintaining factors of restrictive eating difficulties in autistic individuals using qualitative methods, and testing elements of a theoretical model developed via group comparisons of autistic women with and without REDs and non-autistic women with REDs. It presents the first ever group comparison including formally diagnosed autistic women with REDs, offering new insights into their clinical presentation and laying the foundation for future research. It also provides valuable insights into the similarities of autistic women with REDs and those with high autistic traits, which can inform the identification of undiagnosed autistic women in ED settings.

The current thesis demonstrated that the clinical presentation of autistic women with REDs is complex. They may present with fewer traditional disordered eating symptoms, suggesting that shape concerns, and potentially weight concerns, play less of a role in the development and/or maintenance of their REDs. Instead, they present with high levels of additional autism-specific unusual eating behaviours. We did not find evidence that general sensory sensitivities play a direct contributing role to REDs in autistic women. However, there was some preliminary evidence for stronger preference and avoidance of food with certain sensory properties among autistic women with REDs and they still presented with higher levels of sensitivities than non-autistic women with REDs. This is important for ED services to consider, as these sensitivities will likely affect autistic women in treatment.

The meta-synthesis of qualitative studies on autistic adults' experience of accessing and engaging with support for co-occurring mental health difficulties

elucidated the barriers autistic adults face in mental health service settings and ways to overcome them. Together, the findings of the current thesis raises awareness of restrictive eating difficulties in autistic women and will help ED services to become more autism friendly by informing the adaptation to better meet the needs of this population. In the long term, the current thesis may contribute to the development of new autism-informed ED treatments and interventions to prevent of development of restrictive eating disorders in autistic individuals.

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Appendix 1

Interview schedules for Study 1

Interview Schedule for Autistic Women

Hello, thank you for agreeing to take part in our study, we really appreciate it.

- That there are no right or wrong answers, we are just interested in your views and experience.
- Please let me know if you would like me to repeat any questions or ask it in a different or more specific way.
- It is important for you to know that you don't need to answer any questions that you don't feel comfortable with, we can skip them, or go back to them later.
- Don't worry if you feel like you have forgotten to include anything. At the end I will check with you if you would like to add anything and if there are any topics you think we have missed that you might like to tell me about.

Note for interviewer:

General prompts that can be used throughout the interview

- *What/why/who/how?*
- *Can you give me an example, or describe a situation where this was the case?*
- *Could you talk me through this experience/situations?*

Option: use written guide to interview topics to support the interview process.

1. <u>Experience and diagnosis of autism</u>

To start off, could you tell me about your autism?

- What is autism like for you in your day to day life?
  - Are there ways in which autism makes your life more difficult?
  - Are there things that you're better at than others?
  - When did you first notice ____?
- Has this changed with time/as you have grown up?
- What was it like to receive your autism diagnosis?
  - When were you diagnosed with autism?
  - Could you describe how you received your diagnosis? *(reason and process, e.g. school initiated assessment, seeking referral from GP, referral from other MH services)*
- What did you think of the diagnosis?
  - Did you think/suspect you might be on the autism spectrum prior to receiving a diagnosis, or was this something new to you?
  - How did you react when you received the diagnosis?
  - How did other people around you react when you received the diagnosis? (Think about family, friends, teachers/employers reactions)
- What, if anything, changed as a result of being diagnosed?

2. Experience and diagnosis of eating disorder

Could you to tell me about your experiences of eating disorders.

- What was it like to receive your eating disorder diagnosis?
  - When did you receive an eating disorder diagnosis?
  - Could you describe the process of receiving your diagnosis? *(reason and process, e.g. seeking referral from GP, referral from other MH services)*
  - Was this before or after you received the autism diagnosis?
  - How did you react when you received your eating disorder diagnosis?
- Was there anything unusual with regard to your eating before this?
  - What was your eating like when you were younger?
- When did you notice your eating had become an issue /did someone else point it out to you?

3. Causes and maintaining factors

We know that eating disorders are complex and it can be difficult to understand why an eating disorder develops, for both professionals and the individual. But, do you have any insights as to why your eating disorder developed?

  - How did it start?
  - Are there any triggers for you?
  - Do you/did you value your eating disorder at any point?
- Is/Was your relationship to eating always difficult regardless of what else is/was going on in your life or are/were there particular times that makes/made eating easier/more difficult for you?

If participant struggles to identify causes/maintaining factors:

- In eating disorders research, there are many potential reasons why someone might engage in disordered eating. The reasons might apply to some people but not to others. These may or may not have impact you.
  - Some people feel a need to be in control;
  - Some don't realise when they're hungry and what/how much they should be eating;
  - Some get preoccupied with counting calories;
  - Some have difficulties with the smell or texture of different foods;
  - Some engage in restricted eating behaviours to connect and fit in with other people;
  - Some feel pressured by friends, society or things in the media;
  - Some are not happy with the way they look in the mirror;
  - Others want to lose weight

- Did any of these influence you?
- What other things might have played a role for your eating disorder?

Offer an optional break

4. Eating disorder services

Now I'm going to ask you some questions about your experiences with eating disorder services.

- Have you had any involvement with eating disorder services?
- Are you currently involved with them?
- Could you tell me about your experience in eating disorder services?

5. Referral/seeking help process

- What was the referral process like for you?
  - How were you referred to eating disorder services? (e.g. GP, other mental health services)
  - Who initiated your referral? Did you agree? How did you feel about being referred?
  - What was this process like for you? (Wait times?)

6. Experience of treatment

Once seen by a specialist, what treatment options were you offered?

- How did they try to help you?
- Did you take up this option? Why (not)?
  - What is/was it like for you?
  - Can you think of anything that seems to have been particularly helpful?
  - Can you think of anything that might have got in the way, or was difficult?
- What is/was your experience like with therapist/other staff?
- Are/were any other people involved? (Other patients encountered during treatment/family therapy?)

→ Was this consistent or was there anything that made [any of these things] easier/more difficult? Were there any circumstances that made it better/worse?

If applicable discuss experience in inpatient/day patient treatment, individual therapy, group therapy.

- *Inpatient/day patient: What was the environment like on the ward, mealtime?*
- *Individual or group therapy: Do you remember what kind of treatment you were offered? (e.g. CBT); What topics did the therapy cover? Were there any particular topics that were more/less helpful than others?*

7. Discharge/service experience outside of ED

If you have been discharged, what was this like?

- How did you feel about being discharged? (Positive aspects/worries?)
- Have you had any engagement with services since?

- Have you received input related to autism or eating from any other services than discussed already? Any other MH input?
- What other coping strategies or support (by professionals/other people in your life) has helped you/ do you find helpful?
- What one thing stood out to you as the most helpful so far?
- What could services have done differently?

8. Status Quo

How do you manage your eating now? How do you feel about your eating now?

9. Relationship between autism and eating disorder
   - What role (if any), do you think, does/did your autism play in your experience of eating disorder?
   - Are any other things you have noticed that might be different about the experience of eating disorders for autistic people?
     - Have you met anyone else with an eating disorder who doesn't have autism? Did you notice any difference between your struggles with eating and food compared to them?
10. Summary
   - Before we wrap up, is there anything else you would like to add? Anything we have missed? Any questions?

Thank you so much for your time. We'll go through a quick debrief now before we finish.

Interview Schedule for Family Members of Autistic Women

Hello, thank you so much for agreeing to take part in our study, we really appreciate it.

- There are no right or wrong answers, we are just interested in your views and experience.
- Please let me know if you would like me to repeat any questions or ask it in a different or more specific way.
- It is important for you to know that you don't need to answer any questions that you don't feel comfortable with, we can skip them, or go back to them later.
- Don't worry if you feel like you have forgotten to include anything. At the end I will check with you if you would like to add anything and if there are any topics you think we have missed that you might like to tell me about.
-

Note for interviewer: General prompts that can be used throughout the interview

- *What/why/who/how?*
- *Can you give me an example, or describe a situation where this was the case?*
- *Could you talk me through this experience/situations?*

Option: use written guide to interview topics to support the interview process.

1. <u>Introduction</u>

To start off, could you tell me a bit about [your autistic family member with experience of eating disorder] and yourself.

- What is she like? Age? How does she spend her time? What are her interests?
- What is your relationship?
  - Do you live together?
  - Are there any other family members/important people?

<u>2. Experience and diagnosis of autism</u>

Could you tell me a bit about [your daughter's] autism?

- What is autism like for [her] in her day to day life?
  - Are there any things [she] finds particularly challenging?
  - Are there things [she] is good at? Or that are less of a problem for [her]?
  - When did you first notice these things?
- Has this changed over time/as she grew up?
- What was it like for her to receive an autism diagnosis?
  - When was [she] diagnosed?
  - Could you describe how [she] received her diagnosis? (*reason and process, e.g. seeking referral from GP, referral from other MH services*)
- What did you both think of the diagnosis?
  - Did you think/suspect she might be on the autism spectrum prior to her receiving a diagnosis, or was this something new to you?
  - How did both of you react when [she] received the diagnosis?
  - How did others around her react (family, friends, teachers/employers reactions)?

- What, if anything, changed as a result of [her] being diagnosed?

3. Experience and diagnosis of eating disorder

Could you to tell me about [your daughter's] experiences of eating disorders.

- What was it like for her to receive an eating disorder diagnosis?
  - When did she receive an eating disorder diagnosis?
  - Could you describe the process of her receiving the diagnosis? How was [she] diagnosed? (e.g. seeking referral from GP, referral from other MH services)
  - Was this before or after the autism diagnosis?
  - How did you react when she received her eating disorder diagnosis?
- Was there anything unusual with regard to her eating before this?
  - What was her eating like when she was younger?
- When did you notice her eating had become an issue?

4. Causes and maintaining factors

We know that eating disorders are complex and it can be difficult to understand why an eating disorder develops, for professionals, the individual and family alike. But, Is there anything you think might have led up to her eating disorder?

- How did it start?
- Are there any triggers for [her]?
- Can you see any way in which the eating disorder might have added value to her life at any point/ was a good thing?
- Is/Was her relationship to eating always difficult regardless of what else is/was going on in her life or did you notice that there are/were there particular times that makes/made eating easier/more difficult for her?

In eating disorders research, there are many potential reasons why someone might engage in disordered eating. The reasons might apply to some people but not to others.

- Some people feel a need to be in control;
- Some don't realise when they're hungry and what/how much they should be eating;
- Some get preoccupied with counting calories;
- Some have difficulties with the smell or texture of different foods;
- Some engage in restricted eating behaviours to connect and fit in with other people;
- Some feel pressured by friends, society or things in the media;
- Some are not happy with the way they look in the mirror;
- Others want to lose weight

Do you think any of these have influenced your daughter?
What other things might have played a role for her eating disorder?

Offer an optional break

5. Eating disorder services

Now I'm going to ask you some questions about [your daughter's] experience in eating disorder services.

- Has she had any involvement with eating disorder services?
- Is she currently involved with them?
- In general, what do you think was/is her experience of eating disorder services?
  - What is/was it like for her?
  - What was it like for you (from a family member's perspective)?

6. Referral/seeking help process

What was the referral process like?

- How was she referred to eating disorder services? (e.g. GP, other mental health services)
- Who initiated the referral?
- What was this process like for her? (Wait times?)

7. Experience of treatment

Once seen by a specialist, what treatment options were offered to her?

- How did they try to help?
- Did she take up these options? Why (not)?
  - What is/was treatment like for her?
  - Can you think of anything that seems to have been particularly helpful?
  - Can you think of anything that might have got in the way, or was difficult for her?
  - Were you involved in the treatment process at all? (e.g. family therapy)
- What is/was her relationship to her therapist/other staff?
- Are/were any other people (patients) involved? Do you think they (have) affect(ed) her in any way? In what way? Why not?
  - ➔ Were there any circumstances that made it better/worse?

If applicable discuss experience in inpatient/day patient treatment, individual therapy, group therapy.

- *Inpatient/day patient: What was the environment like on the ward, mealtime?*
- *Individual or group therapy: Do you remember what kind of treatment your daughter was offered? (e.g. CBT); Are you aware of what topics her therapy covered? Were there any topics that were more/less helpful than others for her?*

8. Discharge/service experience outside of ED

If she have been discharged, what was this like?

- How did you feel about her being discharged? (Positive aspects/worries?)
- Has she had any engagement from services since?

- Has your daughter received input from any other services that related to her autism or eating? Any other MH input?

- What other coping strategies or support (by professionals/other people in her life) have helped her?
- What one thing stood out to you as the most helpful thing so far?
- What one thing should services have done differently?

9. Status Quo

- How are things now, in your opinion?
- How does she currently manage her eating?

10. Relationship between autism and eating disorder

- What role, do you think, does/did her autism play for her eating disorder?
- Are any other things you have noticed that might be different about the experience of eating disorders for autistic women?
- Do you know of anyone else with an eating disorder who doesn't have autism? Did you notice any difference between [your daughter's] struggles with eating and food compared to their difficulties?

11. Summary

- Before we wrap up, is there anything else you would like to add? Anything we have missed?
- Do you have any questions?

Thank you so much for your time. We'll go through a quick debrief now before we finish.

Interview Schedule for Eating Disorder Healthcare Professionals

Hello, thank you so much for agreeing to take part in our study, we really appreciate it. We are looking to understand more about eating disorders, particularly anorexia nervosa, within autistic women and their experiences of eating disorders services, and we'd like your perspective on this topic. Please let me know if you would like me to repeat my question or ask it in a different way. It is important for you to know that you don't need to answer any questions that you don't feel comfortable with and that there are no right or wrong answers, only your answers. At the end I will check with you if you would like to add anything and if there are any topics you think we have missed that you might like to tell me about.

General prompts:

- *Can you expand on this point?*
- *Can you say a bit more about this?*
- *Can you give me an example?*
- *Could you talk me through this experience?*

1. Introduction:

What is your current job role?
How long have you worked in this role?
How long have you worked in a specialist eating disorder setting?

2. Professional experience and knowledge of eating disorders

To start off, could you tell me about your experience of anorexia nervosa within your profession?

- What's the context in which you work with females with anorexia (e.g. on the ward, in therapy)
- How would you describe the presentation of anorexia symptomatology in females in your work to someone who is not familiar with your field of work?
- Have you come across any difficulties with screening or carrying out diagnostic assessments with females with anorexia? Examples?

3. Professional experience and knowledge of autism

I'd like you to tell me about your experience of autism within your profession?
How familiar are you with autism, particularly in females?

- What is your understanding of autistic traits? Would you know what traits to look out for?
- In which ways do you think autism is/might be relevant in the work you do?
- Do you screen for or carry out diagnostic assessments for autism in females with anorexia? If so, in what situations? What are the challenges with this?

4. Relationship between autism and eating disorders

What are your thoughts/understanding of the relationship between autism and eating disorders?

- Have you ever come across it within your clinical practice? In what ways?
- Were there any challenges? If so, what were they?

- How might autistic women with anorexia differ from non-autistic women with anorexia?

We know that patients with anorexia can present with social communication difficulties, rigid behaviours and interests and might have difficulties to identify and cope with emotions.

- Would you consider these patients to be on the autism spectrum?
- Under what conditions would you consider these traits to be autistic in nature?
- Under what conditions would you consider these traits to be a consequence of their anorexia?

5. Maintaining factors of AN in autism

Based on your professional knowledge and/or experience, can you think of any potential contributing factors to the development of anorexia in autistic women?

- What factors might make them more or less likely to develop an eating disorder?
- What might be the main struggles for autistic women with anorexia?
- Can you think of certain situations that might make autistic women struggle more with their eating disorder? Or situations that make it better?

Eating Disorders Services for Autistic Women

6. Routes of referral

If you suspected a woman with anorexia might have autism, what would you/your service do?

- Who would you consult? Why?
- Would you investigate it yourself/within your service? If so, in which particular situations?
- Would you refer them to a specialist? If so, in which particular situations?

What challenges do you think an autistic woman might face when being referred for an eating disorder?

- Why these challenges in particular?

7. Treatment of eating disorders for autistic women

What challenges do you think autistic women might face when engaging with eating disorder services? How might autistic traits be challenging for patients with anorexia in a service context?

- In what ways might group therapy be a challenge for autistic women?
    - (Engagement with staff/therapist/other patients; communication difficulties; disrupted routines; sensory/environmental concerns)
- In what ways might individual therapy be a challenge for autistic women?
    - (Engagement with staff/therapist/other patients; communication difficulties; disrupted routines; environmental concerns)
- In what ways might inpatient or day patient treatment be a challenge for autistic women?
    - (Engagement with staff/therapist/other patients; communication difficulties; disrupted routines; environmental concerns)

Do you think the care and needs of autistic women are different to the care and needs of a non-autistic women within eating disorders services?

- In what ways would they differ and why?
- What additional support might autistic women with anorexia require?

What might be some of the challenges that therapists and other staff members face when treating autistic women with anorexia?

What might be some of the challenges on a service level?

Could you suggest any therapeutic interventions or particular topics that might help an autistic woman with anorexia? (e.g. emotion regulation, therapeutic interventions involving central coherence/set shifting)

8. Summary

Before we wrap up, is there anything else you would like to add? Anything we have missed?
Do you have any questions?
Thank you so much for your time. We'll go through a quick debrief now before we finish.

Interview Schedule for Autism Healthcare Professionals

Hello, thank you so much for agreeing to take part in our study, we really appreciate it. We are looking to understand more about eating disorders, particularly anorexia nervosa, within autistic women and their experiences of eating disorders services, and we'd like your perspective on this topic. Please let me know if you would like me to repeat my question or ask it in a different way. It is important for you to know that you don't need to answer any questions that you don't feel comfortable with and that there are no right or wrong answers, only your answers. At the end I will check with you if you would like to add anything and if there are any topics you think we have missed that you might like to tell me about.

General prompts:

- *Can you expand on this point?*
- *Can you say a bit more about this?*
- *Can you give me an example?*
- *Could you talk me through this experience?*

1. Introduction:

What is your current job role?
How long have you worked in this role?
How long have you worked in a specialist autism setting?

2. Professional experience and knowledge of autism

- To start off, could you tell me about your experience of autism in females within your profession?
- In what capacity might you come across autistic females in your work? (e.g. diagnostic, care coordination, therapy, consulting professionals from other services)

- In what ways might females with autism present differently to the traditional stereotypes of autistic presentation?
- How would you describe the presentation of autistic traits in females to someone who is not familiar with your field of work?
- Have you come across any difficulties with screening or carrying out diagnostic assessments with autistic females? Examples?

3. Professional experience and knowledge of eating disorders

I'd like you to tell me about your experience of eating disorders within your profession.

- How familiar are you with eating disorders, particularly anorexia? What's your understanding of eating disorder symptomatology? (Would you know what symptoms to look out for?)
- In which ways do you think anorexia might be/is relevant in the your work in autism?

4. Relationship between autism and eating disorders

What are your thoughts on the relationship between autism and eating disorders?

- Have you ever come across it within your clinical practice? In what ways?
- Were there any challenges? What were they?
- How might autistic women with anorexia differ from other autistic women who don't have anorexia?
- Are there any other things **you** have noticed that might be different about the experience of eating disorders for autistic people?

5. Maintaining factors of AN in autism

Based on your professional knowledge and/or experience, can you think of any potential contributing factors to the development of anorexia in autistic women?

- What factors might make them more or less likely to develop an eating disorder?
- What might be the main struggles for autistic women with AN?
- Can you think of certain situations that might make autistic women struggle more with their eating disorder? Or make it better?

Eating Disorders Services for Autistic Women

6. Routes of referral

If you suspected an autistic woman might have an eating disorder, what would you do?

- Who would you consult? Why?
- Would you investigate it yourself and/or support them within your service? If so, why/in which particular situations?
- Would you refer them to a specialist? If so, why/in which particular situations?
- Do you screen for or carry out diagnostic assessments for anorexia/eating disorders in autistic females? In what situations? What are the challenges with this?

What challenges do you think autistic women in particular might face when being referred for an eating disorder?

7. Treatment of eating disorders for autistic women

What challenges do you think autistic women might face when engaging with eating disorder services?

- In what ways might group therapy be a challenge for autistic women?
    - (Engagement with staff/therapist/other patients; communication difficulties; disrupted routines; environmental concerns)
- In what ways might individual therapy be a challenge for autistic women?
    - (Engagement with staff/therapist/other patients; communication difficulties; disrupted routines; environmental concerns)
- In what ways might inpatient or day patient treatment be a challenge for autistic women?
    - (Engagement with staff/therapist/other patients; communication difficulties; disrupted routines; environmental concerns)

Do you think the care and needs of an autistic women would be different to the care and needs of a non-autistic women within eating disorders services?

- In what ways would they differ and why?
- What additional support might an autistic women with anorexia require?

What might be some of the challenges that therapists and other staff members face when treating autistic women with anorexia?

- What might be some of the challenges on a service level?

Could you suggest any therapeutic interventions or particular topics that might help an autistic woman with anorexia? (e.g. emotion regulation, therapeutic interventions involving cognitive styles)

8. Summary

Before we wrap up, is there anything else you would like to add? Anything we have missed?

Do you have any questions?

Thank you so much for your time. We'll go through a quick debrief now before we finish.

Appendix 2

Example of recruitment advert for Study 2

This is the online version of the recruitment advert, based on the original in-person advert. It was adapted to advertise the study to individual participant groups and for use in NHS services.

Appendix 3

Additional participant characteristics and group comparisons for Study 2

Table 1, Appendix 3

Participants' recruitment source, mode of participation, geographic location, and diagnostic categories

		Autism only (n=47)	**Autism+REDs** (n=51)	**REDs only** (n=76)	**REDs high autistic traits** (n=36)	**Group comparison**
Recruitment/ mode of participation	social media, charities, existing research contacts (in-person)	28 (59.6%)	18 (35.3%)	1 (1.3%)	2 (5.6%)	Pearson χ^2 (6)= 70.824, ***p*<.001**, ϕ_c=.411
	social media, charities, existing research contacts (online)	12 (25.5%)	26 (51%)	49 (64.5%)	28 (77.8%)	
	NHS (online)	7 (14.9%)	7 (13.7%)	26 (34.2%)	6 (16.7%)	
Geographic location	South East (including London)	24 (51.1%)	24 (47.1%)	41 (53.9%)	13 (36.1%)	
	South West	3 (6.4%)	9 (17.6%)	5 (6.6%)	0	
	Midlands	5 (10.6%)	3 (5.9%)	4 (5.3%)	5 (13.9%)	

		Autism only (n=47)	**Autism+REDs** (n=51)	**REDs only** (n=76)	**REDs high autistic traits** (n=36)	**Group comparison**
	North East	2 (4.3%)	4 (7.8%)	2 (2.6%)	6 (16.7%)	
	North West	3 (6.4%)	5 (9.8%)	7 (9.2%)	3 (8.3%)	
	Scotland	1 (2.1%)	1 (2%)	4 (5.3%)	0	
	Wales	7 (14.9%)	5 (9.8%)	11 (14.5%)	8 (22.2%)	
	Northern Ireland	2 (4.3%)	0	2 (2.6%)	1 (2.8%)	
Autism diagnoses	Asperger's	17 (36.2%)	15 (29.4%)			Asperger's vs any other autism diagnosis: Pearson $\chi^2(1)=.508$, $p=0.523$, $\phi_c=.072$
	Any other	30 (63.8%)	36 (70.6%)			
	Autism	2 (4.3%)	2 (3.9%)	NA	NA	
	ASD/ASC	28 (59.5%)	32 (62.8%)	NA	NA	
	Asperger's Syndrome	17 (36.2%)	15 (29.4%)	NA	NA	
	PDD-NOS	0	1 (2%)	NA	NA	
	Other	0	1 (2%): "ASD and pathological demand avoidance"	NA	NA	

		Autism only (n=47)	**Autism+REDs** (n=51)	**REDs only** (n=76)	**REDs high autistic traits** (n=36)	**Group comparison**
REDs diagnoses	AN	NA	41 (80.4%)	65 (85.5%)	32 (88.9%)	AN vs any other: Pearson χ^2 (2)=1.255, p=0.534, ϕ_c=.088
	Atypical AN	NA	5 (9.8%)	8 (10.5%)	4 (11.1%)	
	ARFID	NA	4 (7.8%)	0	0	
	Other ED	NA	1 (2%) : "can't remember"	3 (3.9%): OSFED (x2), "Anorexia and ARFID" (x1)	0	

Table 2, Appendix 3

Comparison of online vs in-person participants on key variables

Measure		**Autism only**		**Autism+REDs**		**REDs only**		**REDs high autistic traits**	
		In-person (n=28)	**Online (n=19)**	**In-person (n=18)**	**Online (n=33)**	**In-person (n=2)**	**Online (n=34)**	**In-person (n=1)**	**Online (n=75)**
RAADS-14	Mean (SD)	32.79 (6.16)	34.00 (8.28)	37.17 (3.60)	33.91 (6.51)	32.00 (9.90)	30.94 (5.73)	7	11.11 (5.82)

	Comparison	*t*(54)=-.577, *p*=.567, *g*=-.17		*t*(49)=1.96, *p*=.056, *g*=.57		One-sample *t*(74)=6.088, ***p*<.001,** *g*=5.86		*U*=31, *z*=-.208, *p*=.863, *r*=.034	
EDE_Q global	Mean (SD)	1.54 (1.11)	2.01 (1.55)	3.37 (1.67)	3.51 (1.30)	2.89 (2.26)	4.58 (1.01)	3.96	4.13=4 (1.20)
	Comparison	*t*(45)=-1.2, *p*=.236., *g*=1.32		*t*(49)=-.325, *p*=.746, *g*=1.46		One-sample *t*(74)=1.268, *p*=.209, *g*=1.20		*U*=54, *z*=1.38, *p*=.203, *r*=.227	
HAADS-depression	Mean (SD)	5.75 (4.49)	7.21 (4.16)	10.28 (5.32)	10.21 (5.74)	11.50 (3.54)	12.53 (3.71)	15.00	9.85 (3.91)
	Comparison	*t*(45)=-1.13, *p*=.265, *g*=4.43		*t*(49)=.098, *p*=.924, *g*=5.69		One-sample *t*(74)=-11.27, ***p*<.001,** *g*=3.97		*U*=40, *z*=.427, *p*=.714, *r*=.071	
HAADS-anx	Mean (SD)	10.89 (4.18)	11.63 (5.00)	14.67 (5.15)	15.00 (3.77)	15.50 (7.78)	15.65 (3.77)	9.00	14.04
	Comparison	*t*(45)=-.549, *p*=.585, *g*=4.60		*t*(49)=-.265, *p*=.792, *g*=4.36		One-sample *t*(74)=-2.59, ***p*=.011,** *g*=3.48		*U*=23, *z*=-.139, *p*=.917, *r*=.023	
SPIN	Mean (SD)	35.18 (13.48)	35.05 (13.07)	45.33 (12.76)	44.82 (11.38)	34.50 (36.06)	48.38 (9.28)	20.00	36.71 (31.43)
	Comparison	*t*(45)=.032, *p*=.975, *g*=.009		*t*(49)=.148, *p*=.883, *g*=.043		One-sample *t*(74)=-10.67, ***p*<.001,** *g*=13.61		*U*=37, *z*=.208, *p*=.863, *r*=.034	

Table 3, Appendix 3

COVID-19 related hardships experienced by online participants and their impact

COVID-19 related hardship	**Autism only (n=19)**	**Impact (1-7),** Mean (SD, Range	**Autism+REDs (n=33)**	**Impact (1-7),** Mean (SD, Range	**REDs only (n=75)**	**Impact (1-7),** Mean (SD, Range	**REDs high autistic traits (n=34)**	**Impact (1-7),** Mean (SD, Range
Losing your job or regular income hardship rating	2 (10.53%)	7 (0), 7-7	1 (3.03%)	5.00	5 (6.67%)	6 (1.41), 4-7	2 (5.88%)	4 (4.24), 1-7
A major reduction in income hardship rating	5 (26.32%)	5 (1.87), 3-7	2 (6.06%)	5.5 (0.71), 5-6	13 (17.33%)	4.62 (2.22), 1-7	5 (14.71%)	4.8 (2.28), 1-7
Unable to pay bills/rent/mortgage hardship rating	1 (5.26%)	7.00	0		2 (2.67%)	7 (0), 7-7	1 (2.94%)	6.00
Evicted/lost accommodation hardship rating	0		0		1 (1.33%)	7	0	
Increased caring responsibilities hardship rating	3 (15.79%)	5 (0), 5-5	6 (18.18%)	5 (1.10), 4-7	8 (10.67%)	3.75 (1.17), 3-6	5 (14.71%)	4.8 (1.48), 3-7
Unable to access enough/suitable food hardship rating	1 (5.26%)	6.00	5 (15.15%)	6.2 (0.45), 6-7	7 (9.33%)	6 (0.82), 5-7	6 (17.65%)	5.17 (1.47), 3-7
Unable to access usual support services hardship rating	3 (15.79%)	6.67 (0.58), 6-7	21 (63.64%)	5.24 (1.38), 3-7	34 (45.33%)	5.32 (1.55), 1-7	18 (52.94%)	5.33 (1.57 (2-7)

Unable to access medication hardship rating	2 (10.53%)	4.5 (2.12), 3-6	3 (9.09%)	6 (0), 6-6	1 (1.33%)	4	4 (11.76%)	5 (1.16), 4-6
Being unwell with COVID-19 hardship rating	0		2 (6.06%)	4.5 (2.12), 3-6	6 (8.00%)	3.33 (2.25), 1-7	2 (5.88%)	4.5 (3.54), 2-7
Someone close to you being unwell with COVID-19 hardship rating	2 (10.53%)	5 (2.83), 3-7	4 (12.12%)	4 (2.45), 1-6	13 (17.33%)	3.92 (1.80), 1-6	2 (5.88%)	4 (1.41), 3-5
Increased worry about pre-existing physical health conditions hardship rating	5 (26.32%)	5 (1.58), 3-7	14 (42.42%)	5.64 (1.74), 2-7	25 (33.33%)	4.76 (1.64), 1-7	12 (35.29%)	4.75 (1.66), 1-7
A fear of contracting COVID-19 hardship rating	12 (63.16%)	5 (1.48), 3-7	14 (42.42%)	6.07 (1), 4-7	29 (38.67%)	4.66 (1.34). 3-7	19 (55.88%)	5.16 (1.21), 3-7
Changes to a normal routine hardship rating	16 (84.21%)	4.94 (1.34), 2-7	28 (84.85%)	5.64 (1.55), 3-7	63 (84.00%)	5.67 (1.52), 1-7	31 (91.18%)	5.81 (1.25), 3-7
Changes to social support hardship rating	7 (36.84%)	5.57 (1.13), 4-7	19 (57.58%)	5.32 (1.34), 3-7	45 (60.00%)	5.53 (1.36), 2-7	21 (61.76%)	5.86 (1.11), 4-7
Feeling isolated or lonely hardship rating	10 (52.63%)	5.9 (1.10), 4-7	22 (66.67%)	4.73 (1.52), 2-7	58 (77.33%)	5.78 (1.22), 2-7	26 (76.47%)	5.77 (1.51), 1-7

Changes in the home hardship rating	12 (63.16%)	5.67 (1.56), 3-7	25 (75.76%)	4.84 (1.63), 1-7	56 (74.67%)	4.82 (1.72), 1-7	20 (58.82%)	5.5 (1.32), 3-7
Other hardship rating	0.00		6 (18.18%)	6.5 (1.23), 4-7	9 (12.00%)	6.22 (1.39), 3-7	9 (26.47%)	5.44 (2.01), 1-7
To what extent has your eating behaviour been affected by/changed because of COVID-19 and/or related lockdown measures?	19 (100.00%)	5.89 (1.82), 2-8	33 (100.00%)	6.33 (1.34), 2-8	75 (100.00%)	6.55 (1.63), 2-8	34 (100.00%)	6.56 (1.71), 2-7
To what extent has your mental wellbeing been affected by/changed because of COVID-19 and/or related lockdown measures?	19 (100.00)	5.26 (1.33), 3-7	33 (100.00%)	5.58 (1.62), 1-7	75 (100.00%)	5.69 (1.33), 1-7	34 (100.00%)	5.79 (1.34), 2-7

Appendix 4

Study 2 Screening questions

To ensure you are suitable for our research, it would be great if you could confirm/answer the following questions:

1. What is your age?
2. What is your gender?
3. Do you live in the UK?
4. Are you formally diagnosed with an autism spectrum condition?

- If yes, please could you provide us with some additional information, including your specific autism diagnosis, when you were diagnosed, and if possible, the service you were diagnosed at.

5. Are you formally diagnosed and consider yourself to be currently living with a restrictive eating disorder? Restrictive eating disorders include Anorexia Nervosa, Atypical Anorexia or Avoidant Restrictive Food Intake Disorder (ARFID).

- If yes, please could you provide us with some additional information, including your specific eating disorder diagnosis, when you were diagnosed, and if possible, the service you were diagnosed at.
- If not, have you ever had a formally diagnosed eating disorder in the past (and currently consider yourself to be recovered)?

6. Have you ever been diagnosed with a general learning disability or intellectual disability?

Appendix 5

Study 2 background questionnaire

SEDAF background questionnaire - this was presented as part of an online survey using Qualtrics (2018).

Please answer the following questions about yourself by ticking the appropriate box.

1. Which sex were you assigned at birth?

- ☐ Male
- ☐ Female
- ☐ Other _____

2. How would you describe your gender?

- ☐ Male
- ☐ Female
- ☐ Agender/ gender neutral
- ☐ Other _____

3. How old are you? (In years) _____

4. What is your ethnicity?

- ☐ White British
- ☐ White Irish
- ☐ Other White background

_____

- ☐ Black Caribbean
- ☐ Black African
- ☐ Any other Black background

_____

- ☐ Indian
- ☐ Pakistani
- ☐ Bangladeshi
- ☐ Any other Asian background

_____

- White and Black Caribbean
- White and Black African
- White and Asian
- Any other mixed background

_____

- Chinese
- Any other ethnic group

_____

5. What are your current living arrangements?

- At home with parents and/or grandparents and/or siblings
- At home with partner and/or children
- At home with flatmates or friends
- At home alone
- In supported accommodation
- Other (please specify)

_____

6. Please indicate your highest educational qualification:

- No qualifications
- GCSE/O Level/Level 1 or Level 2 NVQ
- A Level/Level 3 NVQ/Level 3 diploma/International Baccalaureate
- Level 4 NVQ/Level 4 diploma
- Level 5 NVQ/Level 5 diploma/Foundation degree
- Degree (e.g., BSc, BA)/Level 6 NVQ/ Level 6 diploma
- Master's degree/Level 7 NVQ/Level 7 diploma/Postgraduate diploma/PGCE
- PhD/DPhil/Level 8 diploma
- Other (please specify)

_____

7. Are you currently studying?

- Yes, I am in full-time education
- Yes, I am in part-time education
- No

□ Other (e.g. interrupted education with intent to return to studying. Please specify)

_____

8. Are you currently employed?

□ Yes, I am working voluntarily

□ Yes, I am in part-time paid work

□ Yes, I am in full-time paid work

□ No, but I am looking for work

□ No, and I am NOT looking for work

□ Other (please specify)

_____

9. Have you ever received an Autism diagnosis?

□ Yes

□ No If No, please skip to question 10.

9.a) What is the diagnosis you received?

□ Autism

□ Autism Spectrum Disorder (ASD)

□ Asperger Syndrome

□ Pervasive Developmental Disorder- Not Otherwise Specified

□ Other (please give details)

_____

9.b) How old were you when you received this diagnosis? (In years)

_____

9.c) Who made this diagnosis?

□ Psychiatrist

□ Paediatrician

□ Clinical Psychologist

□ Team comprised of some/all of the above (please give details)

_____

□ Other (please give details)

_____

- □ Self-diagnosed
- □ Unsure/cannot remember

10. Do you have any family members who have a diagnosis of Autism?

- □ Yes (please provide details of relation and diagnosis)
  _____
- □ No/not that I am aware of

11. Are you currently living with an eating disorder?

- □ Yes
- □ No If No, please skip to question 12.

11.a) What is your current eating disorder diagnosis?

- □ Anorexia Nervosa
- □ Atypical Anorexia
- □ Avoidant and Restricted Food Intake Disorder
- □ Other (please give details)
  _____

11.b) How old were you when you received this diagnosis? (In years)

_____

11.c) Who made this diagnosis?

- □ Psychiatrist
- □ Paediatrician
- □ Clinical Psychologist
- □ Team comprised of some/all of the above (please give details)
  _____
- □ Other (please give details)
  _____
- □ Self-diagnosed
- □ Unsure/cannot remember

11.d) How old were you when your eating disorder symptoms first started? (In years)

_____

11.e) Since your eating disorder started, what was your lowest ever weight? (please specify whether you use kilograms or stone)

_____

11.f) How old were you when you were at this weight? NB: If you were under the age of 18 at this weight, please provide details of your approximate height at the time.

_____

11.g) Have you been in treatment for your eating disorder?

- □ Yes
- □ No If No, please skip to question 12.

11.h) For how long (roughly) have you had treatment for your eating disorder?

_____ Years ____ Months

11.i) How many times (if any) have you been discharged and re-referred for treatment?

_____ time(s)

Comments: _____

11.j) Which type of healthcare service have you used for your eating disorder? (tick all that apply)

- □ Specialist eating disorder service
- □ General mental health
- □ Child and adolescent mental health services (CAMHS)
- □ GP
- □ Other _____
- □ Not sure

11.k) In treatment for your eating disorder, were you under any of the following (tick all that apply):

- □ Inpatient care
- □ Outpatient care
- □ Day patient care
- □ Community-based care

- ☐ Other _____
- ☐ Not sure

If you ticked any of the above, on a scale of 1-7, how beneficial was the care you received?

Inpatient care:

1	2	3	4	5	6	7
Not beneficial at all			Somewhat beneficial			Extremely beneficial

Outpatient care:

1	2	3	4	5	6	7
Not beneficial at all			Somewhat beneficial			Extremely beneficial

Day patient care:

1	2	3	4	5	6	7
Not beneficial at all			Somewhat beneficial			Extremely beneficial

Community-based care:

1	2	3	4	5	6	7
Not beneficial at all			Somewhat beneficial			Extremely beneficial

Other:

1	2	3	4	5	6	7
Not beneficial at all			Somewhat beneficial			Extremely beneficial

11.l) Did you receive any of the following treatments? (tick all that apply)

- ☐ Medication
- ☐ Dietitian input
- ☐ Occupational therapy
- ☐ Psychological therapy
- ☐ Other _____
- ☐ Not sure

If you ticked any of the above, on a scale of 1-7, how beneficial was the treatment you received?

Medication:

1	2	3	4	5	6	7
Not beneficial at all			Somewhat beneficial		Extremely beneficial	

Dietitian input:

1	2	3	4	5	6	7
Not beneficial at all			Somewhat beneficial		Extremely beneficial	

Occupational therapy:

1	2	3	4	5	6	7
Not beneficial at all			Somewhat beneficial		Extremely beneficial	

Psychological therapy:

1	2	3	4	5	6	7
Not beneficial at all			Somewhat beneficial		Extremely beneficial	

Other:

1	2	3	4	5	6	7
Not beneficial at all			Somewhat beneficial		Extremely beneficial	

11.m) If you had psychological therapy, which approach(es) did you receive? (tick all that apply)

- □ Cognitive behavioural therapy (CBT)
- □ Family therapy
- □ Maudsley Anorexia Nervosa Treatment for Adults (MANTRA)
- □ Specialist Supportive Clinical Management (SSCM)
- □ Dialectical behaviour therapy (DBT)
- □ Other _____
- □ Not sure
- □ N/A

If you ticked any of the above, on a scale of 1-7, how beneficial was the psychological therapy that you received?

Cognitive Behavioural Therapy (CBT):

1 2 3 4 5 6 7

No improvement Some improvement Significant improvement

Family Therapy:

1 2 3 4 5 6 7

No improvement Some improvement Significant improvement

Maudsley Anorexia Nervosa Treatment for Adults (MANTRA):

1 2 3 4 5 6 7

No improvement Some improvement Significant improvement

Specialist Supportive Clinical Management (SSCM):

1 2 3 4 5 6 7

No improvement Some improvement Significant improvement

Dialectical behaviour therapy (DBT):

1 2 3 4 5 6 7

No improvement Some improvement Significant improvement

Other:

1 2 3 4 5 6 7

No improvement Some improvement Significant improvement

11.n) Overall, on a scale of 1-7, how much did your eating disorder treatment lead to an improvement in your eating difficulties?

1 2 3 4 5 6 7

No improvement Some improvement Significant improvement

12. Have you ever had an eating disorder, but currently consider yourself recovered?

- Yes
- No If No, please skip to question 13.

12.a) What was the eating disorder you had?

- Anorexia Nervosa

- □ Atypical Anorexia
- □ Avoidant and Restricted Food Intake Disorder
- □ Other (please give details)

_____

12. b) How old were you when the eating disorder started? (In years)

_____

12.c) Approximately how long did your eating disorder last? (In years and months)

_____

13. Do you have any relatives who have experienced, or are currently experiencing an eating disorder?

- □ Yes (please give details of the relation and diagnosis)

_____

- □ No/not that I am aware of

14. Did you experience any eating or feeding difficulties or any unusual eating behaviours in childhood?

- □ No
- □ Yes (please give details):

_____

15. Have you been diagnosed with any of the following mental health conditions? (please select all that apply)

- □ Depression
- □ Social Anxiety
- □ Specific Phobia
- □ Post-Traumatic Stress Disorder
- □ Obsessive Compulsive Disorder
- □ General Anxiety
- □ Bi-polar Disorder
- □ Addictive Disorder
- □ Personality Disorder
- □ Schizophrenia

□ Other (please specify)

_____

□ None

15. a) Is there anything else you think might be relevant to tell us in regards to your mental health?

□ Yes (please give details)

_____

□ No

16. Do you currently smoke tobacco?

□ Yes, daily

□ Yes, less than daily

□ No, not at all

Additional COVID-19 questions:

1 a) Have you experienced any of the following as a result of COVID-19? Please tick all that apply.

- Lost your job or regular income
- A major reduction in your income (i.e. due to being furloughed, income being reduced by employer, being put on leave by your employer, or not receiving enough work shifts)
- Unable to pay bills/rent/mortgage
- Evicted/lost accommodation
- Increased caring responsibilities (i.e. caring of children, vulnerable family members or friends, or ill family members or friends)
- Unable to access enough/suitable food
- Unable to access usual support services (i.e. support group, mental health services)
- Unable to access medication
- I have been unwell with COVID-19
- Someone close to me has become unwell with COVID-19
- Increased worry about pre-existing physical health conditions
- Changes to normal routine

- Changes to social support
- Feeling isolated or lonely
- Changes in the home (i.e. increased time at home with other members of the household)
- other: _____

The survey was formatted so that for each factor participants have experienced as a result of COVID-19, they will be asked to rate on a Likert scale how much these hardships have impacted them.

2) To what extent has your eating behaviour been affected by/changed because of the COVID-19 virus and or related lockdown measures?

1---------- 2---------- 3 ---------- 4 ---------- 5 ---------- 6 ---------- 7

1= has made it easier/less problematic / 4= not impacted/ 7= more difficult/more problematic

3) To what extent has your mental wellbeing been affected by/changed because of the COVID-19 virus and or related lockdown measures?

1---------- 2---------- 3 ---------- 4 ---------- 5 ---------- 6 ---------- 7

1= my mental wellbeing got much better / 4= no change/ 7= My mental wellbeing got much worse

Appendix 6

SWedish Eating Assessment for Autism spectrum disorders (SWEAA; Karlsson, Råstam, & Wentz., 2013) - Adapted version, as used in Study 2. This was presented as part of an online survey using Qualtrics (2018).

Tick the option that is most appropriate:

Tick box options for each item:

never correct

seldom correct

sometimes correct

usually correct

always correct

A Perception

1. I am bothered by food smells, e.g. I must leave the room or the meal due to the smell
2. I am over sensitive to certain flavours
3. I find it difficult to tell what certain foods taste like
4. I am sensitive to food's texture
5. I prefer foods with a smooth texture, or without lumps (e.g. puree)
6. I do not like eating things that have several ingredients mixed together (e.g. stews)
7. I am bothered by the sound that some foods make when I chew them (e.g. the crunching sound of crisps/crackers)
8. I am bothered by the sounds others make when they are eating
9. I am bothered by other people talking while I am eating
10. It is important that the food is sorted on the plate (e.g. certain foods not touching)
11. I eat the food on my plate in a certain order (e.g. first meat, then potatoes)

B Motor control

1. I find it difficult to chew my food.
2. I drool during meals.
3. I get food around the outside of my mouth when I eat.
4. I find it difficult to swallow my food
5. I spill food when I eat
6. I have good table manners

7. I can drink out of a glass without spilling

C Purchase of food

1. I only buy groceries from a special supermarket/business chain
2. My food has to be a certain brand
3. If I buy food with someone else, I want to check what items are purchased

D Eating behaviour

1. I prefer certain foods depending on their colour
2. I eat the same food every day
3. I avoid trying new food/ dishes
4. I only eat a limited selection of foods, maximum of 10 dishes
5. I eat smaller amounts of food than others
6. I drink excessive fluids

E Mealtime surroundings

1. I require the glass, plate and cutlery to be arranged in a certain way or differently from a standard table setting .
2. I find it difficult to change seats at the dinner table
3. I have certain rituals around meals
4. I have outbursts at the dinner table
5. I complain at the dinner table
6. I find it difficult to eat outside of my home (e.g. at school or at the work place)
7. I find it difficult to eat with relatives
8. I find it difficult to eat with friends
9. I find it difficult to eat in a café
10. I find it difficult to eat in a restaurant
11. I find it difficult to eat when I am abroad

F Social situation at mealtime

1. I eat together with the person/people I live with
2. I eat in my bedroom
3. I adapt my behaviour in accordance to others around the table (e.g. table manners, conversation)
4. I like the company of others during mealtimes
5. I talk with others during a meal

6. I look down at my food most of the time during a meal
7. I say if I think the food is good (when I am invited for a meal)
8. I thank people for the food (when I have been invited for a meal)
9. I use a knife and fork to eat
10. I leave the table as soon as I am done eating.

G Other behaviour associated with disturbed eating

1. I induce vomiting after meals
2. I use diuretics
3. I use diet pills
4. I restrict my eating even if other people think I am too thin
5. I fast
6. I replace meals with nutritional drinks/powder
7. It is important that one person (the same person) prepares my food
8. I refuse to eat

H Hunger/satiety

1. I can feel when I am hungry
2. I can feel when I am full

I Simultaneous capacity

1. I find it difficult to do two things simultaneously (i.e. at the same time) during a meal, e.g. chewing and cutting the food

J Pica

1. I eat things that others consider inedible (e.g. soil or paper)

I am altering my food intake because of the following illness:	Yes	No
a) Diabetes type I	☐	☐
b) Diabetes type II	☐	☐
c) Gluten intolerance	☐	☐
d) Lactose intolerance	☐	☐
e) Other food intolerance	☐	☐

f) Other (Please specify): _____

I avoid eating:	Yes	No
a) Dairy products	☐	☐
b) Beef and pork (e.g. steaks, hamburgers or pork chops)	☐	☐
c) Poultry (e.g. chicken)	☐	☐
d) Fish and seafood	☐	☐
e) Vegetables	☐	☐
f) Fruit	☐	☐
g) Other (Please specify): _____		

I am treated with any of the following medications	Yes	No
a) Growth hormone	☐	☐
b) “Precocious puberty prevention” (e.g. Decapeptyl, Suprefact, Procren)	☐	☐
c) “Antidepressants” (e.g. Fluoxetin, Prozac, Sertralin, Zoloft, Citalopram, Cipramil)	☐	☐
d) “ADHD-medication” (e.g. Concerta, Ritalin or Strattera)	☐	☐
e) Neuroleptics (e.g. Risperidon, Risperdal, Olanzapin, Zyprexa, Seroquel, Abilify)	☐	☐
f) Other (Please specify): _____		

Appendix 7

Study 2 participant information sheet

This is an example of a participant information sheet for Study 2. The below version is informing autistic women with REDs about the online version of the study, based on the initial in-person version. Depending on the respective participant group, section 1 and 2 of the information sheet had a slightly different emphasis, all other sections were the same. Participant sheets for recruitment from NHS services were formatted in line with guidelines of the respective trust.

Participant Information Sheet for Autistic Women with a Restrictive Eating Disorder

UCL Research Ethics Committee Approval ID Number: 12973/002

YOU WILL BE GIVEN A COPY OF THIS INFORMATION SHEET

Title of Study: The influence of social communication styles and cognitive profiles on restrictive eating disorders in women

Department: *Research Department of Clinical, Educational and Health Psychology, UCL / School of Psychology, Cardiff University*

Name and Contact Details of the Researchers: *Janina Brede (*email removed*) / Charli Babb (*email removed*) / Hannah Baker (*email removed*)*

Name and Contact Details of the Principal Researchers: *William Mandy (*email removed*) / John Fox (*email removed*)*

You are being invited to take part in a research project. It is important that you understand exactly what participation will involve and why the research is being done. Please take your time to read this information sheet and discuss it with others if you wish. If anything is not clear, please do not hesitate to ask one of us. Take time to decide whether or not you wish to take part.

1. What is the project's purpose?

The purpose of this project is to gain a better understanding of restrictive eating disorders in autistic individuals with autism. It is estimated that at least 8,000 autistic women suffer with anorexia nervosa in the UK and evidence suggests these women tend to have lower recovery rates than non-autistic women. There is currently a lack of research into eating difficulties in autistic women, which means that eating disorder services lack sufficient understanding and treatment options for this client group.
This project aims to understand what might make autistic women more vulnerable to developing eating disorders and how these difficulties are maintained. Last year, we interviewed a number of autistic women with anorexia, their parents/carers and healthcare professionals to help us understand eating difficulties in autistic women. In the current study, we are hoping to explore this further by understanding how autistic women with eating disorders, autistic women without eating disorders and non-autistic women with eating disorders vary on a number of different measures. With this understanding, we hope to inform eating disorders services on how to become more accessible and beneficial for autistic women.

2. Why have I been chosen?

If you would like to take part in this study, you should meet the following inclusion criteria: (1) female; (2) aged over 18 years; (3) formally diagnosed with autism spectrum disorder (including autism spectrum disorder, autism, Asperger's syndrome, high functioning autism, and pervasive developmental disorder); and (4) clinically diagnosed and currently living with a restrictive eating disorder (including anorexia nervosa, atypical anorexia and avoidant/restrictive food intake disorder (ARFID)). If you meet the inclusion criteria and decide you want to take part, you will be completing the same measures as the other women participating in the study.

3. Do I have to take part?

It is completely up to you whether you take part. If you do decide to take part, you will be given this information sheet to keep and will be asked to sign a consent form. You can withdraw from the study at any time without giving a reason and without it affecting any reimbursements for time and travel that you are entitled to. If you decide to withdraw, you will be asked what you wish to happen to the data you have provided up to that point.

4. What will happen if I decide to take part?

If you decide to take part, you will meet with one of the researchers for around 2.5-3 hours. We will aim to meet with you at a time and place that is convenient for you. We will go through the study information again, and ask you to sign a consent form. Then you will be asked to complete a number of tasks and questionnaires. You will also be asked to provide other details about yourself, such as information about your mental health history and we will measure your weight and height. Some people can find it uncomfortable to be weighed, therefore if you would prefer to do this at home or go on the scales backwards so that you do not see your weight, you can.
Two tasks of the tasks will be sensory activities related to taste and your ability to monitor your heartbeat. The taste task will not involve eating food, but will involve tasting small pieces of taste test paper. There will also be a set of tasks and interview questions to confirm the presence of high autistic traits for research purposes, unless your scores are available from a previous assessment. We routinely video-record these assessments, but you can opt out of being recorded if you wish. The other two tasks will be computer tasks. The researcher will explain what you need to do before you start and answer any questions or concerns you may have.

There will also be a total of 17 questionnaires to complete; some will be short and some may take more time. You will be asked to complete all of the questionnaires fully, however you can take your time completing them and you can take a break at any time. You will have the option to complete them during the face-to-face session while the researcher is present or on your own after the meeting. Some of the questionnaires will be about interaction styles and thinking profiles, some about your eating habits and some will be about other things such as your relationships with others. Some of the questions might seem strange or may not feel relevant to you; however, it is helpful if you can answer all of the questions as best you can. If you are not sure about the meaning or relevance of a question, you can ask the researcher to explain at any time.
Some of the measures screen for eating disordered behaviours, autistic traits, anxiety and depression. You can decide whether you would like to be informed of your scores on these measures, as this may indicate that you are experiencing a mental health difficulty. If you choose to be informed, the researcher will give you feedback after you have taken part in the study about what your scores might mean and give you advice about accessing further support.
If you decide to take part, we will also ask you if you would be happy for us to conduct a structured interview with someone who has known you well since childhood, for example a family member, to gather some more information about what you were like when you were younger. We would ask them questions, such as about your current and childhood social communication style and interests. It is up to you, whether you want to provide us with contact details of a family member for this purpose, and they do not have to talk to us if they do not want to. If you have someone who might be willing to talk to us, we will take their contact details and arrange to talk to them either in person or over the phone. This would take 30 min of their time.
If for any reason you find the meeting distressing or uncomfortable, you can stop at any time. When you have completed all measures, you will be debriefed and receive further information about ways to access support if you feel you might need it. You will be offered a £30 voucher to thank you for your time and we will reimburse your expenses on the production of a receipt if you are traveling to meet with us.

5. What will happen after the study?

You will be asked whether you would like to be contacted if there is opportunity to be involved in future research or to receive a copy of the research report resulting from this study. This is completely voluntary and you would be appropriately compensated for any further input. Should you wish to be involved, your contact details will be stored securely and separately from other data.

6. What will happen with my data/the answers I give?

If you consent to take part in the study, your data (the answers you gave on the questionnaires and tasks) will be stored on a database anonymously so your responses will not be identifiable. You can choose to withdraw your data at any time and you do not have to give a reason.

7. What are the possible disadvantages and risks of taking part?

The meeting with the researcher is quite a long process, so you may feel fatigued after. Some of the questions on the questionnaires may bring up some sensitive topics, which you may find uncomfortable or upsetting to think about. We understand these may be distressing to so we encourage you to let us know if it feels like too much.
If you chose to find out your scores on the autism and mental health related measures you complete, there may be a chance that your scores indicate you are experiencing mental health difficulties such as anxiety, depression or eating difficulties. This might be upsetting or worrying for you. If this is the case, you can talk to the researcher. Although we will not be able to make a

diagnosis based on the questionnaires or provide clinical advice, we can provide guidance on where to access further support. If you would prefer not to know about your scores on the questionnaires, this is okay too.
Some people find sensory-related tasks (e.g. to do with taste) uncomfortable. If at any point you feel uncomfortable during these tasks and want to stop, you can just let the researcher know. You can do this verbally or we can agree at the start how you would like to show us when you do not want to answer a question (e.g. hand signal).

8. What are the possible benefits of taking part?

While there are no other immediate benefits for those participating in the project, it is hoped that this work will help to inform future research and clinical practice so that eating disorders services and other mental health services will become more accessible particularly for autistic individuals. You will be offered a £30 voucher as a thank you for taking part.

9. What if something goes wrong?

If you are unhappy or dissatisfied about any aspects of your participation, we encourage you to let us know, so we can try to resolve any concerns and find a solution. If you wish to raise a complaint, you should contact one of the Principal Researchers, Will Mandy or John Fox (contact details above). However, if you feel your complaint has not been handled to your satisfaction, you can contact the Chair of the UCL Research Ethics Committee at ethics@ucl.ac.uk quoting the Ethics Committee Approval ID Number for this study as stated above.

10. Will my taking part in this project be kept confidential?

All the information that we collect about you during the course of the research will be kept strictly confidential. All data is stored without any identifying details under secure conditions at UCL/Cardiff University. You will not be able to be identified in any ensuing reports or publications.

11. Limits to confidentiality

Please note that assurances on confidentiality will be strictly adhered to unless evidence of potential harm or danger to you or someone else is uncovered. In such cases the University may be obliged to contact relevant statutory bodies/agencies. Before meeting with the researcher, we will routinely ask everyone for their GP contact details. If you tell us that you or someone else is at risk or being harmed we will need to disclose this information to your GP and may ask for your permission to share the information with responsible services. If this is not necessary, we will return your GPs contact details to you after the interview and will not record this information. 4 Version 1.1 03.10.19

12. What will happen to the results of the research project?

We plan to distribute the findings via publications in peer reviewed academic journals, social media, including a blog, and conference presentations. We also plan to publish tailored reports to share our findings with the autism community and clinical professionals. The research team will ensure that all responses are anonymised, so that you cannot be identified. The researchers in this project are all involved with a range of clinical training activities, and will circulate relevant findings to directly and rapidly improve clinical practice (e.g. within mental health services). You will have the option to be sent a summary of the research and be contacted at the end of the study to discuss the findings of the study with the researchers. You may also contact the researchers and ask for copies of any publications if you wish to read them.

13. Data Protection Privacy Notice

The data controller for this project will be University College London (UCL). The UCL Data Protection Office provides oversight of UCL activities involving the processing of personal data. UCL's Data Protection Officer is Lee Shailer and he can be contacted at data-protection@ucl.ac.uk**.**
Your personal data will be processed for the purposes outlined in this notice. The legal basis that would be used to process your personal data will be the provision of your consent. You can provide your consent for the use of your personal data in this project by completing the consent form that has been provided to you.
If you are concerned about how your personal data is being processed, please contact UCL in the first instance at data-protection@ucl.ac.uk. If you remain unsatisfied, you may wish to contact the Information Commissioner's Office (ICO). Contact details, and details of data subject rights, are available on the ICO website at: https://ico.org.uk/for-organisations/data-protection-reform/overview-of-the-gdpr/individuals-rights/

14. Who is organising and funding the research?

The research is part funded by Autistica – a charity that funds and campaigns for research to increase our understanding of autism, improve diagnosis and develop evidence-based interventions.

15. Contact for further information

Should you have any questions about the study, please find our contact details below:

Charli Babb (researcher)
CUCHDS Building
School of Psychology
Cardiff University
Park Place
Cardiff CF10 3AT
[redacted]

Janina Brede (researcher)
University College London
Department for Clinical,
Educational and Health Psychology
1–19 Torrington Place
London WC1E 7HB
[redacted]

Hannah Baker (researcher)
University College London
Department for Clinical,
Educational and Health Psychology
1–19 Torrington Place
London WC1E 7HB
[redacted]

Appendix 8

Study 2 consent form

This is an example of the consent form for Study 2. The below version is the consent form for participants from any of the participant groups, who were recruited via non-NHS pathways. This consent form was displayed as part of the online survey.

Consent Form

Title of Study: The influence of social communication styles and cognitive profiles on restrictive eating disorders in women

Department: *Research Department of Clinical, Educational and Health Psychology, UCL / School of Psychology, Cardiff University*
Name and Contact Details of the Researchers: *Janina Brede (*email removed*) / Charli Babb (*email removed*)*
Name and Contact Details of the Principal Researchers: *William Mandy (*email removed*) / John Fox (*email removed*)*
Name and Contact Details of the UCL Data Protection Officer: Lee Shailer (email removed*)*

Thank you for considering taking part in this research. The researchers organising the study (Janina Brede and Charli Babb) must provide you with an information sheet about the project and give you the opportunity to ask any questions you may have before you agree to take part. If you have any questions arising from this consent form or the information sheet, please contact the researcher before you decide whether to join in.

By initialling each box below you are consenting to this element of the study. It will be assumed that un-initialled boxes mean that YOU DO NOT consent to that part of the study. Not giving consent for any one element may mean that you are deemed ineligible for the study.

Participant Statements:
Tick Box

● I confirm that I have read and understood the Information Sheet for the above study. I have had an opportunity to consider the information and what will be expected of me. I have also had the opportunity to ask questions which have been answered to my satisfaction.	
● I understand that my participation is voluntary and that I am free to withdraw at any time without giving a reason and without my medical care or legal rights being affected.	
● I understand that if I decide to withdraw, any personal data I have provided up to that point may still be used in the study, unless I request otherwise.	
● I consent to my answers and personal information being used for the purposes of this research study only, as explained to me in the Information Sheet. I understand that such information will be handled in accordance with all applicable data protection legislation.	
● I understand that all personal information will remain confidential and that all efforts will be made to ensure I cannot be identified. I understand that my data gathered in this study will be stored securely. It will not be possible to identify me in any publications.	

• I understand the potential risks of participating as outlined in the Information Sheet, and that I can contact the research team to get advice on how to access support should I become distressed during the course of the research.	
• I understand the direct and indirect benefits of participating as outlined in the Information Sheet.	
• I understand that the data will not be made available to any commercial organisations.	
• I understand that in order to process the thank-you voucher, my contact details may be shared with the Cardiff University or UCL Finance Department. You will be asked to indicate whether you would like to receive a thank-you voucher at the end of the survey.	
• I confirm that I understand the inclusion criteria as detailed in the Information Sheet, and that I fit into this inclusion criteria.	
• I am aware of who I should contact if I wish to lodge a complaint as outlined in the Information Sheet.	
• I voluntarily agree to take part in this study.	

The following questions about preferences for future contact were presented at the end of the survey:

If you would like to receive a copy of the publication/report that will result from this study, please tick the appropriate box below.

Yes, I would like to receive a copy of the resulting publication/report	
No, I would not like to receive any resulting publication/report	

If you would like your contact details to be retained so that you can be contacted in the future by UCL researchers who would like to invite you to participate in follow up studies to this project, or in future studies of a similar nature, please tick the appropriate box below.

Yes, I would be happy to be contacted in this way.	
No, I would not like to be contacted.	

Some of the measures used in this study screen for autistic traits, eating disordered behaviours, anxiety and depression. Please indicate whether you would like to be given more information about your scores on these measures. If you choose to be informed, the researcher will give you feedback about what your scores might mean and give you advice about accessing further support. Please tick the appropriate box below.

Yes, I would like to be informed about my scores on mental health measures.	
• I understand by choosing to receive feedback about my scores that the researchers will not be able to diagnose or provide clinical advice and intervention related to mental health issues.	
No, I would not like to be informed about my scores on mental health measures.	

We would like to conduct an interview with someone who has known you well since childhood (such as a parent or an older sibling) to gather some more information about what you were like when you were younger. This would take around 30 minutes of their time and would be done over the phone. It is completely optional. It is up to you whether you are happy for us to do this interview with a family member. And your family member does not have to talk to us if they do not want to. Please indicate below whether you would be happy for a member of the research team to contact a family member for this purpose. If so, we would get in touch with you after you completed this survey to get their contact details. We request that you ask them for permission before providing us with these details.

Yes, I am happy for the study researcher to get in touch, so I can provide them with a family members contact details.	
No, please to not get in touch about this.	

Appendix 9

Study 2 participant debrief

This is an example of the participant debrief for Study 2. The below version is the debrief for participants from all groups, who completed the online version of the study, based on the initial in-person version.

Research Debrief

Title of Study: The influence of social communication styles and cognitive profiles on restrictive eating disorders in women

Thank you very much for taking part in our study. Your contribution has been vital to improving our understanding of restrictive eating disorders in autistic women and will help to improve eating disorder services and the care they provide to autistic individuals.

This document is supplementary to the participant information sheet which you have already received. It will tell you what will happen with the information you have provided and lists some further resources that you may find useful.

1. ***What will happen to the information which I have provided?***

As part of the study, you provided information about yourself, completed some online tasks, and answered a number of questionnaires. All the information we have collected will be stored securely and will remain confidential. This means you will not be personally identifiable by the answers you gave. Only the researchers involved in this project will have direct access to the information we collected.

Once we have collected information from everyone taking part in the study, we will analyse all of the information together. We will report the findings in terms of group results; so your answers will be included with others who identified themselves as having autism and/ or eating difficulties. It will not be possible to identify individual responses in the findings which we publish.

2. ***Will I be told about the findings of the study?***

Please let us know if you would like to receive a written summary of the findings and be contacted at the end of the study to discuss any findings with the researchers. We plan to distribute the findings via publications in academic journals, social media, including our blog (https://sedaf18.blogspot.co.uk/), and conferences. We also plan to publish tailored reports to share our findings with the autism community and clinical professionals. We will anonymise all personal data to ensure you and other participants will not be identifiable. If you have not already indicated that you are interested in receiving a copy in the consent form, you may contact us if you would like a copy of any publication.

3. ***What if I change my mind about including my answers in the study?***

If you change your mind about taking part in this study, you can request for your data to be withdrawn, without having to provide justification. You can do this by contacting one of the researchers. You will have until 01/12/2020 to let us know if you do not wish your information to be included in the study.

4. ***What should I do if I have any questions or concerns after taking part?***

If you have any questions or comments about your taking part in the study, please don't hesitate to contact one of the researchers. We welcome your feedback and comments about the study. If for any reason you feel distressed as a result of the questionnaires or tasks which you have completed, please let us know so we can think with you about how you could access support for this. You can also contact your GP with any questions or concerns with regards to autism, eating disorders, or mental and physical health in general.

5. ***Where can I find out more information and access support related to topics explored in this study?***

If you would like more information about eating disorders and support for individuals struggling with eating disorders, you may find the Beat website useful: https://www.beateatingdisorders.org.uk/.

If you would like more information about autism and support for individuals on the autism spectrum, you may find the National Autistic Society website useful: http://www.autism.org.uk/.

If you are ever experiencing mental health problems or need urgent support, you can also contact the Samaritans via contact details on their website (www.samaritans.org) or by calling: 116 123 (24 hours a day, free to call).

More information, support, and resources for autistic people during the COVID-19 pandemic can
be found at:

https://www.autistica.org.uk/what-is-autism/coronavirus

https://www.autism.org.uk/services/helplines/coronavirus.aspx

More information, support, and resources for people with an eating disorder during the COVID-19 pandemic can be found at:

https://www.beateatingdisorders.org.uk/coronavirus

Contact for further information

Should you have any further comments or questions about the study, please find our contact details below:

removed

Thank you for reading this debrief sheet and for taking part in this research study

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Appendix 10

UCL Ethical approval

UCL RESEARCH ETHICS COMMITTEE
OFFICE FOR THE VICE PROVOST RESEARCH

22nd May 2019

Dr Will Mandy
Research Department of Clinical, Educational and Health Psychology
UCL

Dear Dr Mandy

Notification of Ethics Approval with Provisos
Project ID/Title: 12973/002: The influence of autism on restricted eating disorders in women

Further to your satisfactory responses to the Committee's comments, I am pleased to confirm in my capacity as Joint Chair of the UCL Research Ethics Committee (REC) that your study has been ethically approved by the UCL REC until **1st February 2021.**

Ethical approval is subject to the following conditions:

Notification of Amendments to the Research
You must seek Chair's approval for proposed amendments (to include extensions to the duration of the project) to the research for which this approval has been given. Each research project is reviewed separately and if there are significant changes to the research protocol you should seek confirmation of continued ethical approval by completing an 'Amendment Approval Request Form'
http://ethics.grad.ucl.ac.uk/responsibilities.php

Adverse Event Reporting – Serious and Non-Serious
It is your responsibility to report to the Committee any unanticipated problems or adverse events involving risks to participants or others. The Ethics Committee should be notified of all serious adverse events via the Ethics Committee Administrator (ethics@ucl.ac.uk) immediately the incident occurs. Where the adverse incident is unexpected and serious, the Joint Chairs will decide whether the study should be terminated pending the opinion of an independent expert. For non-serious adverse events the Joint Chairs of the Ethics Committee should again be notified via the Ethics Committee Administrator within ten days of the incident occurring and provide a full written report that should include any amendments to the participant information sheet and study protocol. The Joint Chairs will confirm that the incident is non-serious and report to the Committee at the next meeting. The final view of the Committee will be communicated to you.

Final Report
At the end of the data collection element of your research we ask that you submit a very brief report (1-2 paragraphs will suffice) which includes in particular issues relating to the ethical implications of the research i.e. issues obtaining consent, participants withdrawing from the research, confidentiality, protection of participants from physical and mental harm etc.

Office of the Vice Provost Research, 2 Taviton Street
University College London
Tel: +44 (0)20 7679 8717
Email: ethics@ucl.ac.uk
http://ethics.grad.ucl.ac.uk/

In addition, please:

- ensure that you follow all relevant guidance as laid out in UCL's Code of Conduct for Research: https://www.ucl.ac.uk/srs/file/579
- note that you are required to adhere to all research data/records management and storage procedures agreed as part of your application. This will be expected even after completion of the study.

With best wishes for the research.

Yours sincerely

[redacted]

Professor Lynn Ang
Joint Chair, UCL Research Ethics Committee

Cc: Janina Brede & Hannah Barker

Appendix 11

NHS Health Research Authority Ethical Approval Letter

Ymchwil Iechyd a Gofal Cymru
Health and Care Research Wales

NHS
Health Research Authority

Dr John Fox
School of Psychology
70 Park Place
Cardiff
CF10 3AT

Email: Wales.REC6@wales.nhs.uk

15 November 2019

Dear Dr Fox

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

Study title:	**The influence of social communication styles and cognitive profiles on restrictive eating disorders in women**
IRAS project ID:	**259480**
Protocol number:	**1743-19**
REC reference:	**19/WA/0303**
Sponsor	**Research and Innovation Services, Cardiff University**

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

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

How should I work with participating NHS/HSC organisations in Northern Ireland and Scotland?
HRA and HCRW Approval does not apply to NHS/HSC organisations within Northern Ireland and Scotland.

If you indicated in your IRAS form that you do have participating organisations in either of these devolved administrations, the final document set and the study wide governance report (including this letter) have been sent to the coordinating centre of each participating nation. The relevant national coordinating function/s will contact you as appropriate.

Appendix 12

Tests of normality

Table 1, Appendix 12

Kolmogorov-Smirnov tests for each variable by group

	Autism only	Autism+REDs	REDs only	REDs high autistic traits
RAADS-14 total	D(47)=.137 p=.028	D(51)=.160, p=.002	D(76)=.062, p=.200	D(36)=.166, p=.013
AQ total	D(19)=.165 p=.189	D(33)=.158, p=.035	D(75)=.084, p=.200	D(34)=.083, p=.200
EDE-Q global score	D(47)=.134, p=.035	D(51)=.099, p=.200	D(76)=.116, p=.013	D(36)=.146, p=.051
EDE-Q restraint	D(47)=.155, p=.005	D(51)=.122, p=.055	D(76)=.159, p<.001	D(36)=.194, p=.001
EDE-Q eating concerns with outliers	D(47)=.231, p<.001	D(51)=.122, p=.055	D(76)=.081, p=.200	D(36)=.171, p=.010
EDE-Q eating concerns - after outliers addressed	D(47)=.236 p<.001	D(51)=.122, p=.055	D(76)=.081, p=.200	D(36)=.171, p=.010
EDE-Q shape concerns with outliers	D(47)= 0.133 , p= 0.036	D(51)= 0.153 , p= 0.004	D(76)= 0.202 , p= 0.000	D(36)= 0.229 , p= 0.000
EDE-Q shape concerns - after outliers addressed	D(47)= 0.133 , p= 0.036	D(51)= 0.153 , p= 0.004	D(76)= 0.202 , p= 0.000	D(36)= 0.225 , p= 0.000
EDE-Q weight concerns	D(47)= 0.134 , p= 0.035	D(51)= 0.142 , p= 0.012	D(76)= 0.152 , p= 0.000	D(36)= 0.166 , p= 0.014
EDE-Q global score	D(47)= 0.134 , p= 0.035	D(51)= 0.099 , p= .200*	D(76)= 0.116 , p= 0.013	D(36)= 0.146 , p= 0.051
HADS depression	D(47)= 0.139 , p= 0.023	D(51)= 0.069 , p= .200*	D(76)= 0.084 , p= .200*	D(36)= 0.116 , p= .200*
HADS anxiety with outliers	D(47)= 0.092 , p= .200*	D(51)= 0.104 , p= .200*	D(76)= 0.108 , p= 0.028	D(36)= 0.173 , p= 0.008
HADS anxiety - after outliers addressed	D(47)= 0.092 , p= .200*	D(51)= 0.104 , p= .200*	D(76)= 0.108 , p= 0.028	D(36)= 0.144 , p= 0.056

SPIN total original with outlier	D(47)= 0.070 , p= .200*	D(51)= 0.089 , p= .200*	D(76)= 0.078 , p= .200*	D(36)= 0.084 , p= .200*
SPIN total -after outliers addressed	D(47)= 0.070 , p= .200*	D(51)= 0.089 , p= .200*	D(76)= 0.078 , p= .200*	D(36)= 0.084 , p= .200*
CAT-Q total	D(47)= 0.131 , p= 0.043	D(51)= 0.129 , p= 0.033	D(76)= 0.057 , p= .200*	D(36)= 0.146 , p= 0.050
SWEAA A perception total	D(47)= 0.105 , p= .200*	D(51)= 0.076 , p= .200*	D(76)= 0.073 , p= .200*	D(36)= 0.141 , p= 0.068
SWEAA B motor control total with outlier	D(47)= 0.127 , p= 0.055	D(51)= 0.126 , p= 0.043	D(76)= 0.151 , p= 0.000	D(36)= 0.135 , p= 0.095
SWEAA B motor control total - after outliers addressed	D(47)= 0.127 , p= 0.055	D(51)= 0.126 , p= 0.043	D(76)= 0.147 , p= 0.000	D(36)= 0.135 , p= 0.095
SWEAA C purchase of food total	D(47)= 0.123 , p= 0.073	D(51)= 0.157 , p= 0.003	D(76)= 0.109 , p= 0.026	D(36)= 0.133 , p= 0.112
SWEAA D eating behaviours total	D(47)= 0.160 , p= 0.004	D(51)= 0.123 , p= 0.053	D(76)= 0.085 , p= .200*	D(36)= 0.143 , p= 0.061
SWEAA E mealtime surroundings total	D(47)= 0.090 , p= .200*	D(51)= 0.146 , p= 0.008	D(76)= 0.088 , p= .200*	D(36)= 0.101 , p= .200*
SWEAA F social situation at mealtime total with outlier	D(47)= 0.121 , p= 0.081	D(51)= 0.126 , p= 0.042	D(76)= 0.121 , p= 0.008	D(36)= 0.120 , p= .200*
SWEAA F social situation at mealtime total -after outliers addressed	D(47)= 0.104 , p= .200*	D(51)= 0.126 , p= 0.042	D(76)= 0.121 , p= 0.008	D(36)= 0.120 , p= .200*
SWEAA G other disturbed eating behaviours total with outliers	D(47)= 0.196 , p< 0.001	D(51)= 0.142 , p= 0.012	D(76)= 0.084 , p= .200*	D(36)= 0.182 , p= 0.004
SWEAA G other disturbed eating behaviours total- after outliers addressed	D(47)= 0.178 , p= 0.001	D(51)= 0.142 , p= 0.012	D(76)= 0.084 , p= .200*	D(36)= 0.182 , p= 0.004
SWEAA H hunger satiety total with outliers	D(47)= 0.147 , p= 0.012	D(51)= 0.167 , p= 0.001	D(76)= 0.175 , p= 0.000	D(36)= 0.201 , p= 0.001
SWEAA H hunger satiety total - after outliers addressed	D(47)= 0.147 , p= 0.012	D(51)= 0.167 , p= 0.001	D(76)= 0.175 , p= 0.000	D(36)= 0.207 , p= 0.000

SWEAA I simultaneous capacity total with outlier	D(47)= 0.252 , p= 0.000	D(51)= 0.234 , p= 0.000	D(76)= 0.323 , p= 0.000	D(36)= 0.186 , p= 0.003
SWEAA I simultaneous capacity total -after outliers addressed	D(47)= 0.252 , p= 0.000	D(51)= 0.234 , p= 0.000	D(76)= 0.329 , p= 0.000	D(36)= 0.186 , p= 0.003
SWEAA J Pica total	D(47)= 0.466 , p= 0.000	D(51)= 0.503 , p= 0.000	D(76)= 0.537 , p= 0.000	D(36)= 0.466 , p= 0.000
SWEAA total with outlier	D(47)= 0.101 , p= .200*	D(51)= 0.092 , p= .200*	D(76)= 0.072 , p= .200*	D(36)= 0.202 , p= 0.001
SWEAA total - after outliers addressed	D(47)= 0.101 , p= .200*	D(51)= 0.081 , p= .200*	D(76)= 0.072 , p= .200*	D(36)= 0.190 , p= 0.002
GSQ total hyper sensitivity	D(47)= 0.090 , p= .200*	D(51)= 0.056 , p= .200*	D(76)= 0.093 , p= 0.100	D(36)= 0.076 , p= .200*
GSQ total hypo sensitivity	D(47)= 0.095 , p= .200*	D(51)= 0.104 , p= .200*	D(76)= 0.067 , p= .200*	D(36)= 0.091 , p= .200*
GSQ total	D(47)= 0.077 , p= .200*	D(51)= 0.076 , p= .200*	D(76)= 0.097 , p= 0.077	D(36)= 0.130 , p= 0.129
GSQ visual	D(47)= 0.130 , p= 0.048	D(51)= 0.098, p= .200*	D(76)= 0.124 , p= 0.008	D(36)= 0.133 , p= .170
GSQ auditory	D(47)= 0.113 , p= 0.173	D(51)= 0.117 , p= .130	D(76)= 0.105 , p= 0.046	D(36)= 0.084 , p= .200*
GSQ gustatory	D(47)= 0.090 , p= .200*	D(51)= 0.112 , p= .190	D(76)= 0.105 , p= 0.039	D(36)= 0.088 , p= .200*
GSQ olfactory	D(47)= 0.105 , p= .200*	D(51)= 0.084 , p= .200*	D(76)= 0.137 , p= 0.001	D(36)= 0.119 , p= .200*
GSQ tactile	D(47)= 0.121 , p= 0.083	D(51)= 0.093 , p= .200*	D(76)= 0.121 , p= 0.008	D(36)= 0.122 , p= 0.199
GSQ vestibular	D(47)= 0.087 , p= 0.200*	D(51)= 0.094 , p= .200*	D(76)= 0.117 , p= 0.015	D(36)= 0.092 , p= .200*
GSG proprioception	D(47)= 0.154 , p= 0.008	D(51)= 0.110 , p= .200*	D(76)= 0.096 , p= 0.094	D(36)= 0.127 , p= .200*
BMI	D(47)=.092, p=.200*	D(51)=.142, p=.021	D(76)=.092, p=.200	D(36)=,119, p=.200
Taste test Sweet	p<.001	p=.009		

Taste test Sour	p=.008	p=.033
Taste test Salty	p<.001	p=.027
Taste test Bitter	p<.001	p<.001
Taste test Total	p=.112	p=.033
Taste test Accuracy	p=.112	p=.033
Taste test Sweet Pleasantness	p=.055	p=.174
Taste test Sour Pleasantness	p=.200	p=.029
Taste test Salty Pleasantness	p=.200	p=.200
Taste test Bitter Pleasantness	p=.200	p=.170

Note. Green writing = assumption of normality met

Table 2, Appendix 12

Skewness and kurtosis raw scores and z-scores for each variable by group

	Autism only				Autism+REDs				REDs only				REDs high autistic traits			
	Skewness		Kurtosis		Skewness		Kurtosis		Skewness		Kurtosis		Skewness		Kurtosis	
	raw score	z-score	raw score	z-score	raw score	z-score	raw score	z-score	raw score	z-score	raw score	z-score	raw score	z-score	raw score	z-score
RAADS-14 total	-0.78	-2.25	0.03	0.05	-1.01	-3.03	0.65	0.99	-0.14	-0.50	-0.82	-1.51	0.30	0.76	-1.12	-1.45
AQ total	-0.82	-1.56	-0.22	-0.22	-0.85	-2.07	0.11	0.14	-0.12	-0.44	-0.45	-0.81	-0.12	-0.29	-0.83	-1.05
EDE-Q global score	0.97	2.79	0.86	1.27	-0.55	-1.65	-0.67	-1.02	-0.64	-2.31	-0.46	-0.84	-0.92	-2.33	0.58	0.76
EDE-Q restraint	0.75	2.16	-0.43	-0.63	-0.46	-1.37	-0.80	-1.21	-0.54	-1.96	-0.86	-1.58	-1.00	-2.54	0.08	0.11
EDE-Q eating concerns with outliers	1.82	2.16	3.13	-0.63	-0.25	-1.37	-1.14	-1.21	-0.12	-1.96	-0.69	-1.58	-0.95	-2.54	0.43	0.11
EDE-Q eating concerns - after outliers addressed	1.44	4.16	1.31	1.93	-0.25	-0.75	-1.14	-1.74	-0.12	-0.42	-0.69	-1.27	-0.95	-2.41	0.43	0.56
EDE-Q shape concerns with outliers	0.63	1.83	-0.30	-0.45	-1.01	-3.04	-0.03	-0.05	-1.04	-3.76	0.19	0.34	-2.05	-5.21	4.44	5.78
EDE-Q shape concerns - after outliers addressed	0.63	1.83	-0.30	-0.45	-1.01	-3.04	-0.03	-0.05	-1.04	-3.76	0.19	0.34	-1.51	-3.85	1.87	2.43

EDE-Q weight concerns	0.52	1.49	-0.33	-0.48	-0.67	-2.01	-0.56	-0.85	-0.97	-3.52	0.24	0.43	-0.98	-2.50	0.26	0.33
EDE-Q global score	0.97	2.79	0.86	1.27	-0.55	-1.65	-0.67	-1.02	-0.64	-2.31	-0.46	-0.84	-0.92	-2.33	0.58	0.76
HADS depression	0.67	1.93	-0.12	-0.17	0.03	0.08	-0.72	-1.09	-0.16	-0.59	-0.21	-0.38	-0.11	-0.28	-0.50	-0.66
HADS anxiety with outliers	0.15	0.42	-0.61	-0.89	-0.70	-2.10	0.56	0.85	-0.50	-1.80	-0.22	-0.40	-1.50	-3.82	3.94	5.13
HADS anxiety - after outliers addressed	0.15	0.42	-0.61	-0.89	-0.70	-2.10	0.56	0.85	-0.50	-1.80	-0.22	-0.40	-0.85	-2.16	0.91	1.19
SPIN total original with outlier	-0.29	-0.82	-0.16	-0.24	-0.73	-2.18	1.42	2.17	0.03	0.10	-0.66	-1.21	-0.99	-2.53	2.51	3.27
SPIN total -after outliers addressed	-0.12	-0.36	-0.56	-0.83	-0.73	-2.18	1.42	2.17	0.03	0.10	-0.66	-1.21	-0.99	-2.53	2.51	3.27
CAT-Q total	-0.59	-1.70	-0.55	-0.80	-0.42	-1.24	-0.23	-0.35	-0.06	-0.21	-0.49	-0.89	-0.57	-1.45	0.66	0.85
SWEAA A perception total	0.42	1.21	0.37	0.54	-0.14	-0.43	-0.26	-0.39	0.43	1.56	-0.16	-0.29	-0.69	-1.76	0.20	0.26
SWEAA B motor control total with outlier	0.33	0.95	-0.59	-0.86	1.12	3.35	1.40	2.13	1.70	6.16	4.97	9.11	0.73	1.87	0.42	0.55
SWEAA B motor control total -after outliers addressed	0.33	0.95	-0.59	-0.86	1.12	3.35	1.40	2.13	0.83	3.01	-0.05	-0.09	0.73	1.87	0.42	0.55
SWEAA C purchase of food total	0.32	0.93	-0.03	-0.04	-0.74	-2.21	0.20	0.31	-0.14	-0.52	-0.99	-1.82	-0.10	-0.25	-0.71	-0.93
SWEAA D eating behaviours total	-0.07	-0.20	-0.95	-1.39	-0.20	-0.59	0.03	0.04	-0.16	-0.57	-0.19	-0.34	-0.88	-2.25	0.84	1.09
SWEAA E mealtime surroundings total	0.37	1.06	0.28	0.41	-0.45	-1.35	0.02	0.03	-0.32	-1.17	-0.71	-1.29	-0.34	-0.86	0.01	0.01
SWEAA F social situation at mealtime total with outlier	0.91	2.63	1.72	2.52	0.39	1.17	-0.73	-1.11	0.60	2.17	-0.42	-0.77	0.15	0.37	-0.40	-0.53
SWEAA F social situation at mealtime total -after outliers addressed	0.40	1.15	-0.14	-0.20	0.39	1.17	-0.73	-1.11	0.60	2.17	-0.42	-0.77	0.15	0.37	-0.40	-0.53
SWEAA G other disturbed eating behaviours total with outliers	1.66	4.78	2.93	4.31	0.33	1.00	-0.26	-0.39	-0.08	-0.30	-0.26	-0.47	0.88	2.24	0.59	0.77
SWEAA G other disturbed eating behaviours total- after outliers addressed	1.30	3.76	1.11	1.64	0.33	1.00	-0.26	-0.39	-0.08	-0.30	-0.26	-0.47	0.88	2.24	0.59	0.77
SWEAA H hunger satiety total with outliers	0.75	2.16	0.37	0.55	0.23	0.69	-0.44	-0.67	0.44	1.60	0.35	0.65	-0.10	-0.25	0.51	0.67
SWEAA H hunger satiety total -after outliers addressed	0.75	2.16	0.37	0.55	0.23	0.69	-0.44	-0.67	0.44	1.60	0.35	0.65	-0.49	-1.25	0.00	0.00

SWEAA I simultaneous capacity total with outlier	1.21	3.48	0.94	1.38	0.59	1.76	-0.54	-0.82	1.23	4.47	0.57	1.05	0.26	0.66	-1.11	-1.45
SWEAA I simultaneous capacity total -after outliers addressed	1.21	3.48	0.94	1.38	0.59	1.76	-0.54	-0.82	1.03	3.74	-0.25	-0.46	0.26	0.66	-1.11	-1.45
SWEAA J Pica total	2.12	6.11	3.47	5.09	4.01	12.02	17.87	27.25	5.32	19.29	27.95	51.30	1.92	4.90	2.56	3.34
SWEAA total with outlier	0.19	0.55	0.22	0.32	0.53	1.59	0.54	0.82	0.23	0.85	-0.49	-0.89	0.29	0.74	0.97	1.26
SWEAA total - after outliers addressed	0.19	0.55	0.22	0.32	0.34	1.02	0.01	0.02	0.23	0.85	-0.49	-0.89	0.18	0.45	1.07	1.39
GSQ total hyper sensitivity	0.41	1.18	0.22	0.33	0.11	0.33	0.53	0.81	0.23	0.82	-0.33	-0.61	0.29	0.74	0.25	0.33
GSQ total hypo sensitivity	0.03	0.09	-0.19	-0.27	1.04	3.12	1.94	2.96	0.26	0.93	-0.24	-0.44	0.13	0.32	-0.15	-0.19
GSQ total	0.25	0.73	-0.19	-0.27	0.71	2.12	1.46	2.23	0.24	0.87	-0.25	-0.47	0.25	0.65	0.24	0.31
GSQ visual	0.43	1.24	0.49	0.71	0.31	0.88	0.25	0.36	0.41	1.47	-0.59	-1.07	0.66	1.57	1.36	1.66
GSQ auditory	-0.41	-1.17	-0.41	-0.59	-0.41	-1.17	0.19	0.28	-0.18	-0.63	-0.30	-0.54	-0.38	-0.91	0.24	0.29
GSQ gustatory	0.19	0.55	0.48	0.70	-0.01	-0.03	-0.88	-1.28	0.44	1.55	-0.41	-0.75	0.28	0.67	-0.42	-0.51
GSQ olfactory	0.53	1.53	0.57	0.83	-0.04	-0.12	-0.35	-0.50	0.53	1.88	0.08	0.14	0.63	1.50	2.59	3.16
GSQ tactile	0.85	2.43	-0.14	-0.21	0.22	0.63	-0.56	-0.81	0.36	1.29	-0.67	-1.20	0.29	0.68	-0.93	-1.13
GSQ vestibular	-0.09	-0.25	-0.73	-1.05	0.12	0.36	-0.37	-0.54	0.59	2.10	0.06	0.11	-0.01	-0.03	-0.40	-0.48
GSG proprioception	0.62	1.76	0.80	1.16	0.24	0.67	0.03	0.05	0.17	0.61	-0.38	-0.68	0.73	1.74	0.17	0.20
BMI	0.35	1.01	-0.49	-0.71	1.52	4.34	4.01	5.82	0.78	2.76	0.61	1.10	0.25	0.59	0.75	0.92
Taste test Sweet	-0.77	-1.66	-0.54	-0.60	-1.32	-2.07	1.41	1.14								
Taste test Sour	-0.06	-0.13	-0.18	-0.20	-0.39	-0.62	-1.45	-1.17								
Taste test Salty	-0.88	-1.90	-0.61	-0.67	0.35	0.56	-1.45	-1.17								
Taste test Bitter	-0.93	-2.01	-0.66	-0.74	-1.46	-2.28	1.39	1.13								
Taste test Total	-0.46	-0.99	-1.01	-1.12	-0.34	-0.53	-0.74	-0.60								
Taste test Accuracy	-0.46	-0.99	-1.01	-1.12	-0.34	-0.53	-0.74	-0.60								
Sweet Pleasantness	-1.01	-2.17	1.53	1.70	-0.49	-0.77	-1.00	-0.81								
Sour Pleasantness	0.07	0.15	-1.01	-1.12	0.34	0.54	-1.32	-1.07								
Salty Pleasantness	0.08	0.17	-0.92	-1.02	0.82	1.29	0.78	0.63								
Bitter Pleasantness	0.30	0.65	-1.10	-1.22	0.42	0.65	-0.45	-0.36								

Note. Green writing = assumption of normality met. Red writing = assumption of normality violated to critical degree according to Schmider et al. (2010).

Appendix 13

Test of homogeneity of variance

Table 1, Appendix 13

Levene's test to assess the assumptions of homogeneity of variance

Measure	Model	Levene's Test	Assumption of homogeneity of variance met?
RAADS-14	Unadjusted	$F(3, 206) = .821$, $p = .48$	Y
	Adjusted for age	$F(3, 206) = .78$, $p = .508$	Y
	Adjusted for age, depression, anxiety, social anxiety	$F(3, 206) = 1.23$, $p = .299$	Y
RAADS-14 childhood ratio	Unadjusted	$F(3,206) = 33.67$, $p < .001$	N
	Adjusted for age	$F(3,206) = 33.68$, $p < .001$	N
	Adjusted for age, depression, anxiety, social anxiety	$F(3,206) = 30.02$, $p < .001$	N
AQ‡	Unadjusted	$F(3,157) = 3.025$, $p = .031$	N
	Adjusted for age	$F(3,157) = 2.765$, $p = .044$	N
	Adjusted for age, depression, anxiety, social anxiety	$F(3, 157) = 3.249$, p=.023	N
CAT-Q	Unadjusted	$F(3, 206) = 1.756$, $p = .157$	Y
	Adjusted for age	$F(3,206) = 1.342$, $p = .262$	Y
	Adjusted for age, depression, anxiety, social anxiety	$F(3,206) = 1.40$, $p = .244$	Y
EDE-Q global	Unadjusted	$F(3, 206) = .93$, $p = .428$	Y
	Adjusted for age	$F(3,206) = 1.07$, $p = .363$	Y
	Adjusted for age, depression, anxiety, social anxiety	$F(3,206) = 1.51$, $p = 212$	Y
SWEAA total	Unadjusted	$F(3,206) = 2.524$, $p = .059$	Y
	Adjusted for age	$F(3,206) = 2.35$, $p = .073$	Y
	Adjusted for age, depression, anxiety,	$F(3.206) = .920$, $p = .434$	Y

Measure	Model	Levene's Test	Assumption of homogeneity of variance met?
	social anxiety		
EDE-Q restraint	Unadjusted	$F(3, 206) = .097$, $p = .962$	Y
	Adjusted for age	$F(3,206) = .229$, $p = .876$	Y
	Adjusted for age, depression, anxiety, social anxiety	$F(3,206) = 1.049$, $p = .372$	Y
EDE-Q eating concerns	Unadjusted	$F(3,206) = 2.26$, $p = .082$	Y
	Adjusted for age	$F(3,206) = 2.266$, $p = .082$	Y
	Adjusted for age, depression, anxiety, social anxiety	$F(3,206) = .584$, $p = .626$	Y
EDE-Q shape concerns	Unadjusted	$F(3, 206) = 3.21$, $p = .024$	N
	Adjusted for age	$F(3,206) = 3.233$, $p = .023$	N
	Adjusted for age, depression, anxiety, social anxiety	$F(3,206) = 2.710$, $p = .046$	N
EDE-Q weight concerns	Unadjusted	$F(3, 206) = 2.10$, $p = .102$	Y
	Adjusted for age	$F(3,206) = 2.044$, $p = .109$	Y
	Adjusted for age, depression, anxiety, social anxiety	$F(3,206) = 3.021$, $p = .031$	N
SWEAA A perception total	Unadjusted	$F(3, 206) = .474$, $p = .701$	Y
	Adjusted for age	$F(3, 206) = .716$, $p = .543$	Y
	Adjusted for age, depression, anxiety, social anxiety	$F(3, 206) = .247$, $p = .863$	Y
SWEAA B motor control total	Unadjusted	$F(3,206) = 5.48$, $p = .001$	N
	Adjusted for age	$F(3, 206) = 5.378$, $p = .001$	N
	Adjusted for age, depression, anxiety, social anxiety	$F(3, 206) = 4.909$, $p = .001$	N
SWEAA C purchase of food total	Unadjusted	$F(3, 206) = 3.04$, $p = .030$	N
	Adjusted for age	$F(3, 206) = 2.776$, $p = .042$	N
	Adjusted for age, depression, anxiety, social anxiety	$F(3, 206) = 2.640$, $p = .051$	Y

Measure	Model	Levene's Test	Assumption of homogeneity of variance met?
SWEAA D eating behaviours total	Unadjusted	$F(3, 206) = 1.08$ $p = .361$	Y
	Adjusted for age	$F(3, 206) = 1.319$, $p = .269$	Y
	Adjusted for age, depression, anxiety, social anxiety	$F(3, 206) = .618$, $p = .604$	Y
SWEAA E mealtime surroundings total	Unadjusted	$F(3, 206) = 2.18$, $p = .091$	Y
	Adjusted for age	$F(3, 206) = 2.345$, $p = .074$	Y
	Adjusted for age, depression, anxiety, social anxiety	$F(3, 206) = 5.687$, $p = .001$	N
SWEAA F social situation at mealtime total	Unadjusted	$F(3,206) = .731$, $p = .534$	Y
	Adjusted for age	$F(3, 206) = 557$, $p = .644$	Y
	Adjusted for age, depression, anxiety, social anxiety	F (3, 206) = .447, $p = .719$	Y
SWEAA G other disturbed eating behaviours total	Unadjusted	$F(3, 206) = 7.26$, $p < .001$	N
	Adjusted for age	F (3, 206) = 7.23, $p < .001$	N
	Adjusted for age, depression, anxiety, social anxiety	F (3, 206) = 6.706, $p <$ .001	N
SWEAA H hunger satiety	Unadjusted	$F(3,206) = .540$, $p = .659$	Y
	Adjusted for age	F (3, 206) = .495, $p = .686$	Y
	Adjusted for age, depression, anxiety, social anxiety	F (3, 206) = .504, $p = .680$	Y
SWEAA I simultaneous capacity	Unadjusted	$F(3, 206) = 1.378$, $p = .251$	Y
	Adjusted for age	F (3, 206) = 1.180, $p =$ .318	Y
	Adjusted for age, depression, anxiety, social anxiety	F (3, 206) = .657, $p = .580$	Y
GSQ total hyper sensitivity	Unadjusted	$F(3, 206) = .818$, $p = .485$	Y
	Adjusted for age	$F(3, 206) = .803$, $p = .493$	Y
	Adjusted for age, depression, anxiety, social anxiety	$F(3, 206) = 1.967$, $p = .120$	Y

Measure	Model	Levene's Test	Assumption of homogeneity of variance met?
GSQ total hypo sensitivity	Unadjusted	$F(3, 206) = 6.020$, $p = .001$	N
	Adjusted for age	$F(3, 206) = 6.120$, $p = .001$	N
	Adjusted for age, depression, anxiety, social anxiety	$F(3, 206) = 5.620$, $p = .001$	N
GSQ visual	Unadjusted	$F(3, 206) = 1.353$, $p = .258$	Y
	Adjusted for age	$F(3, 206) = 1.443$, $p = .231$	Y
	Adjusted for age, depression, anxiety, social anxiety	$F(3, 206) = 1.284$, $p = .281$	Y
GSQ auditory	Unadjusted	$F(3, 206) = 1.248$, $p = .293$	Y
	Adjusted for age	$F(3, 206) = 1.161$, $p = .326$	Y
	Adjusted for age, depression, anxiety, social anxiety	$F(3, 206) = 2.867$, $p = .038$	N
GSQ gustatory	Unadjusted	$F(3, 206) = 2.103$, $p = .101$	Y
	Adjusted for age	$F(3, 206) = 1.948$, $p = .123$	Y
	Adjusted for age, depression, anxiety, social anxiety	$F(3, 206) = 2.051$, $p = .108$	Y
GSQ olfactory	Unadjusted	$F(3, 206) = .797$, $p = .497$	Y
	Adjusted for age	$F(3, 206) = .630$, $p = .596$	Y
	Adjusted for age, depression, anxiety, social anxiety	$F(3, 206) = 1.123$, $p = .341$	Y
GSQ tactile	Unadjusted	$F(3, 206) = 1.988$, $p = .117$	Y
	Adjusted for age	$F(3, 206) = 1.871$, $p = .136$	Y
	Adjusted for age, depression, anxiety, social anxiety	$F(3, 206) = 2.938$, $p = .034$	Y
GSQ vestibular	Unadjusted	$F(3, 206) = 4.630$, $p = .004$	N
	Adjusted for age	$F(3, 206) = 4.115$, $p = .007$	N
	Adjusted for age, depression, anxiety, social anxiety	$F(3, 206) = 2.170$, $p = .093$	Y

Measure	Model	Levene's Test	Assumption of homogeneity of variance met?
GSG proprioception	Unadjusted	$F(3, 206) = 5.779$, $p = .001$	N
	Adjusted for age	$F(3, 206) = 5.741$, $p = .001$	N
	Adjusted for age, depression, anxiety, social anxiety	$F(3, 206) = 4.987$, $p = .002$	N
Age		$F(3, 206) = 2.163$, $p = .093$	Y
HAADS Depression		$F(3, 206) = 4.036$, $p = .008$	N
HAADS anxiety		$F(3, 206) = 2.304$, $p = .078$	Y
SPIN		$F(3, 206) = 1.913$, $p = .129$	Y
BMI*		$F(3, 192) = 18.942$, $p = .001$	N

Note. ‡reduced sample size for AQ comparison due to missing data: Autism only (n=19), Autism+REDs (n=33), REDs only (n=75), REDs with high autistic traits (n=34). * reduced sample sizes due to missing BMI data: : Autism only (n=46), Autism+REDs (n=46), REDs only (n=73), REDs with high autistic traits (n=31),

Appendix 14

Full search strategy for systematic review

An electronic database search in three bibliographic databases within the Ovid interface was conducted on the 18th of December 2019 (see detailed search strategy below). Results were combined and duplicates were removed in Endnote. Reference lists of included studies, relevant position pieces and existing systematic reviews on related topics were manually scanned for additional studies. Experts in the field were contacted to obtain any missed studies. The electronic database search was repeated on the 12th of December 2020.

Medline search

Database: Ovid MEDLINE(R) and Epub Ahead of Print, In-Process & Other Non-Indexed Citations and Daily <1946 to December 17, 2019>
Search Strategy:

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1 exp Child Development Disorders, Pervasive/ (33600)
2 autis*.mp. [mp=title, abstract, original title, name of substance word, subject heading word, floating sub-heading word, keyword heading word, organism supplementary concept word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier, synonyms] (48899)
3 ASC.mp. [mp=title, abstract, original title, name of substance word, subject heading word, floating sub-heading word, keyword heading word, organism supplementary concept word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier, synonyms] (8651)
4 ASD.mp. [mp=title, abstract, original title, name of substance word, subject heading word, floating sub-heading word, keyword heading word, organism supplementary concept word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier, synonyms] (21924)
5 Asperger*.mp. [mp=title, abstract, original title, name of substance word, subject heading word, floating sub-heading word, keyword heading word, organism supplementary concept word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier, synonyms] (2724)
6 pervasive developmental disorder*.mp. [mp=title, abstract, original title, name of substance word, subject heading word, floating sub-heading word, keyword heading word, organism supplementary concept word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier, synonyms] (2007)
7 or/1-6 (65432)
8 mental health services/ or community mental health services/ or exp counseling/ or emergency services, psychiatric/ or social work, psychiatric/ (95836)
9 exp Health Services Accessibility/ (107441)

10 (health services needs and demand).mp. [mp=title, abstract, original title, name of substance word, subject heading word, floating sub-heading word, keyword heading word, organism supplementary concept word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier, synonyms] (52094)
11 "Health Services Needs and Demand"/ (52012)
12 psychiatric rehabilitation/ or psychiatry/ or community psychiatry/ or preventive psychiatry/ (41137)
13 Hospitals, Psychiatric/ (24997)
14 Psychiatric Nursing/ (17327)
15 (mental health adj5 (service* or facility* or care or provision or unit or treatment or therap* or psychotherap* or professional*)).mp. [mp=title, abstract, original title, name of substance word, subject heading word, floating sub-heading word, keyword heading word, organism supplementary concept word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier, synonyms] (83136)
16 (mental illness adj5 (service* or facility* or care or provision or unit or treatment or therap* or psychotherap* or professional*)).mp. [mp=title, abstract, original title, name of substance word, subject heading word, floating sub-heading word, keyword heading word, organism supplementary concept word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier, synonyms] (3821)
17 (comorbid* adj5 (service* or facility* or care or provision or unit or treatment or therap* or psychotherap*)).mp. [mp=title, abstract, original title, name of substance word, subject heading word, floating sub-heading word, keyword heading word, organism supplementary concept word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier, synonyms] (16268)
18 (psychopathology adj5 (service* or facility* or care or provision or unit or treatment or therap* or psychotherap* or professional*)).mp. [mp=title, abstract, original title, name of substance word, subject heading word, floating sub-heading word, keyword heading word, organism supplementary concept word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier, synonyms] (2007)
19 (psychiatric adj5 (service* or facility* or care or provision or unit or treatment or therap* or psychotherap* or professional*)).mp. [mp=title, abstract, original title, name of substance word, subject heading word, floating sub-heading word, keyword heading word, organism supplementary concept word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier, synonyms] (41089)
20 (anxiet* adj5 (service* or facility* or care or provision or unit or treatment or therap* or psychotherap*)).mp. [mp=title, abstract, original title, name of substance word, subject heading word, floating sub-heading word, keyword heading word, organism supplementary concept word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier, synonyms] (16513)
21 (obsessive-compulsive adj5 (service* or facility* or care or provision or unit or treatment or therap* or psychotherap*)).mp. [mp=title, abstract, original title, name of substance word, subject heading word, floating sub-heading word, keyword heading word, organism supplementary concept word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier, synonyms] (2482)

22 (PTSD adj5 (service* or facility* or care or provision or unit or treatment or therap* or psychotherap*)).mp. [mp=title, abstract, original title, name of substance word, subject heading word, floating sub-heading word, keyword heading word, organism supplementary concept word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier, synonyms] (4531)
23 (depress* adj5 (service* or facility* or care or provision or unit or treatment or therap* or psychotherap*)).mp. [mp=title, abstract, original title, name of substance word, subject heading word, floating sub-heading word, keyword heading word, organism supplementary concept word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier, synonyms] (56020)
24 (mood disorder* adj5 (service* or facility* or care or provision or unit or treatment or therap* or psychotherap*)).mp. [mp=title, abstract, original title, name of substance word, subject heading word, floating sub-heading word, keyword heading word, organism supplementary concept word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier, synonyms] (2141)
25 (psychosis adj5 (service* or facility* or care or provision or unit or treatment or therap* or psychotherap*)).mp. [mp=title, abstract, original title, name of substance word, subject heading word, floating sub-heading word, keyword heading word, organism supplementary concept word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier, synonyms] (4406)
26 (psychotic* adj5 (service* or facility* or care or provision or unit or treatment or therap* or psychotherap*)).mp. [mp=title, abstract, original title, name of substance word, subject heading word, floating sub-heading word, keyword heading word, organism supplementary concept word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier, synonyms] (5928)
27 (schizophreni* adj5 (service* or facility* or care or provision or unit or treatment or therap* or psychotherap*)).mp. [mp=title, abstract, original title, name of substance word, subject heading word, floating sub-heading word, keyword heading word, organism supplementary concept word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier, synonyms] (21128)
28 (bipolar adj5 (service* or facility* or care or provision or unit or treatment or therap* or psychotherap*)).mp. [mp=title, abstract, original title, name of substance word, subject heading word, floating sub-heading word, keyword heading word, organism supplementary concept word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier, synonyms] (6756)
29 (mania adj5 (service* or facility* or care or provision or unit or treatment or therap* or psychotherap*)).mp. [mp=title, abstract, original title, name of substance word, subject heading word, floating sub-heading word, keyword heading word, organism supplementary concept word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier, synonyms] (1529)
30 (tic disorder adj5 (service* or facility* or care or provision or unit or treatment or therap* or psychotherap*)).mp. [mp=title, abstract, original title, name of substance word, subject heading word, floating sub-heading word, keyword heading word, organism supplementary concept word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier, synonyms] (37)
31 (eating disorder* adj5 (service* or facility* or care or provision or unit or treatment or therap* or psychotherap*)).mp. [mp=title, abstract, original title, name of substance word, subject heading word, floating sub-heading word, keyword heading word, organism supplementary concept word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier, synonyms] (3095)

32 (anorexi* adj5 (service* or facility* or care or provision or unit or treatment or therap* or psychotherap*)).mp. [mp=title, abstract, original title, name of substance word, subject heading word, floating sub-heading word, keyword heading word, organism supplementary concept word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier, synonyms] (2720)
33 (bulimi* adj5 (service* or facility* or care or provision or unit or treatment or therap* or psychotherap*)).mp. [mp=title, abstract, original title, name of substance word, subject heading word, floating sub-heading word, keyword heading word, organism supplementary concept word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier, synonyms] (1135)
34 (ADHD adj5 (service* or facility* or care or provision or unit or treatment or therap* or psychotherap*)).mp. [mp=title, abstract, original title, name of substance word, subject heading word, floating sub-heading word, keyword heading word, organism supplementary concept word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier, synonyms] (4231)
35 (attention deficit adj5 (service* or facility* or care or provision or unit or treatment or therap* or psychotherap*)).mp. [mp=title, abstract, original title, name of substance word, subject heading word, floating sub-heading word, keyword heading word, organism supplementary concept word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier, synonyms] (2572)
36 (substance abuse adj5 (service* or facility* or care or provision or unit or treatment or therap* or psychotherap*)).mp. [mp=title, abstract, original title, name of substance word, subject heading word, floating sub-heading word, keyword heading word, organism supplementary concept word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier, synonyms] (11479)
37 (substance dependen* adj5 (service* or facility* or care or provision or unit or treatment or therap* or psychotherap*)).mp. [mp=title, abstract, original title, name of substance word, subject heading word, floating sub-heading word, keyword heading word, organism supplementary concept word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier, synonyms] (418)
38 (personality disorder* adj5 (service* or facility* or care or provision or unit or treatment or therap* or psychotherap*)).mp. [mp=title, abstract, original title, name of substance word, subject heading word, floating sub-heading word, keyword heading word, organism supplementary concept word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier, synonyms] (3131)
39 (trauma adj5 (service* or facility* or care or provision or unit or treatment or therap* or psychotherap*)).mp. [mp=title, abstract, original title, name of substance word, subject heading word, floating sub-heading word, keyword heading word, organism supplementary concept word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier, synonyms] (21064)
40 (psycholog* adj5 (service* or facility* or care or provision or unit or treatment or therap* or psychotherap* or professional*)).mp. [mp=title, abstract, original title, name of substance word, subject heading word, floating sub-heading word, keyword heading word, organism supplementary concept word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier, synonyms] (181801)
41 (health service* adj4 access*).tw. (5453)
42 (healthcare adj4 experience*).tw. (2943)
43 (health care adj4 barrier*).mp. [mp=title, abstract, original title, name of substance word, subject heading word, floating sub-heading word, keyword heading

word, organism supplementary concept word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier, synonyms] (2740)
44 (healthcare adj4 barrier*).mp. [mp=title, abstract, original title, name of substance word, subject heading word, floating sub-heading word, keyword heading word, organism supplementary concept word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier, synonyms] (1405)
45 (health care adj4 experience*).mp. [mp=title, abstract, original title, name of substance word, subject heading word, floating sub-heading word, keyword heading word, organism supplementary concept word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier, synonyms] (4382)
46 (health service* adj4 barrier*).mp. [mp=title, abstract, original title, name of substance word, subject heading word, floating sub-heading word, keyword heading word, organism supplementary concept word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier, synonyms] (787)
47 (health service* adj4 experience*).mp. [mp=title, abstract, original title, name of substance word, subject heading word, floating sub-heading word, keyword heading word, organism supplementary concept word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier, synonyms] (1023)
48 (health care adj4 access*).mp. [mp=title, abstract, original title, name of substance word, subject heading word, floating sub-heading word, keyword heading word, organism supplementary concept word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier, synonyms] (14164)
49 (healthcare adj4 access*).mp. [mp=title, abstract, original title, name of substance word, subject heading word, floating sub-heading word, keyword heading word, organism supplementary concept word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier, synonyms] (6235)
50 (psychiatr* adj4 experience*).mp. [mp=title, abstract, original title, name of substance word, subject heading word, floating sub-heading word, keyword heading word, organism supplementary concept word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier, synonyms] (3010)
51 "Attitude of Health Personnel"/ (118680)
52 exp "patient acceptance of health care"/ or exp patient satisfaction/ or patient preference/ (225082)
53 or/8-52 (926476)
54 7 and 53 (5063)

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Embase search
Database: Embase Classic+Embase <1947 to 2019 December 18>
Search Strategy:
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1 autis*.tw. (59665)
2 ASC.tw. (12468)
3 ASD.tw. (31159)
4 Asperger*.tw. (2860)
5 pervasive developmental disorder*.tw. (2698)
6 autism/ or asperger syndrome/ or childhood disintegrative disorder/ or "pervasive developmental disorder not otherwise specified"/ (62953)
7 or/1-6 (96093)

8 (health services needs and demand).tw. (7)
9 (mental health adj5 (service* or facility* or care or provision or unit or treatment or therap* or psychotherap* or professional*)).tw. (57252)
10 (mental illness adj5 (service* or facility* or care or provision or unit or treatment or therap* or psychotherap* or professional*)).tw. (4911)
11 (comorbid* adj5 (service* or facility* or care or provision or unit or treatment or therap* or psychotherap*)).tw. (21419)
12 (psychopathology adj5 (service* or facility* or care or provision or unit or treatment or therap* or psychotherap* or professional*)).tw. (2214)
13 (psychiatric adj5 (service* or facility* or care or provision or unit or treatment or therap* or psychotherap* or professional*)).tw. (50562)
14 (anxiet* adj5 (service* or facility* or care or provision or unit or treatment or therap* or psychotherap*)).tw. (23095)
15 (obsessive-compulsive adj5 (service* or facility* or care or provision or unit or treatment or therap* or psychotherap*)).tw. (3235)
16 (PTSD adj5 (service* or facility* or care or provision or unit or treatment or therap* or psychotherap*)).tw. (5694)
17 (depress* adj5 (service* or facility* or care or provision or unit or treatment or therap* or psychotherap*)).tw. (71004)
18 (mood disorder* adj5 (service* or facility* or care or provision or unit or treatment or therap* or psychotherap*)).tw. (2646)
19 (psychosis adj5 (service* or facility* or care or provision or unit or treatment or therap* or psychotherap*)).tw. (7115)
20 (psychotic* adj5 (service* or facility* or care or provision or unit or treatment or therap* or psychotherap*)).tw. (5623)
21 (schizophreni* adj5 (service* or facility* or care or provision or unit or treatment or therap* or psychotherap*)).tw. (25885)
22 (bipolar adj5 (service* or facility* or care or provision or unit or treatment or therap* or psychotherap*)).tw. (10098)
23 (mania adj5 (service* or facility* or care or provision or unit or treatment or therap* or psychotherap*)).tw. (2231)
24 (tic disorder adj5 (service* or facility* or care or provision or unit or treatment or therap* or psychotherap*)).tw. (50)
25 (eating disorder* adj5 (service* or facility* or care or provision or unit or treatment or therap* or psychotherap*)).tw. (3999)
26 (anorexi* adj5 (service* or facility* or care or provision or unit or treatment or therap* or psychotherap*)).tw. (3682)
27 (bulimi* adj5 (service* or facility* or care or provision or unit or treatment or therap* or psychotherap*)).tw. (1361)
28 (ADHD adj5 (service* or facility* or care or provision or unit or treatment or therap* or psychotherap*)).tw. (6335)
29 (attention deficit adj5 (service* or facility* or care or provision or unit or treatment or therap* or psychotherap*)).tw. (3305)
30 (substance abuse adj5 (service* or facility* or care or provision or unit or treatment or therap* or psychotherap*)).tw. (7913)
31 (substance dependen* adj5 (service* or facility* or care or provision or unit or treatment or therap* or psychotherap*)).tw. (539)
32 (personality disorder* adj5 (service* or facility* or care or provision or unit or treatment or therap* or psychotherap*)).tw. (3158)

33 (trauma adj5 (service* or facility* or care or provision or unit or treatment or therap* or psychotherap*)).tw. (26710)
34 (psycholog* adj5 (service* or facility* or care or provision or unit or treatment or therap* or psychotherap* or professional*)).tw. (38261)
35 (health service* adj4 access*).tw. (6469)
36 (healthcare adj4 experience*).tw. (3966)
37 (health care adj4 barrier*).tw. (3180)
38 (healthcare adj4 barrier*).tw. (1903)
39 (health care adj4 experience*).tw. (5120)
40 (health service* adj4 barrier*).tw. (932)
41 (health service* adj4 experience*).tw. (1239)
42 (health care adj4 access*).tw. (16247)
43 (healthcare adj4 access*).tw. (8464)
44 (psychiatr* adj4 experience*).tw. (4410)
45 mental health service/ (57936)
46 counseling/ or directive counseling/ or e-counseling/ or family counseling/ or patient counseling/ or patient guidance/ (119107)
47 psychiatric emergency service/ (172)
48 health care need/ (28605)
49 psychosocial rehabilitation/ (1338)
50 social psychiatry/ (3686)
51 mental hospital/ or halfway house/ or mental day hospital/ (33463)
52 psychiatric nursing/ or community psychiatric nursing/ or psychogeriatric nursing/ (16316)
53 health personnel attitude/ or nurse attitude/ or occupational therapist attitude/ or pharmacist attitude/ or physician assistant attitude/ or physician attitude/ or physiotherapist attitude/ or psychotherapist attitude/ or rescue personnel attitude/ (169805)
54 or/8-53 (724511)
55 7 and 54 (4758)

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PsychINFO search
Database: PsycINFO <1806 to December Week 2 2019>
Search Strategy:
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1 autis*.mp. [mp=title, abstract, heading word, table of contents, key concepts, original title, tests & measures, mesh] (54273)
2 ASC.mp. [mp=title, abstract, heading word, table of contents, key concepts, original title, tests & measures, mesh] (841)
3 ASD.mp. [mp=title, abstract, heading word, table of contents, key concepts, original title, tests & measures, mesh] (17320)
4 Asperger*.mp. [mp=title, abstract, heading word, table of contents, key concepts, original title, tests & measures, mesh] (4443)
5 pervasive developmental disorder*.mp. [mp=title, abstract, heading word, table of contents, key concepts, original title, tests & measures, mesh] (3192)
6 (health services needs and demand).mp. [mp=title, abstract, heading word, table of contents, key concepts, original title, tests & measures, mesh] (25)

7 (mental health adj5 (service* or facility* or care or provision or unit or treatment or therap* or psychotherap* or professional*)).mp. [mp=title, abstract, heading word, table of contents, key concepts, original title, tests & measures, mesh] (91157)
8 (mental illness adj5 (service* or facility* or care or provision or unit or treatment or therap* or psychotherap* or professional*)).mp. [mp=title, abstract, heading word, table of contents, key concepts, original title, tests & measures, mesh] (6459)
9 (comorbid* adj5 (service* or facility* or care or provision or unit or treatment or therap* or psychotherap*)).mp. [mp=title, abstract, heading word, table of contents, key concepts, original title, tests & measures, mesh] (8051)
10 (psychopathology adj5 (service* or facility* or care or provision or unit or treatment or therap* or psychotherap* or professional*)).mp. [mp=title, abstract, heading word, table of contents, key concepts, original title, tests & measures, mesh] (5916)
11 (psychiatric adj5 (service* or facility* or care or provision or unit or treatment or therap* or psychotherap* or professional*)).mp. [mp=title, abstract, heading word, table of contents, key concepts, original title, tests & measures, mesh] (47928)
12 (anxiet* adj5 (service* or facility* or care or provision or unit or treatment or therap* or psychotherap*)).mp. [mp=title, abstract, heading word, table of contents, key concepts, original title, tests & measures, mesh] (20344)
13 (obsessive-compulsive adj5 (service* or facility* or care or provision or unit or treatment or therap* or psychotherap*)).mp. [mp=title, abstract, heading word, table of contents, key concepts, original title, tests & measures, mesh] (4269)
14 (PTSD adj5 (service* or facility* or care or provision or unit or treatment or therap* or psychotherap*)).mp. [mp=title, abstract, heading word, table of contents, key concepts, original title, tests & measures, mesh] (6717)
15 (depress* adj5 (service* or facility* or care or provision or unit or treatment or therap* or psychotherap*)).mp. [mp=title, abstract, heading word, table of contents, key concepts, original title, tests & measures, mesh] (49509)
16 (mood disorder* adj5 (service* or facility* or care or provision or unit or treatment or therap* or psychotherap*)).mp. [mp=title, abstract, heading word, table of contents, key concepts, original title, tests & measures, mesh] (2089)
17 (psychosis adj5 (service* or facility* or care or provision or unit or treatment or therap* or psychotherap*)).mp. [mp=title, abstract, heading word, table of contents, key concepts, original title, tests & measures, mesh] (8352)
18 (psychotic* adj5 (service* or facility* or care or provision or unit or treatment or therap* or psychotherap*)).mp. [mp=title, abstract, heading word, table of contents, key concepts, original title, tests & measures, mesh] (5964)
19 (schizophreni* adj5 (service* or facility* or care or provision or unit or treatment or therap* or psychotherap*)).mp. [mp=title, abstract, heading word, table of contents, key concepts, original title, tests & measures, mesh] (23696)
20 (bipolar adj5 (service* or facility* or care or provision or unit or treatment or therap* or psychotherap*)).mp. [mp=title, abstract, heading word, table of contents, key concepts, original title, tests & measures, mesh] (6100)
21 (mania adj5 (service* or facility* or care or provision or unit or treatment or therap* or psychotherap*)).mp. [mp=title, abstract, heading word, table of contents, key concepts, original title, tests & measures, mesh] (2075)
22 (tic disorder adj5 (service* or facility* or care or provision or unit or treatment or therap* or psychotherap*)).mp. [mp=title, abstract, heading word, table of contents, key concepts, original title, tests & measures, mesh] (27)

23 (eating disorder* adj5 (service* or facility* or care or provision or unit or treatment or therap* or psychotherap*)).mp. [mp=title, abstract, heading word, table of contents, key concepts, original title, tests & measures, mesh] (5435)
24 (anorexi* adj5 (service* or facility* or care or provision or unit or treatment or therap* or psychotherap*)).mp. [mp=title, abstract, heading word, table of contents, key concepts, original title, tests & measures, mesh] (3208)
25 (bulimi* adj5 (service* or facility* or care or provision or unit or treatment or therap* or psychotherap*)).mp. [mp=title, abstract, heading word, table of contents, key concepts, original title, tests & measures, mesh] (2215)
26 (ADHD adj5 (service* or facility* or care or provision or unit or treatment or therap* or psychotherap*)).mp. [mp=title, abstract, heading word, table of contents, key concepts, original title, tests & measures, mesh] (4379)
27 (attention deficit adj5 (service* or facility* or care or provision or unit or treatment or therap* or psychotherap*)).mp. [mp=title, abstract, heading word, table of contents, key concepts, original title, tests & measures, mesh] (2581)
28 (substance abuse adj5 (service* or facility* or care or provision or unit or treatment or therap* or psychotherap*)).mp. [mp=title, abstract, heading word, table of contents, key concepts, original title, tests & measures, mesh] (10369)
29 (substance dependen* adj5 (service* or facility* or care or provision or unit or treatment or therap* or psychotherap*)).mp. [mp=title, abstract, heading word, table of contents, key concepts, original title, tests & measures, mesh] (549)
30 (personality disorder* adj5 (service* or facility* or care or provision or unit or treatment or therap* or psychotherap*)).mp. [mp=title, abstract, heading word, table of contents, key concepts, original title, tests & measures, mesh] (6989)
31 (trauma adj5 (service* or facility* or care or provision or unit or treatment or therap* or psychotherap*)).mp. [mp=title, abstract, heading word, table of contents, key concepts, original title, tests & measures, mesh] (10274)
32 (psycholog* adj5 (service* or facility* or care or provision or unit or treatment or therap* or psychotherap* or professional*)).mp. [mp=title, abstract, heading word, table of contents, key concepts, original title, tests & measures, mesh] (73074)
33 (health service* adj4 access*).tw. (2486)
34 (healthcare adj4 experience*).tw. (1167)
35 (health care adj4 barrier*).mp. [mp=title, abstract, heading word, table of contents, key concepts, original title, tests & measures, mesh] (1469)
36 (healthcare adj4 barrier*).mp. [mp=title, abstract, heading word, table of contents, key concepts, original title, tests & measures, mesh] (487)
37 (health care adj4 experience*).mp. [mp=title, abstract, heading word, table of contents, key concepts, original title, tests & measures, mesh] (2052)
38 (health service* adj4 barrier*).mp. [mp=title, abstract, heading word, table of contents, key concepts, original title, tests & measures, mesh] (530)
39 (health service* adj4 experience*).mp. [mp=title, abstract, heading word, table of contents, key concepts, original title, tests & measures, mesh] (643)
40 (health care adj4 access*).mp. [mp=title, abstract, heading word, table of contents, key concepts, original title, tests & measures, mesh] (5528)
41 (healthcare adj4 access*).mp. [mp=title, abstract, heading word, table of contents, key concepts, original title, tests & measures, mesh] (1804)
42 (psychiatr* adj4 experience*).mp. [mp=title, abstract, heading word, table of contents, key concepts, original title, tests & measures, mesh] (4012)
43 autism spectrum disorders/ or autistic traits/ (41925)
44 health care seeking behavior/ (4271)

45 community mental health services/ or community mental health centers/ or community psychiatry/ or community psychology/ (12844)
46 psychotherapeutic counseling/ or family therapy/ (22575)
47 counseling/ or community counseling/ or psychotherapeutic counseling/ or rehabilitation counseling/ or counseling psychology/ (28183)
48 health service needs/ (5777)
49 psychiatry/ or adolescent psychiatry/ or community psychiatry/ or social psychiatry/ (32640)
50 psychiatric hospitalization/ or psychiatric hospital admission/ or psychiatric hospital discharge/ or psychiatric hospital readmission/ (10160)
51 mental health personnel/ or clinical psychologists/ or psychiatric hospital staff/ or psychiatric nurses/ or psychiatric social workers/ or psychiatrists/ or psychotherapists/ (36786)
52 1 or 2 or 3 or 4 or 5 or 43 (56121)
53 6 or 7 or 8 or 9 or 10 or 11 or 12 or 13 or 14 or 15 or 16 or 17 or 18 or 19 or 20 or 21 or 22 or 23 or 24 or 25 or 26 or 27 or 28 or 29 or 30 or 31 or 32 or 33 or 34 or 35 or 36 or 37 or 38 or 39 or 40 or 41 or 42 or 44 or 45 or 46 or 47 or 48 or 49 or 50 or 51 (431290)
54 52 and 53 (4274)

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Appendix 15

Quality assessment for studies included in systematic review

Mixed methods appraisal tool, version 2018 (MMAT; Hong et al., 2018)

Screening Questions

- S1. Are there clear research questions?
- S2. Do the collected data allow to address the research questions?

1. Qualitative Studies

- Is the qualitative approach appropriate to answer the research question?
- Are the qualitative data collection methods adequate to address the research question?
- Are the findings adequately derived from the data?
- Is the interpretation of results sufficiently substantiated by data?
- Is there coherence between qualitative data sources, collection, analysis and interpretation?

2. Randomized Controlled Trials

- 2.1. Is randomization appropriately performed?
- 2.2. Are the groups comparable at baseline?
- 2.3. Are there complete outcome data?
- 2.4. Are outcome assessors blinded to the intervention provided?
- 2.5 Did the participants adhere to the assigned intervention?

3. Non-Randomised Studies: e.g. case-control studies, cohort-studies, cross sectional analytical studies

- 3.1. Are the participants representative of the target population?
- 3.2. Are measurements appropriate regarding both the outcome and intervention (or exposure)?
- 3.3. Are there complete outcome data?
- 3.4. Are the confounders accounted for in the design and analysis?

- 3.5. During the study period, is the intervention administered (or exposure occurred) as intended?

4. Quantitative Descriptive Studies: incidence and prevalence studies without comparison, surveys

- 4.1. Is the sampling strategy relevant to address the research question?
- 4.2. Is the sample representative of the target population?
- 4.3. Are the measurements appropriate?
- 4.4. Is the risk of nonresponse bias low?
- 4.5. Is the statistical analysis appropriate to answer the research question?

5. Mixed Method Studies

- 5.1. Is there an adequate rationale for using a mixed methods design to address the research question?
- 5.2. Are the different components of the study effectively integrated to answer the research question?
- 5.3. Are the outputs of the integration of qualitative and quantitative components adequately interpreted?
- 5.4. Are divergences and inconsistencies between quantitative and qualitative results adequately addressed?
- 5.5. Do the different components of the study adhere to the quality criteria of each tradition of the methods involved?

Table 1, Appendix 15

MMAT quality ratings for the included studies

ID	Method	% of non-screening questions answered with 'yes'	First author	Year	Screening questions		1. Qualitative studies					2. Randomised controlled trials	3. Non-randomized studies					4. Qualitative descriptive studies					5. Mixed method studies				
					S1	S2	1.1	1.2	1.3	1.4	1.5	N/A	3.1	3.2	3.3	3.4	3.5	4.1	4.2	4.3	4.4	4.5	5.1	5.2	5.3	5.4	5.5
1	qual	5/5; 100%	Adamson, James Kinnaird, Emma Glennon, Danielle Oakley, Madeleine	2020	y	y	y	y	y	y	y																

			Tchanturia, Kate																										
2	qual	5/5; 100%	Ainsworth, K., A. E. Robertson, H. Welsh, M. Day, J. Watt, F. Barry, A. Stanfield and C. Melville	2020	y	y	y	y	y	y	y																		
3	qual	5/5; 100%	Anderson, C. and C. Butt	2018	y	y	y	y	y	y	y																		
4	qual	5/5; 100%	Anderson, C., A. Lupfer and P. T. Shattuck	2018	y	y	y	y	y	y	y																		
5	mixed	14/15; 93%	Au-Yeung, S. K., L. Bradley, A. E. Robertson, R. Shaw, S. Baron-Cohen and S. Cassidy	2019	y	y	y	y	y	y	y							y	y	y	n	y					y	y	y	y	y
6	qual	5/5; 100%	Camm-Crosbie, L., L. Bradley, R. Shaw, S. Baron-Cohen and S. Cassidy	2019	y	y	y	y	y	y	y																		

7	qual	5/5; 100%	Cheak-Zamora, Nancy C.: Teti, Michelle	2015	y	y	y	y	y	y	y											
8	qual	5/5, 100%	Coleman-Fountain, Buckley & Beresford	2020	y	y	y	y	y	y	y											
9	mixed	12/15; 80%	Cooper, K.: Loades, M. E.: Russell, A. J.	2018	y	y	y	y	y	y	y											
10	qual	5/5; 100%	Coxon, Sabrina	2016	y	y	y	y	y	y	y											
11	mixed	12/15; 80%	Crane, L., F. Adams, G. Harper, J. Welch and E. Pellicano	2019	y	y	y	y	y	y	y											
12	mixed	12/15; 80%	Crane, L.: Davidson, I.: Prosser, R.: Pellicano, E.	2019	y	y	y	y	y	y	y											
13	qual	5/5, 100%	Elichaoff, Frauke	2015	y	y	y	y	y	y	y											
14	qual	5/5; 100%	Griffith, G. M., V. Totsika, S. Nash and R. P. Hastings	2012	y	y	y	y	y	y	y											
15	qual	5/5; 100%	Henry, Ardail Rashad	2014	y	y	y	y	y	y	y											
16	qual	5/5, 100%	Jordan, Marczak & Knibbs,	2020	y	y	y	y	y	y	y											
17	qual	4/5; 80%	Joseph-Kent, Karen E.	2018	y	y	y	y	n	y	y											

18	qual	5/5; 100%	Kinnaird, Emma: Norton, Caroline: Stewart, Catherine: Tchanturia, Kate	2019	y	y	y	y	y	y	y
19	qual	5/5; 100%	Kinnaird, Emma: Norton, Caroline: Tchanturia, Kate	2017	y	y	y	y	y	y	y
20	qual	5/5; 100%	Lake, Johanna K.: Milovanov, Alexander: Sawyer, Amanda: Lunsky, Yona	2015	y	y	y	y	y	y	y
21	qual	5/5, 100%	Mack	2020	y	y	y	y	y	y	y
22	qual	5/5; 100%	Maddox, B. B.: Crabbe, S.: Beidas, R. S.: Brookman-Frazee, L.: Cannuscio, C. C.: Miller, J. S.: Nicolaidis, C.: Mandell, D. S.	2019	y	y	y	y	y	y	y
23	qual	5/5; 100%	Maloret, P. and T. Scott	2018	y	y	y	y	y	y	y

24	mixed	6/15; 40%	McMorris, Carly A.: Baraskewich, Jessica: Ames, Megan A.: Shaikh, Komal T.: Ncube, Busisiwe L.: Bebko, James M.	2018	y	y	y	n	n	n	n											y	n	n	y	y	n	n	y	y	n
25	mixed	10/15, 66,6%	Merrick, King, McConachie, Parr, Le Couteur & Transition Collaborative Group	2020	y	y	y	n	y	n	y						y	y	n	y	y						y	n	y	y	n
26	mixed	10/15, 66,6%	Murphy & McMorrow	2015	y	y	y	y	n	n	y											y	y	y	n	y	y	n	y	y	n
27	qual	5/5; 100%	Newlove-Delgado, T.: Ford, T. J.: Stein, K.: Garside, R.	2018	y	y	y	y	y	y	y																				
28	qual	5/5; 100%	Robertson, A. E.: Stanfield, A. C.: Watt, J.: Barry, F.: Day, M.: Cormack, M.: Melville, C.	2018	y	y	y	y	y	y	y																				

29	qual	5/5; 100%	Rodgers, J. Herrema, R. Garland, D. Osborne, M. Cooper, R. Heslop, P. Freeston, M.	2018	y	y	y	y	y	y	y
30	qual	5/5; 100%	Russell, A. Gaunt, D. Cooper, K. Horwood, J. Barton, S. Ensum, I. Ingham, B. Parr, J. Metcalfe, C. Rai, D. Kessler, D. Wiles, N.	2019	y	y	y	y	y	y	y
31	qual	5/5; 100%	Spain, D.: Rumball, F.: O'Neill, L.: Sin, J.: Prunty, J.: Happe, F.	2017	y	y	y	y	y	y	y
32	qual	5/5; 100%	Tint, A.: Weiss, J. A.	2018	y	y	y	y	y	y	y

33	mixed	13/15; 87%	Unigwe, S.: Buckley, C.: Crane, L.: Kenny, L.: Remington, A.: Pellicano, E. - not sure if quant aspects should be rated as survey or cross-sectional analytical (3/4) EC - I would have said survey… JB: agreed	2017	y	y	y	y	y	y	y					y	y	y	n	y	y	n	y	y	y
34	qual	5/5; 100%	Van Hees, V.: Moyson, T.: Roeyers, H.	2015	y	y	y	y	y	y	y														

Appendix 16

Primary participants' quotes illustrating analytic themes and subthemes of the meta-synthesis

Table 1, Appendix 16

Primary quotes illustrating analytic themes and subthemes

Themes and subthemes	Example quote
1. Lonely, difficult service experience	*See main text*
1.1 Barriers at every step	*'I cannot tell you how many intakes we went to and after maybe an hour or 2 hours or tons of paperwork, they would go, "Oh yeah. We do not have that expertise. We really cannot do the autism." And I was like could somebody have told me at that initial phone call you cannot do the autism? Because that was 3 hours of our life we are never going to get back. I cannot tell you how many of those intakes I walked away from in tears'* (Parent, F, US)[3]
Difficulties accessing support	*See main text*
Services being based around neurotypical norms	*See main text*
Clinicians' lack of awareness and stereotyped attitudes	*'They thought that I was stubborn and lazy and unwilling to help myself, and they let me know it. They ended up asking me not to come back, because my case was too "complex"'* (Autistic adult, F, UK)[18]
System/ organisational barriers	Financial barriers: *'The only therapy that has been paid for, not by me but by the system [is CBT] and that is absolute rubbish. It doesn't help me.'* (Autistic adult, UK)[14] Lack of training: *'Certainly in the department we all recognised that we really don't have an awful lot of training, and not a lot of training in adaptation for CBT working with this group'* (Therapist, UK)[2]
1.2 Negative consequences	*'They never told me 'you were wrong'. There were comments like, 'You just want to be special,' or not really knowing how to relate to the sensory things I tried to explain … It made me feel like I was either a freak or*

	making things up or it was all in my head.' (Autistic adult, F, UK)[10]
Iatrogenic harm and distrust in the service system	*See main text*
Tension in personal relationships	*'The support doesn't really meet my needs and so my mother has to do more for me and her health hasn't been too good really. So sometimes I try to suffer in silence so that I do not let her in my flat so [that] she cannot see what a mess I am in, and that I haven't food in to eat.'* (Autistic adult, M, UK)[6] *'It is difficult with engagement because sometimes the family want the person to come more than the person'* (Therapist, UK)[2]
Inappropriate use of medication	*'… my GP tries to keep throwing antidepressants at me but [I] think [I] just need to understand myself better [and] get other conditions diagnosed.'* (Autistic adult, UK)[5]
2. Complexity needs flexibility	*'I don't tend to find myself following a particular model because it's very rare that one will satisfactorily fit, so it's more idiosyncratic, and it will depend on the person's ability'* (Therapist, F, UK)[31]
2.1 Impact of being autistic on treatment	*'If there was someone who both understood the condition and me, I feel progress would be made.'* (Autistic adult, M, UK)[6]
Interaction between autism and mental health difficulties	*'Emphasis needs to be placed on figuring out which behaviours are anorexia based, and which are autism based. If someone is refusing to eat their dinner, it could be because their eating disorder is telling them that it will make them fat, or, the food could be touching, is an autistic sensory issue. The behaviours are exactly the same, but the causes can be so different. Knowing all of this, if doctors and therapists and dieticians can be flexible regarding autistic patients, they're going to see much better outcomes'* (Autistic adult, UK)[18]
Communication	*See main text*
Working with emotions	'*… [it's] just Asperger's with me […] - [I] learnt to hide my emotions and feelings to survive school and home without being hurt, so only [got] visibly upset in the last moment when [it became] unbearable. Because they cannot read my face [doesn't] mean [I'm] not having those emotions before …*' (Autistic adult, UK)[5]
Thinking styles	*"It can be really hard to shift, cognitive process issues, not being able to move from one topic to another"* (Therapist, UK)[9]

Sensory sensitivities	*'On the unit I found it extremely difficult to sleep, the buzzer on the door of the unit used to really irritate me and sounded really loud, but it didn't seem to affect anybody else. The beeping noise of the fire alarms will keep me awake at night. I found myself in a situation where every night I spent in hospital my sleep was broken. There is also a constant humming noise, that when I felt anxious it sounded louder than it did when I wasn't feeling so anxious, I think it might be the air-conditioning or the heating system, not too sure'* (Autistic adult, UK)[23]
Need for predictability	*'Set the expectations about what happens in therapy. You should just make those expectations clear from the beginning'* (Autistic adult, US)[22]
2.2 Need for a comprehensive and flexible approach	*'It can be anything and we try and be as flexible as we possibly can to give individuals that come through the door the opportunity to engage with what we're offering, so there are no strict and rigid rules and regulations. We're as flexible as we can be'* (Therapist, F, UK)[10]
Being bespoke and evidence-based	*'So, in a way, probably what we're talking about is a kind of tool-kit of interventions that can be customised to a particular patient, where the skill of the therapist, actually, is critical.'* (Therapist, M, UK)[31]
Adjusting timings and expectations for outcomes	Timing of sessions: *'NHS [National Health Service] counselling is good for people who can immediately connect to another person. If you have autism it takes time, and by the time you are starting to make some kind of connection you have run out of sessions.'*(Autistic adult, F, UK)[6]
Bridging formal and informal support	*'I think if we could allow [family] opportunities to come and have [support] skills topped up… and more family members trained in that kind of information. I think that is what would make the biggest difference to our service users'* (Therapist, UK)[2]
3. Collaboration and empowerment	*'But we have to try to find a way, a clinical bridge, you know, a way in to communicating with these clients, because, you know, they need our help and the onus is on us really to find a way of helping'* (Therapist, F, UK)[10]
Building therapeutics relationships	*'I could tell that she was clearly reading the notes and reflecting on the sessions and just, 'you said this,' or 'I know you talk about doing that'. She'd often ask me stuff that I'd said the week before . . . and that was really really lovely. It shows that she actually was quite interested and that we got on and I really, really appreciated that.'* (Autistic adult, UK)[30]

Listening to autistic voices	*'I have had my share of ineffectual medications and therapies, including ignorant psychiatrists and counsellors who made things worse rather than better because they seemed to decide what the problem was and what was best without actually listening to me. However, I have also had some very good counsellors and GPs who have listened, been good at talking to me in a way I can engage with, and worked with me rather than simply talking at me.'*(Autistic adult, M, UK)[6] *'I accept you for who you are and I'm going to try and understand where you're coming from and your experience to the best of my ability because it's your experience.'* (Therapist, F, US)[21]
Enabling independence, self-advocacy and self-care	*'My treatment has given me more compassion for myself as a human being'* (Autistic adult, M, UK)[6]

Note. First order quotes (participants' direct quotes) are presented to illustrate the analytic themes and subthemes of the thematic meta-synthesis. Details about the participant are provided, including participant group, gender (where available) and location, and study IDs are used to link them to the original paper (see Table 1).