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University of Southampton

Faculty of Environmental and Life Sciences

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An Exploration of Traumatic Life Experiences and Traumatic Sequelae in Autistic Individuals

by

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Thesis for the degree of Doctorate in Clinical Psychology

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University of Southampton

Abstract

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The first chapter of this thesis is a systematic review of the literature exploring the experiences that are perceived as traumatic, and the resulting trauma-related symptomology, in autistic individuals. The narrative and thematic synthesis suggested that autistic individuals report perceiving a similar range of experiences to be traumatic, and experience similar trauma-related symptomology to the general population. Several potentially unique traumatic events and trauma-related symptoms were found. Additionally, differences were implied in the way that trauma presents in autistic adults compared with autistic children and individuals with co-occurring Intellectual disabilities. High quality research is needed to enrich understanding of trauma in autistic individuals from first-hand perspectives. This chapter concludes with clinical implications and recommendations for future research.

The second chapter of this thesis is a qualitative empirical study exploring the experiences of autistic adults who have engaged in psychological support for trauma-related symptoms. Individual semi-structured interviews were completed with eight participants, aged 30-50 years old. Interview transcripts were analysed using Interpretative Phenomenological Analysis, identifying four themes: 'Accessing support that fits my needs', 'Recognising trauma in autistic adults', 'Clinician understanding of the context of autism' and 'Not just doing therapy at me but working with me to do therapy'. The findings provided insight into the barriers experienced by autistic adults in accessing appropriate trauma-focused psychological support, the importance of clinician authenticity, and meaningful adaptations to therapeutic mechanisms. This chapter concludes with directions for future research and clinical implications for psychological support providers and clinicians in meeting the needs of this population.

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Research Thesis: Declaration of Authorship

Print name: Charlotte Scrivens

Title of thesis: Exploring Traumatic Life Experiences and Traumatic Sequelae in Autistic Individuals

I declare that this thesis and the work presented in it are my own and has been generated by me as the result of my own original research.

I confirm that:

1. This work was done wholly or mainly while in candidature for a research degree at this University;
2. Where any part of this thesis has previously been submitted for a degree or any other qualification at this University or any other institution, this has been clearly stated;
3. Where I have consulted the published work of others, this is always clearly attributed;
4. Where I have quoted from the work of others, the source is always given. With the exception of such quotations, this thesis is entirely my own work;
5. I have acknowledged all main sources of help;
6. Where the thesis is based on work done by myself jointly with others, I have made clear exactly what was done by others and what I have contributed myself;
7. None of this work has been published before submission

Signature: Date:

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Chapter 1 Exploring Traumatic Life Events and Trauma-related Symptomology in Autistic Individuals: A Systematic Review of the Existing Literature

This paper has been prepared in the format required for the *Review Journal of Autism and Developmental Disorders*.

1.1 Abstract

Autistic individuals have an elevated risk of experiencing potentially traumatic events and developing trauma-related symptomology, yet knowledge about these experiences in autistic people is lacking. This article provides a systematic review and narrative synthesis of the literature describing traumatic experiences and trauma-related symptomology in autistic individuals, with and without co-occurring Intellectual disabilities (ID). Twenty-nine studies, consisting of varied designs and methodology, met eligibility criteria. The findings suggested that autistic individuals report finding a similar range of experiences traumatic, and experience similar trauma-related symptomology to the general population. Several potentially unique traumatic events and trauma-related symptoms were reported, including exacerbation of autism-related behaviours in autistic children and autistic adults with ID. Future qualitative exploration is warranted to develop a clearer picture of trauma and trauma-related symptoms in autistic people. High quality studies should explore mechanisms related to autism that may influence what experiences are perceived as traumatic and the resulting psychological sequelae. Implications for clinicians and researchers are discussed.

1.1.1 Keywords

Autism, trauma, Post-traumatic stress disorder, traumatic events, trauma symptoms

1.2 Introduction

Autism spectrum disorder (ASD)¹ is a neurodevelopmental condition characterised by difficulties in reciprocal social interaction, social communication and restricted and repetitive behaviours and interests (American Psychiatric Association, (APA) 2013). Autistic individuals are at an increased risk of experiencing mental health problems compared with the general population (Hollocks et al., 2019). Much of the literature has focused on the occurrence of depression and anxiety in autistic individuals, whilst trauma-related symptomology has been relatively neglected by research. This is surprising, as the literature suggests that autism increases the risk of experiencing potentially traumatic events (Haruvi-Lamdan et al., 2018; Kerns et al., 2015; Rumball et al., 2020) and subsequent consequences of exposure to trauma, including post-traumatic stress disorder (PTSD) (Fuld, 2018; Kerns et al., 2015; Rumball, 2019). These risks are proposed to be elevated further for the estimated 45% of autistic individuals with co-occurring Intellectual disabilities (ID) (Kerns et al., 2015; Lai et al., 2014; Peterson et al., 2019). PTSD is defined as a sequelae to experiencing potentially traumatic events (i.e. exposure to death, threatened death, actual or threatened serious injury, or actual or threatened sexual violence), characterised by altered arousal, re-experiencing of trauma, avoidance, negative changes in cognition and mood and an impact on social and/or occupational functioning (The Diagnostic and Statistical Manual of Mental Disorders (DSM-5), Criterion A; APA, 2013) (Appendix A). PTSD is the most common chronic stress disorder reported in the general population (Haruvi-Lamdan et al., 2020); estimated to occur at an increased rate in autistic individuals (Rumball et al., 2020). PTSD in autistic individuals has been associated with suicidal ideation and actions, deficits in adaptive functioning and a reduced quality of life (Fuld, 2018; Kerns et al., 2015; Rumball, 2019; Storch et al., 2013). Therefore, a clear picture of the current evidence base and directions for future research is warranted.

¹ The author uses identity-first language purposefully from this point forward. Identity first language does not separate their experience of autism from who they are. Identity-first language is an accepted convention in the autistic community.

It is acknowledged that the DSM-5 comes from a medical, realist ontological stance, whilst this review is interested in the lived experiences of autistic individuals and thus, embodies a subjective, constructionist approach. However, clinicians frequently refer to the DSM-5 framework in making sense of trauma presentations. There are also doubts regarding the way that the clinical world perceives traumatised autistic individuals (Frueh et al., 2006). Therefore, this review attempts to merge the information about the causes and nature of trauma in autistic people following the DSM-5 criteria (Appendix A), a framework familiar to clinicians, with autistic peoples lived experiences of trauma. The knowledge gleaned from this endeavour may help clinicians to formulate when presented with this population, facilitating autistic individuals to access appropriate trauma-focused support.

Traumatic events in autistic people have been explored by several studies in recent years, with the majority employing small samples or individual cases. Difficulties associated with the core elements of autism may increase susceptibility to exposure to potentially traumatic events (Haruvi-Lamdan et al., 2018; Kerns et al., 2015; Rumball et al., 2020). Predisposing factors have been suggested relating to the unique characteristics of sensation, perception, social awareness, cognition, and global understanding associated with autism (Lai et al., 2014). In autistic children, several factors have been proposed to increase susceptibility to experiencing trauma and exacerbated emotional reactions to traumatic events, including social isolation, peer rejection, difficulties adopting socially appropriate behaviours, poor support network, emotional dysregulation and communication difficulties (Carter, 2009; Estell et al., 2009; Kerns et al., 2015; Rotheram-Fuller et al., 2010; Rowley et al., 2012).

Research has implied that autistic individuals may be at greater risk of perceiving experiences as traumatic outside of those defined as 'Criterion A events' (APA, 2013). Studies have proposed that this may be due to autism-related heightened stress reactivity and altered perceptual experiences (Brewin et al., 2019; Haruvi-Lamdan et al., 2018). The incidence of bullying and social victimisation in autistic individuals has received considerable attention, with the literature suggesting an increased occurrence of these experiences and a greater likelihood of such events being perceived as traumatic, compared to the general population (Hoover, 2015; Maiano et al., 2016). Rumball et al., (2020) also identified a broad range of traumas as catalysts for self-reported PTSD symptoms in a sample of autistic adults. In this sample, the most prevalent DSM-5 traumas were sexual and physical abuse, whereas bullying, bereavement, and mental health 'breakdowns' were the most frequently reported non-DSM-5 traumas (Rumball et al., 2020). Currently, research investigating the prevalence of other

traumatic experiences in autistic individuals is in its infancy. Consequently, the similarities and differences between the events that are experienced as traumatic by autistic adults and autistic children, with and without co-occurring ID, are unclear.

Case reports and qualitative studies have documented descriptions of trauma-related symptoms in autistic individuals, mainly from the clinician perspective. Quantitative studies have also investigated the relationships between potentially traumatic events and trauma-related symptomology in this population. Increases in behaviours associated with autism following the incidence of trauma have been reported in both, autistic adults with ID, and autistic children (Kildahl et al., 2020; Mehtar & Mukaddes, 2011). Additionally, there is emerging evidence reporting that, for autistic individuals with severe ID, PTSD may manifest as behavioural re-enactments of the trauma and increased agitation, in line with trauma-related symptom presentation in typically developing (TD) youth (McCarthy et al., 2017; Mevissen, et al., 2016). Furthermore, studies have proposed that autistic people may express symptoms of psychological distress in idiosyncratic ways, however, little is known regarding trauma-related symptom presentation (Kildahl et al., 2020).

This review aimed to explore the existing research into the types of events causing trauma and trauma-related symptomology in autistic people, to determine the current state of the evidence base, identify limitations and gaps in the literature, and propose recommendations regarding future research. Given the scarcity of studies exploring traumatic events and the resulting psychological sequelae in autistic individuals, studies of all designs featuring reports of individuals across the lifespan were considered relevant. As research has suggested that a broader range of experiences may be perceived as traumatic by autistic individuals (Brewin et al., 2019; Haruvi-Lamdan et al. 2018; Kerns et al., 2015), this review sought to include studies reporting diverse traumatic events and symptoms. This review addresses the questions: What life experiences are reported to be traumatising and result in trauma symptoms in autistic individuals? How do traumatic sequelae manifest in autistic individuals? Are there differences between the experiences of trauma and trauma-related symptomology experienced by autistic children and adults, with and without co-occurring ID?

1.3 Methodology

The protocol for this review was registered on the PROSPERO register of systematic reviews (registration CRD42021218863).

1.3.1 Search strategy

The conduct and reporting of this review adhered to the general principles recommended by The Centre for Reviews and Dissemination (CRD, 2009). A systematic search of the literature was conducted on 26th November 2020. The search was rerun on 28th January 2021, prior to analysis, to ensure the systematic review reflected all available literature. After several scoping searches four electronic bibliographic databases were searched for relevant published and unpublished literature, from 1980 (the year PTSD formally entered the DSM-III; APA, 1980) until November 2020. These databases were PsychINFO via EBSCO, MEDLINE via EBSCO, Education Resources Information Center (ERIC) and Web of Science (core collection). The two databases hosted by EBSCO were searched using a 'title' and 'abstract' search. The Web of Science and ERIC databases were searched using a 'topic' search.

The importance of including Grey literature in a systematic review search strategy has been acknowledged (Paez, 2017). Three grey literature databases were searched: PubMed, OpenGrey and The British Library. PubMed was searched using the search terms in a 'title' and 'abstract' search. OpenGrey and The British Library were searched using the key words 'autism', 'PTSD' and 'traumatic experiences'. All searches were restricted to studies dated from 1980-2020. No language restrictions were imposed, and the bibliographic software RAYYAN (Ouzzani, 2016) was used to store and manage the results of this search.

1.3.2 Search terms

Searches were devised in collaboration with a librarian. The search terms were developed from three key words relevant to the systematic review questions, formulated using the SPIDER tool (Cooke et al., 2012). The SPIDER tool was utilised as this has been suggested to be an appropriate framework for systematic narrative reviews of qualitative literature (Methley et al., 2014). Table 1 depicts how the search terms were prepared for use on PsycINFO/MEDLINE.

Table 1. Search terms for PsycINFO/MEDLINE

SPIDER tool	Key words	
Sample	Autism	Autis* OR ASD OR Asperger* OR "Autism Spectrum Disorders" OR
Phenomenon of interest	PTSD	PTSD OR "post traumatic stress disorder*" OR "Posttraumatic Stress Disorder" OR "Complex PTSD" OR DESNOS
Design and research type/ evaluation	Traumatic experiences	(traum* OR abus*) Near/2 (symptom* OR experienc*) OR event*)

1.3.3 Inclusion and exclusion criteria

This systematic review aimed to explore the life experiences of autistic individuals in terms of traumatic events and trauma sequelae, thus, the inclusion criteria reflected the key words identified by the SPIDER tool. To ensure included studies were relevant to the aim of the systematic review, factors for exclusion were also considered. Table 2 illustrates the generated eligibility criteria.

Table 2. Eligibility criteria for the systematic review

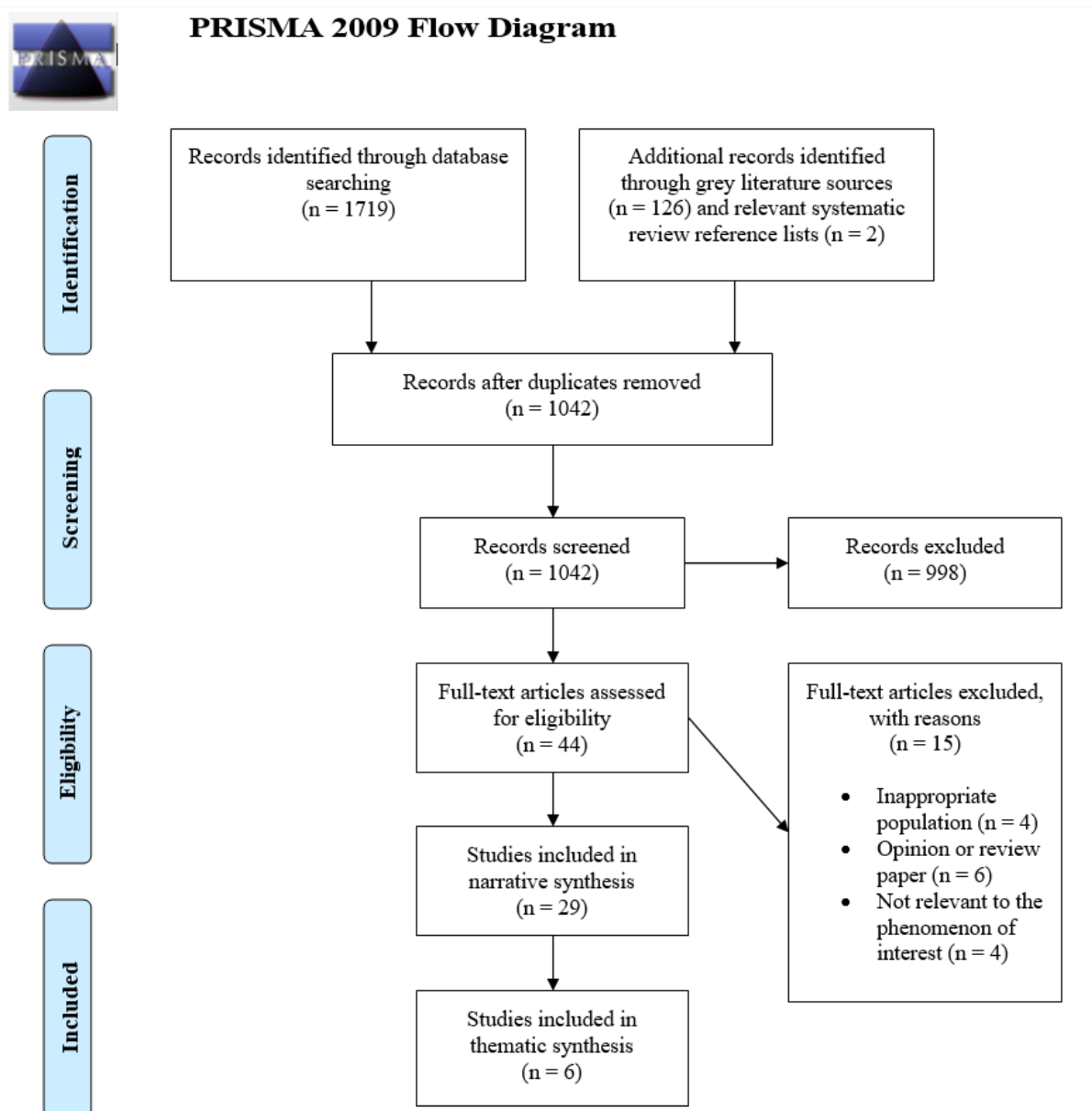
Inclusion criteria	Exclusion criteria
---------------------------	---------------------------

-
- Formal diagnosis of ASD
 - Participants of any age
 - Study features discussion of PTSD/trauma events or PTSD/trauma presentation/symptomology
 - Case and group level studies
 - Qualitative or quantitative accounts of PTSD/trauma events or PTSD/trauma presentation/symptomology from autistic individuals or therapists/professionals and quantitative outcomes of measures of PTSD/trauma symptomology
 - Papers dated from 1980-2020
 - Published and grey literature
 - Papers containing original data
 - Study not focused on autistic individuals
 - Diagnosis of ASD is unclear or not confirmed by a trained clinician
 - Study not focused on PTSD/traumatic experiences
 - Study focused on future experiences
 - Secondary data reviews
 - Audio files, books, and conference proceedings
 - No English version available.
 - Opinion only paper
 - Paper dated prior to 1980.
-

1.3.4 Data selection

Figure 1. presents the full data selection process using a Preferred Reporting Items for Systematic Reviews and Meta-Analyses flow diagram (PRISMA; Moher et al., 2009).

Figure 1. PRISMA diagram for the current review



Initial electronic and hand searches were conducted and identified 1719 citations sourced from the databases: PsychINFO (n = 486), MEDLINE (n = 463), ERIC (n = 44) and Web of Science (n = 726). Searches of grey literature sources resulted in an additional 126 citations: PubMed (n = 2), OpenGrey (n = 98), and The British Library (n = 26). The reference lists of included full-text studies and relevant systematic reviews were examined for additional relevant literature. This resulted in the identification of two eligible full-text studies. Once duplicates were removed (n = 807) 1,042 unique citations

remained to be screened for inclusion by two reviewers (Figure 1). The titles and abstracts were assessed for their relevance to the review (stage 1 screening). A total of 998 data items were excluded resulting in forty-four potential titles being retained. The full texts of the remaining forty-four titles were obtained. The relevance of each of the studies was assessed according to the inclusion criteria (table 2). After applying inclusion criteria to the forty-four full-text papers (stage 2 selection), fifteen citations were excluded. Of these studies, grounds for exclusion included failing to report on the correct population, irrelevance to the phenomenon of interest and review or opinion papers (figure 1).

Twenty nine full-text papers were found to meet the inclusion criteria for the review. Two reviewers independently screened all the titles, abstracts, and full-text papers to ensure consistency with the exclusion criteria. Any discrepancies were discussed and resolved by consensus. In cases where consensus could not be agreed ($n = 2$), a third reviewer determined if the data item should be included.

1.3.5 Quality assessment

The quality of the included articles was critically appraised using either the Critical Appraisal Skills Programme Qualitative Checklist (CASP, 2018) (Appendix D), a modified version of the Checklist for Case Reports (The Joanna Briggs Institute, JBI, 2016) (Appendix E) or an adapted quality assessment tool, the Effective Public Health Practice Project quality assessment tool for quantitative studies (EPHPP; Thomas et al., 1999) (Appendix F), depending on study design. Several items from the EPHPP were omitted as they were not relevant to the current review questions. Two additional questions were added to the JBI to assess suitability for Thematic Analysis (TA) (Appendix E). A priori decision was made that studies would not be excluded from the review based on the outcomes of quality assessment, as there is currently little evidence to support excluding studies from qualitative systematic reviews based on their quality (Thomas & Harden, 2008).

1.3.6 Data extraction

Data relating to the study characteristics, (e.g. sample size, demographics, IQ, ASD diagnosis, and comorbidities), design, included measures and quality were extracted from the studies (Appendices A and B), alongside data pertaining to traumatic events (table 3), and trauma-related symptomology in autistic individuals (table 4). Extraction of data was completed by copying the relevant text from the

articles and pasting this into a data extraction document created on Microsoft Excel. When copying and pasting extracted data was not possible, data was entered manually into the Excel spreadsheet.

1.3.7 Data synthesis

The data extracted from the included studies was summarised using the descriptive and exploratory narrative synthesis approach. Narrative synthesis is suggested to be well suited to making sense of diverse studies featuring a range of research methods (Pino & Mortari 2014), thus, was appropriate for this review due to heterogeneity in the study designs. Relevant literature was collated by the review author and critically appraised, summarised and triangulated regarding the specific review questions (Petticrew & Roberts 2006). The aim of narrative synthesis is to enhance a body of knowledge rather than simply summarising research findings (Rodgers et al., 2009). Originally, it was intended to subject findings of this review to TA to determine recurring themes. However, this was only possible for the qualitative Interpretative Phenomenological Analysis (IPA) studies and three case reports as data richness was lacking in the remaining studies. For the six studies, the six steps of TA (Braun & Clarke, 2006) were employed: (1) extracted data were read repeatedly, (2) relevant units of meaning were identified, (3) all units were given descriptive codes, (4) codes were collated into themes, (5) themes were grouped under main themes, (6) themes were summarised descriptively under the thematic headings using narrative synthesis.

1.4 Results

1.4.1 Characteristics of included studies

Each study was assigned a unique reference number (tables 3 and 4) and will be referred to by this number hereafter.

1.4.2 Qualitative studies

Three IPA papers (1, 2, 3) reported descriptions of traumatic events and trauma symptomology in autistic individuals by a total sample of twenty-three clinicians. Papers one and two (N = 18 clinician's) reported on the same data set. Paper three stated information about an autistic individual (male, late twenties) with mild ID, and studies one and two reported on individuals with mild, moderate, severe

and profound ID. All three papers reported information about adults and were conducted in Norway. Studies one and two featured informants from six hospitals in Norway who were employed in inpatient or outpatient mental health units supporting people with autism and ID. Paper three featured informants employed at a specialised psychiatric ward. For a full summary of demographic characteristics, see Appendix B.

1.4.3 Case studies

Twelve papers reported case studies outlining traumatic events and trauma symptomology in autistic individuals (four females; eight males). The autistic individuals were aged between 5 and 'late 30's', with four papers reporting on adults (4, 11, 13, 15) and eight on children (5, 6, 7, 8, 9, 10, 12, 14). Seven papers referred to autistic individuals without co-occurring ID, one paper reported on an autistic individual with 'borderline' ID, and two papers reported on autistic people with mild ID. Two papers did not include information about intellectual functioning of the individual. All but one case (15), had been referred to clinical services for specialist assessment and/or treatment. The studies were conducted in a range of countries (United Kingdom (UK) (n = 4), United States of America (USA) (n = 4), Canada (n = 2), Turkey (n = 1) and Germany (n = 1)) between 1993-2020. For a full summary of demographic characteristics, see Appendix B.

1.4.4 Group studies

A range of trauma measures were used across the studies (see appendix C). Nine studies reported on traumatic events (17, 18, 19, 22, 23, 25, 26, 27, 28) and thirteen studies reported on trauma-related symptomology (16, 17, 18, 19, 20, 21, 22, 24, 25, 26, 27, 28, 29), using questionnaires (n = 10), interviews (n = 1), online surveys (n = 1) and collation of existing medical records (n = 1). The studies employed diverse designs, including case-control (n = 6), cohort (n = 3), cross-sectional, within groups (n = 2), interview (n = 1) and one-time survey (n = 2). Of these studies, six were designed to assess correlations between potentially traumatic life events and trauma-related symptoms in a purely autistic sample. Three studies compared traumatised vs non-traumatised autistic individuals, four compared autistic people and TD peers, and one compared association between brain function and childhood experiences in autistic and TD adults. A total of 2225 cases were reported across the fourteen included papers. Sample size varied from 12-1166, with a median of 30.5. The majority of

studies recruited children (n = 8), with only six studies including adults. Thirteen of the papers reported the gender of their samples, all of which consisted of both males and females. The highest proportion of females recruited was 61.9% (22). Studies were conducted in England (n = 1), France (n = 1), Italy (n = 1), Israel (n = 1), Japan (n = 1), The Netherlands (n = 1), Turkey (n = 1), and the USA (n = 1). Nine studies reported on autistic individuals without co-occurring ID. One study (24) reported on individuals with a broad range of intellectual functioning (mild ID (7.2%), moderate ID (39.1%) and severe ID (26.1%)). Six studies reported on individuals with co-occurring ID but did not state the level of intellectual functioning, and five studies did not comment on the intellectual functioning of reported cases. For a full summary of demographic characteristics, see Appendix C.

1.4.5 Quality assessment and risk of bias

Risk of bias in individual studies was assessed systematically, prior to data extraction. The included studies had heterogeneous designs; most had small samples and the majority did not include a comparison group. Over half of the studies reviewed were case reports or qualitative studies, thus, were inherently limited in their ability to produce generalisable findings relevant to other autistic individuals. Despite this, numerous studies presented detailed descriptions of trauma presentation in autistic individuals, relevant to the review questions. The methodological quality of the case reports and qualitative studies is detailed in Appendices D and E. As expected, case reports varied in quality according to the JBI. Data richness was lacking in several of the case reports, thus, two additional questions (3a and 4a, appendix E) were added to the JBI to assist in determining whether individual studies were suitable for thematic analysis. Studies that met the standard for both additional questions were included in the qualitative synthesis. Although the CASP does not offer scoring criteria for the overall assessment of the quality of a study, the included qualitative studies (1, 2, 3) met the standards of every question on the CASP, reflecting an overall high level of quality.

The EPHPP was employed to assess the risk of bias in selection, study design, blinding and data collection across the fourteen quantitative studies. Details of individual study ratings are presented in Appendix F. Overall, the EPHPP indicated a 'moderate' global rating for one study (26) and 'weak' global ratings for the remaining 13 studies. Only one study (28) was scored as 'strong' regarding selection bias, recruiting from a wide variety of sources and individuals across the autistic spectrum. Three studies received a 'weak' rating for selection bias (19, 20, 27), suggesting limits to the

generalisability of their findings beyond specific groups. As these samples were self-selecting, they likely represent autistic individuals who are motivated to participate in research and may have an agenda for doing so, for instance, opting to participate in a study about Applied Behavioural Analysis (ABA) due to a desire to express the issues they perceive with ABA interventions. Similarly, samples selected via clinic settings represent individuals who are specifically seeking treatment and may differ from other traumatised autistic people.

There was large heterogeneity within the quantitative study designs. None of the studies adopted a 'gold standard' randomised control trial design, however, this was anticipated as it is not possible to randomise people to trauma or autism groups. Numerous studies employed case-control and cohort study designs. Although a lack of randomisation may lead to bias when forming conclusions about the treatment within the cohort studies, this review did not focus on this data, and was interested specifically in the information pertaining to traumatic events and trauma-related symptomology. None of the studies stated whether participants were blinded to the purpose of the research. Although it is useful for participants to be blind to the purpose of the study, there are ethical issues regarding withholding information from autistic individuals. Research has suggested that honesty and transparency may be particularly important due to the difficulties autistic people experience in reading the intentions of other people (Fletcher-Watson et al., 2021). In terms of data collection, Cronbach's alpha of between 0.79-0.94 were reported in studies that measured trauma using questionnaire measures (19, 22, 26). Seven other studies also utilised questionnaire measures of trauma but did not report details of the reliability or validity of the measures. Notably, none of the studies employed measures of trauma that have been validated for use with autistic individuals.

Despite all except one quantitative study receiving a 'weak' quality rating, all the group studies were included in this review due to the inherent difficulties in doing research with this population leading to an absence of high quality studies reporting on traumatic events and/or traumatic symptomology (Helverschou et al., 2011). It is not possible to systematically review the main source of bias identified (i.e. the risk of studies not reporting all details of the traumatic events and/or trauma-related symptoms present). Many of the studies reported traumatic events and trauma-related symptomology using the DSM-5 framework (Appendix A). Therefore, less typical traumatic events and trauma-related symptoms are unlikely to have been reported. Potential issues of publication bias are also relevant. It is acknowledged that published case reports tend to report unusual cases, thus, this

may bias the current review findings of atypical descriptions. Regarding the quantitative studies, bias towards the publication of significant results is well documented (Mlinarić et al., 2017). Therefore, this review may have missed studies that did not find differences between autistic and NT populations, or research that did not report any significant correlations with trauma.

1.4.6 Narrative synthesis

1.4.6.1 Traumatic life experiences reported by autistic individuals

The traumatic experiences of the samples were reported in all twenty-nine papers that met eligibility criteria for the review. The traumatic life experiences of autistic individuals reported across the literature to date are presented in Table 3; events have been organised according to DSM-5 traumatic events (Appendix A) and other traumatic events.

1.4.6.1.1 DSM-5 Criterion A traumatic events

A range of traumatic events were reported by autistic individuals, clinicians, and parents of autistic children within the studies, including witnessing and experiencing all forms of abuse. The most common traumatic events were experiencing physical abuse (reported in 19 studies), and sexual abuse/assault, (reported in 16 studies). A range of DSM-5 traumatic events were reported including earthquakes, fires, witnessing domestic violence, aversive medical procedures, witnessing harm to others and suicide or attempted suicide of a family member (table 3). The least commonly reported events were war and bombings, and traffic accidents, cited in one (1,2) and two studies (9, 18), respectively. None of the studies reported experiences of repeated or extreme exposure to aversive details of traumatic events (in person or through work related electronic media); corresponding to DSM-5, Criterion A.4. There were no differences evident between the DSM-5 traumatic experiences reported by studies of children, and reports on adults. In consideration of disparities between the experiences reported by autistic individuals with and without ID, 81% of the studies reporting on autistic individuals with ID reported sexual abuse, compared with 55% of studies on autistic individuals without ID. However, this finding is tentative due to unclear and omitted details of sample intellectual functioning in numerous studies.

1.4.6.1.2 Other traumatic events experienced by autistic individuals

Seventeen of the studies highlighted traumatic events that are less commonly reported in the general population and not reflected in DSM-5 criterion A. Bullying and social victimisation (including stigmatization, rejection and ostracism) were the most prevalent, reported in thirteen studies. Study 17 suggested bullying and social victimisation to be widespread in their sample of autistic adults (with no intellectual impairment), with 60% reporting a negative social event as causing them the most distress of the traumatic events they discussed. In this study, exposure to negative social events was related to the incidence of PTSD. Five studies commented on the incidence of institutional abuse experienced at school (1, 2, 5, 20, 27), with study 20 documenting the emotional and behavioural impact of prolonged institutional abuse in a sample of autistic youth. Prolonged and multiple traumas relating to emotional abuse and neglect were also prevalent (1, 2, 6, 7, 8, 10, 13, 14, 16, 18, 20, 23, 26), with 33% (n = 13) of children in study 26 and 12% (n = 11) of children in study 16 experiencing emotional abuse. Study 21 suggested a novel traumatic event in their investigation of the relationship between experiences of ABA interventions and trauma-related symptomology. Their findings indicated that 46% of the 460 ABA-exposed individuals met the DSM-5 diagnostic threshold for PTSD and were 86% more likely to meet PTSD criteria compared to autistic individuals who had not experienced ABA. Similarly, autistic adult respondents of a one-time survey (27) reported potentially unique traumatic events including a visit from a police officer, social difficulties, abandonment by mother/wife, psychological therapy and the ASD diagnostic process. Other distinctive traumatic events cited in the literature included the death of a pet, repeated physical coercion (inappropriate management of challenging behaviour), historical isolation, insufficient adaptation of the environment to autism challenges, and a sibling moving away from home.

Table 3. Trauma experiences reported in included studies

Number of study	First author (year)	Trauma types (DSM criterion A)	Trauma types (not easily classified by DSM criteria)
1	Kildahl, Helverschou, Bakken & Oddli (2020)	Sexual abuse (n = 15), violence (n = 14), rape (n = 4), death threats (n = 1), war and bombings (n = 2), witnessing violence (n = 1)	Severe bullying (n = 3), institutional abuse (n = 2), neglect (n = 7)
2	Kildahl, Helverschou, Bakken & Oddli(2020)	Sexual abuse (n = 15), violence (n = 14), rape (n = 4), death threats (n = 1), war and bombings (n = 2), witnessing violence (n = 1)	Severe bullying (n = 3), institutional abuse (n = 2), neglect (n = 7) sister moving away from home (n = 1), guinea pig dying (n = 1), inappropriate management of challenging behaviour (repeated physical coercion), surroundings not sufficiently adapted to autism challenges
3	Kildahl, Helverschou & Oddli (2020)	Sexual coercion by peer who also had ID	-
4	Carrigan & Allez (2017)	Violent sexual assault	-
5	Cook et al. (1993)	Physical abuse from school staff, witnessing physical abuse of peers at school	-
6	Fazel et al. (2020)	Physical and sexual abuse	Bullying and other peer related difficulties, historic experiences at school, emotional abuse and neglect
7	Gerhardt & Smith (2020)	Physical and verbal abuse, witnessing domestic violence	Neglect by biological mother

Number of study	First author (year)	Trauma types (DSM criterion A)	Trauma types (not easily classified by DSM criteria)
8	Guest & Ohrt (2018)	Physical abuse from birth, domestic violence from mother's boyfriends, witnessing physical abuse of siblings	Witnessing drug abuse at home, extreme parental neglect
9	Ipci et al. (2017)	Traffic accident, witnessing serious injury to grandmother	-
10	King & Desaulnier (2011)	Physical and sexual assault by peers at summer camp	Emotional abuse by peers at summer camp
11	Kosatka & Ona (2014)	Physical abuse by peers at school	-
12	Reese & Deutsch (2020)	Acute sexual assault	-
13	Robinson (2018)	-	Historic isolation, stigmatization, rejection, chronic bullying
14	Trelles Thorne et al. (2015)	Physical abuse, exposure to domestic violence	Early maternal neglect, emotional abuse
15	Weiss & Lunskey (2010)	Several sexual assaults during adolescence and adulthood	-
16	Brenner et al. (2018)	Physical abuse (13%), sexual abuse (8%), both sexual and emotional abuse (1%), both physical and sexual abuse (1%), both physical and emotional abuse (16%)	Emotional abuse (12%)
17	Haruvi-Lamdan et al. (2020)	Physical violence	Negative social events (e.g. bullying, ostracism) (most distressing event for 60% of sample), verbal violence

Number of study	First author (year)	Trauma types (DSM criterion A)	Trauma types (not easily classified by DSM criteria)
18	Hoch & Youssef (2020)	Domestic violence, physical abuse, sexual assault, death, other accident, car accident, physical illness, community violence, fire, natural disaster, medical	Emotional abuse, physical neglect
19	Hoover & Romero (2019)	Physical bullying	Verbal bullying and teasing, victimization
20	Howlin & Clements (1995)	Physical abuse	Emotional abuse, neglect, verbal abuse, exposed to punitive, negative, and abusive regime at school
21	Kupferstein (2018)	-	Exposure to Applied Behaviour Analysis intervention
22	Lobregt-van Buuren et al. (2019)	Physical abuse by parents (n = 3), witnessing violence between parents (n = 2), sexual assault by father (n = 1), sexual abuse by sister (n = 2), unexpected death of close relative (n = 3), suicide attempt by parent (n = 2), suicide attempt as child (n = 1), assault/rape (n = 2), adverse treatments in hospital during childhood (n = 1)	Bullied at school/work (n = 11), emotional mismatch parents and child (n = 4), adultery (mother) (n = 1), experiencing crime (n = 2), jarring divorce parents/ partner (n = 2)
23	McDonnell et al. (2019)	All forms of abuse	Physical neglect
24	Mehtar & Mukaddes (2011)	Witnessing or victim of an accident or disaster (n= 9), witnessing or victim of violence, physical or sexual abuse (n = 9), multiple traumas (n = 3)	-

Number of study	First author (year)	Trauma types (DSM criterion A)	Trauma types (not easily classified by DSM criteria)
25	Okazaki et al. (2020)	Sexual abuse	-
26	Paul et al. (2018)	Robbery (10.3%), personal theft (23.1%), assault with weapon (23.1%), assault without weapon (56.4%), attempted assault (38.5%), bias attack (30.8%), physical abuse by caregiver (7.7%), gang or group assault (10.3%), peer or sibling assault (66.7%), nonsexual genital assault (5.1%), dating violence (2.6%), sexual assault by known adult (2.6%), flashing/sexual exposure (2.6%), witness to domestic violence (2.6%), witness to parent assault of sibling (5.1%), witness to assault with weapon (12.8%), witness to assault without weapon (28.2%), burglary of family household (15.4%), murder of family member or friend (5.1%)	Vandalism (25.6%), psychological/emotional abuse (33.3%), neglect (2.6%), bullying (46.2%), emotional bullying (59%), verbal sexual harassment (7.7%)
27	Rumball et al. (2020)	Injury of family member (n = 1), own violence to others (n = 1), own illness (n = 2), sexual abuse (n = 11), suicide attempt (n = 1), threat to life from other individual (n = 3), learning of /witnessing sexual abuse of another individual (n = 1), serious injury to another individual (n = 3), suicide attempt of close friend/family member (n = 2), sudden death of close friend/family member (n = 2), abduction (n = 1), serious injury (n = 1), physical abuse (n = 8)	Police visit to house (n = 1), social difficulties (n = 3), death of pet (n = 1), abandonment mother/wife (n = 3), psychological therapy (n = 1), bullying (n = 6), bereavement (n = 5), parents divorce (n = 1), ASD diagnostic process (n = 1), vomiting (n = 1), own mental health (n = 5), mental health family (n = 1), boarding school (n = 1)
28	Taylor & Gotham (2016)	Death of someone close due to serious accident, injury, or illness (n = 5), serious accident, injury, or illness of someone close that was life threatening or caused long-term disability (n = 5), serious accident, injury, or life-threatening illness of close other (n = 1), family member	Parental divorce or separation (n = 3), someone at home not having a job for a long time when he/she wanted to be working (n = 1), bullied by his/her peers to such an extent

Number of study	First author (year)	Trauma types (DSM criterion A)	Trauma types (not easily classified by DSM criteria)
29	Valenti et al. (2012)	being sexually, physically, or emotionally abused (n = 3), family being in a major fire, flood, earthquake, or other natural disaster (n = 2), substance abuse of someone in the home (n = 2), assault or mugging of someone in the home (n = 2), loss of home because of a natural disaster (n = 2), time spent living in an orphanage, foster home, or group home (n = 1), close other shot or threatened with another weapon (n = 1), suicide of close other (n = 1), suicide of someone in the home (n = 2), witnessing someone in the home being sexually, physically, or emotionally abused (n = 2) Earthquake	that he/she had to go to the doctor or considered changing schools (n = 5), someone in the home being sent away or kicked out of the house because he/she did something wrong (n = 3) , forced to live apart from one or both parents (n = 4) -

Key: - = not reported in study

1.4.6.2 Trauma-related symptoms reported by autistic individuals

Twenty-one papers (all qualitative studies, ten case studies and eight group studies) were eligible for inclusion in the trauma-related symptomology synthesis. Data extracted from individual studies are illustrated in table 4; symptoms have been organised according to DSM-5 symptom groups (Appendix A) and symptoms not easily classified by the DSM-5.

1.4.6.2.1 DSM-5 Trauma-related symptomology in autistic individuals

Diverse trauma-related symptoms were reported across the studies, fitting with the DSM-5 criteria (Appendix A). Fourteen studies reported DSM criterion (B) Re-experiencing symptoms. Re-experiencing was described as co-occurring abrupt changes to alertness and responsiveness (1, 2), verbal and behavioral reenactment (1, 2, 4), anxiety and agitation in response to symbolic events (5, 14, 20), nightmares (4, 7, 8, 14), flashbacks (4, 5, 6, 8, 16, 26) and intrusive thoughts (15). Several studies provided qualitative descriptions such as ‘watching a video’ (4) and ‘intrusive recollections of the events, “as clear as when it happened”’ (15). Only seven studies described DSM criterion (C) Avoidance symptoms (1, 3, 4, 5, 10, 11, 20, 26). Avoidance was expressed as avoidance of people or places associated with the traumatic event (1, 4, 11, 26, 20), distress and attempted escape when coming in to contact with a reminder of the event (11) and global avoidance (1, 3, 4). Fourteen studies reported DSM criterion (D) Negativism symptoms. Of these studies, the most prevalent symptoms mentioned were sadness (1, 3, 7, 11, 14, 16, 20, 26), guilt and shame (1, 3, 4, 28). DSM Criterion (E) Arousal symptoms were the most frequently discussed, reported in eighteen studies. Arousal symptoms were conceptualised as hypervigilance (2, 3, 4, 5, 8, 9, 11, 26), anger and aggression (1, 3, 4, 5, 6, 8, 9, 10, 14, 20, 23, 24), tension and alertness (1, 2, 3, 4, 26), irritability (1, 3, 4, 14, 16, 26), restlessness (1, 24), attentional changes (4, 7, 23, 24, 26), self-injurious behaviours (1, 14, 20), and sleep disturbances (1, 3, 4, 5, 10, 11, 14, 20, 24, 26). There were no notable differences in these symptom groups between studies reporting on children and studies of adults, with and without co-occurring ID. Study 17 administered questionnaires investigating potentially traumatic events and PTSD symptoms relating to participants’ most distressing event. The results demonstrated higher PTSD rates, re-experiencing, and psychological arousal (female only) for the autistic adults compared with a TD group.

1.4.6.2.2 Other trauma-related symptomology in autistic individuals

Fifteen of the studies reported trauma-related symptoms that are not easily classified by the DSM-5 criteria. A number of symptoms were reported specifically in relation to children and adults with ID. Exacerbation of behaviours associated with autism was prevalent following traumatic experiences, cited in six studies. Studies reported increases in stereotypic movements (odd posturing, rocking, and motor mannerisms) (2, 5, 10, 24) and deterioration in speech and nonverbal communication (2, 10, 24, 29). Functional skills were also reported to be affected in autistic children, including loss of daily living skills (29), difficulties in social relationships (7, 20, 24), increased focus on restricted or intense interests (24), and increased ritualistic behaviours (24).

Alongside specific interactions with autism, somatic complaints such as generalised pain, stomach aches, lethargy and headaches were also discussed (16, 2, 26). Less common symptoms included selective mutism (9), tics (8), eating disorders (26), significant weight loss (5), psychotic symptoms (6, 10), and sudden aggression or self-injury (1, 2, 6). Unusual sexual preoccupations were also mentioned following the incidence of sexual abuse (3).

The studies reporting on autistic children highlighted developmental regression following traumatic experiences. This included fear of the dark, changes in voice, enuresis, resumption of thumb sucking and parental separation anxiety (5, 9, 14, 26). None of the studies reporting on autistic adults (without co-occurring ID) included descriptions of trauma-related symptoms that were not easily classified by the DSM-5. In a neurological study (25), the associations between childhood experiences and event-related potential components during the auditory odd-ball task were investigated. Findings indicated that in autistic adults the higher the severity of sexual abuse, the larger the amplitude of P300 at Fz, Cz, C3, and C4. This effect was not evident at Fz and C4 for the TD group, suggesting differences in the impact of sexual abuse on brain function between autistic and TD adults.

Table 4. Trauma-related symptomology reported in included studies

Number of study	First author (year)	DSM criterion (B) Re-experiencing	DSM criterion (C) Avoidance	DSM criterion (D) Negativism	DSM criterion (E) Arousal	Not easily classified
1	Kildahl, Helverschou, Bakken & Oddli (2020)	Co-occurring abrupt changes to alertness and responsivity, verbal and behavioral reenactment	Specific avoidance of trauma triggers,unspecific or global avoidance, lack of planned avoidance	Fundamental insecurity in other people, sadness and hopelessness, guilt and shame, loss of positive feelings and vitality, negative self-image	Irritability and anger, tension, difficulties relaxing, reduced tolerance for discomfort and frustration, visibly alert, tense and anxious, restless and unable to calm down, sleep disturbances, reactive aggressive and self-injurious behaviors	Sudden, unexpected episodes of aggression or self-injury
2	Kildahl, Helverschou,	-	-	-	Visibly alert, tense and anxious	Sudden, unexpected episodes of

	Bakken & Oddli (2020)					aggression or self-injury, exacerbated autism symptoms, exacerbated symptoms of co-occurring conditions, somatic complaints and pain
3	Kildahl, Helverschou, & Oddli (2020)	-	Withdrawal	Feelings of guilt and shame, flat mood, communications of distress	Irritability, guarded and anxious, disproportionate and unpredictable reactions leading to angry outbursts	Unusual sexual preoccupations interpersonally sensitive (often misunderstanding seemingly innocent or harmless utterances)
4	Carrigan & Allez (2017)	Re-experiencing the event, (as if 'watching a video'), nightmares, suppressing	Refusal to leave the house due to fears he would meet his attackers, avoiding the	Guilt, self-blame	Difficulties concentrating on television programmes or books, hypervigilance,	-

		trauma memories, flashbacks of the trauma	location where the attack happened		angry outbursts, arguments with parents, belief that people are out to get him and not to be trusted, difficulty falling and staying asleep, remaining alert for threat	
5	Cook et al. (1993)	Standing in front of the mirror making hitting gestures and angry noises, anxiety and agitation in response to symbolic events such as getting on to the expressway that led back to school, increase in intrusive memories with associated anxiety and	Reluctance to discuss any school incidents, resisted returning to school	Loss of interest in enjoyed activities, fearful, would not be touched during crying spells, although previously was able to be comforted by parents	Anger when talking about being hit, agitation, sleep disturbances, awoke frequently at 3 or 4 A.M	Fear of the dark, increased rocking and crying spells, significant weight loss

		agitation at anniversary				
6	Fazel et al. (2020)	Intrusive memories, reliving symptoms, dissociation, seeing the abuser as a “real” vision but with novel content leading to a belief that the abuser was in her home and cooperating with a family member and staff in the unit	-	-	'Behavioral outbursts', aggitation, aggression,	Self-harm, psychotic symptoms
7	Gerhardt & Smith (2020)	Nightmares	-	Depressed mood, anger	Anxiety, concentration problems, worry, hyperactivity, impulsivity, discussed experiences of abuse and neglect in detail, but in a	Impaired social relationships

					very emotionally detached manner, feeling like he was always 'on edge'	
8	Guest & Ohrt (2018)	Traumatic memories, nightmares	-	Anger	Aggression, hypervigilance, anxiety	Tics
9	Ipci et al. (2017)	-	-	Fear	Hitting, biting, hypervigilance,	Selective mutism, changes in voice developmental regression
10	King & Desaulnier (2011)	-	Covering eyes and ears, running away from the family room when company visited	Panic attacks, withdrawal from interactions with others	Aggressive outbursts, fire-setting, initial insomnia, afraid to go to sleep	Increased stereotypical behavior, described seeing "ghosts and clowns", sexually assaulted staff member, odd posturing, speech

						and communication skills deteriorated
11	Kosatka & Ona (2014)	Re-experiencing	Avoidance of strangers	Anhedonia, anxiety and depression	Sleep difficulties, hyperarousal	-
14	Trelles Thorne et al. (2015)	Nightmares, becoming emotionally dysregulated when abuse mentioned	-	Fear of a strange man coming into his room and harming the family, sadness and withdrawal frustrated and oppositional	Waking multiple times in the night, aggressive and self-injurious behaviour, temper tantrums (throwing things and biting and kicking others), hyperactivity and impulsivity	Wetting the bed, behavioural problems at home and at school, declining academic performance
15	Weiss & Lunsky (2010)	Intrusive recollections of the events (“as clear as when it happened”), her mind would replay the events in vivid detail, intense distress	-	Anger	-	-

		when being reminded of the assaults				
16	Brenner et al. (2018)	Intrusive thoughts, distressing memories	-	Loss of interest	Irritability	Lethargy
17	Haruvi-Lamdan et al. (2020)	Individuals with ASD reported significantly higher levels of re-experiencing than TD group	-	Individuals with ASD reported marginally significant higher levels of negative alterations in mood and cognition	Individuals with ASD reported significantly higher levels of hyper-arousal symptoms than TD	-
20	Howlin & Clements (1995)	Fears of going to school, overactivity	Resistance to going to school	Mood disturbance (sudden swings, screaming, irritability), general fear and phobias, increase in problems related	Aggressive behaviour, temper tantrums, self-injurious behaviours, sleep disturbance	Increase of stress-related behaviours, relationship problems (over-clingy or rejecting), increased reluctance to be

				to eating, loss of interest in previously enjoyed activities		separated from parents
23	McDonnell et al. (2019)	-	-	-	Aggression, tantrums, hyperactivity	-
24	Mehtar & Mukaddes (2011)	Reported, but not exemplified, agitation and restlessness (N = 16)	-	Appetite disturbance (N = 13), regression in sharing with people, apathy	Aggressiveness and angry outbursts (N = 17), distractibility (N = 17), sleep disturbances (N = 17), increase in disruptive behaviour, self-harm behaviour, increased activity levels	Increase in restricted interest area (N = 14), increase in ritual behaviours, stereotypic movement, and motor mannerisms (N = 14), deterioration of nonverbal communication skills, regression in social interaction (N = 16), worsening in peer

						relationships (N = 12)
25	Okazaki et al. (2020)	-	-	-	-	A relationship between sexual abuse and brain function. The more severe the sexual abuse the larger the amplitude of P300 at Fz, Cz, C3, and C4.
26	Paul et al. (2018)	Flashback (33.3%), nightmares (25.6%)	Avoidance behaviour (30.8%)	Sadness (12.8%), self-deprecation (35.9%), selective amnesia of facts (25.6%), anhedonia (2.6%), pessimism (33.3%), social isolation (17.9%), emotional anaesthesia (12.8%)	Irritability (33.3%), insomnia (38.5%), hypervigilance (23.1%), attention or concentration problems (35.9%), anxiety (28.2%), risk behaviour (7.7%)	Enuresis (7.7%), resumption of thumb sucking (2.6%), eating disorder (7.7%), suicide attempt (7.7%), scarification (5.1%), somatic complaints (10.3%), putting back into action in games or activities

29	Valenti et al. (2012)	-	-	-	-	Loss of skill in communication and daily living
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Key: - = not reported in study

1.4.7 Thematic synthesis

Thematic synthesis of clinician perspectives of trauma symptomology in autistic individuals was conducted on direct quotations extracted from six of the studies (1, 2, 3, 4, 6, 10). The included studies employed qualitative IPA (1, 2, 3) or case report designs (4, 6, 10). These were the only studies where data richness allowed for TA. The superordinate themes corresponded with the DSM-5 PTSD criteria (Appendix A); thus, themes were labelled according to re-experiencing, avoidance, negativism, and arousal. One additional theme (other trauma-related symptoms) and twelve subthemes were identified. The findings are reflected in Table 5 and discussed below with example quotations.

Table 5. Themes, subthemes and frequency across studies

Theme	Subtheme	Studies included in the subtheme
Re-experiencing	Co-occurring abrupt changes to alertness and responsivity	1
	Verbal and behavioural expression of re-experiencing	1, 2, 4, 5
Avoidance		1, 3, 5
Negativism	Indirect communications of distress	3
	Low mood and hopelessness	1, 3
	Negative self-image	1, 3
Arousal	Hypervigilance	1, 2, 3
	Irritability	1, 2, 3
	Sleep problems	1
Other trauma-related symptoms	Increases in behaviours associated with autism	1, 2
	Sexual preoccupations	1, 3
	Sudden, unexpected episodes of aggression or self-injury	1, 2
	Possible hallucinations	6, 10

1.4.7.1 Re-experiencing

Across studies, clinicians interpreted observable changes in alertness and responsivity to be manifestations of the autistic individual re-experiencing trauma, as reflected in Criterion B of the DSM-5. Manifestation of re-experiencing varied, with clinicians describing both behavioural and verbal re-enactments of traumatic events.

1.4.7.1.1 Co-occurring abrupt changes to alertness and responsivity

Re-experiencing in autistic individuals was marked by an observable absence and dissociative state that appeared to occur without warning or pattern. A clinician explained how one individual was aggressive towards others during re-experiencing and appeared unable to control their behaviour:

“He just blacks out and it’s like he looks right through you and just attacks... it’s impossible to reach him” (1)

For others, there was a clear pattern of behaviour leading to the onset of re-experiencing, with an expression of marked distress, followed by a lack of consciousness of their surroundings:

“It often started with wandering, increasing restlessness, expressions of despair, and then suddenly...they’re in a world of their own” (1)

1.4.7.1.2 Verbal and behavioural expression of re-experiencing

Clinicians reported that their autistic clients gave ‘typical’ descriptions of re-experiencing, in line with the DSM-5 definition, such as, *“Re-experiencing the event, as if watching a video” (4)*.

However, the clinicians acknowledged that some autistic individuals, particularly those with limited verbal language, may not express their subjective experience in this way. For these individuals’, clinicians inferred that re-experiencing could be observed as verbalisation of phrases relating to the traumatic event accompanied by a high level of distress:

“She would scream “take that dick away” or “take your hands off me”. You sort of saw her reliving it. It was hard to reach her and help her get out of it” (1)

Many referred to challenges in identifying re-experiencing symptoms in autistic individuals. Difficulties were reported regarding differentiating between communication differences associated with autism, such as echolalia and idiosyncratic speech, and trauma symptoms. Numerous accounts highlighted the risk of diagnostic overshadowing:

“One patient who spoke indirectly about abuse he said, “it smells like something is burning here.” He spoke in a sort of code, which we could easily have misunderstood as just general, idiosyncratic speech” (2)

Behavioural re-enactments of traumatic events were commonly cited, particularly in studies reporting on autistic people with ID:

“I met one patient who sort of threw himself out the door while using a different voice...he sort of acts it out.” (1)

Clinicians perceived that for some autistic individuals, re-experiencing may manifest as abrupt, self-injurious behaviour or aggression towards themselves:

“Standing in front of the mirror making hitting gestures and angry noises” (5)

The clinician’s described how recognition of these behaviours in the context of trauma was highly dependent on those around the person knowing their trauma history and understanding their usual presentation.

1.4.7.2 Avoidance

Avoidance was the least commented on DSM-5 symptom category, mentioned in four of the studies. Some autistic individuals demonstrate specific avoidance of situations directly related to the traumatic event:

“After getting beat up, he did not want to walk the streets of that town” (1)

Avoidance was also described as more generalised, occurring across settings. Clinicians reported that they had witnessed both sudden and gradual onset of global avoidance, characterised by withdrawal from their environment and a sense of helplessness:

“It often starts gradually. Something happens and they just stop doing things, can’t be with other people, and just stay in bed – isolating themselves” (1)

1.4.7.3 Negativism

Negative changes in mood and cognition were commonly identified in autistic individuals with trauma-related symptoms. In individuals with co-occurring ID, negative emotions were reported to be more difficult to identify, with the perception that these individuals may express negative emotions in indirect ways. Low mood and negative self-image were also verbally and behaviourally expressed in both direct, and indirect ways.

1.4.7.3.1 Indirect communications of distress

One clinician described how an autistic adult carried out behavioural acts in what was perceived to be deliberate attempts to communicate his negative feelings and suicidal ideation:

“He would for instance find pictures of tombstones on the Internet and leave the browser open before asking for help with his computer.” (3).

These expressions of distress were perceived to be subtle, thus, requiring curiosity from the clinician in order to interpret behaviours in the context of previous trauma.

1.4.7.3.2 Low mood and hopelessness

Feelings of sadness and hopelessness were perceived as characteristic in autistic individuals with trauma-related symptoms, to varying degrees of severity. For some, this was described as an enduring state of unhappiness:

“He was very rarely happy” (3)

Clinician’s described how these emotions were not necessarily all-encompassing, but were usually constant and easily triggered:

“there was a sort of depressive cloud looming in the background. And it didn’t take much to bring it out and for him to say, “now this day is ruined” (1)

1.4.7.3.3 Negative self-image

Expressions of guilt and self-blame were perceived as portraying negative self-image. One clinician explained how an individual became ‘interpersonally sensitive’ following trauma. This led to a fear of making mistakes and a sensitivity to criticism:

“He sort of couldn’t receive feedback on his behaviour” (3)

In cases of individuals with more severe communication difficulties, this was suggested to be expressed through self-directed negative utterances:

“I remember one of them shouted at himself, shouting ‘no’ and his own name repeatedly” (1)

Clinicians inferred that these utterances were expressions of feelings of guilt and indicated that the individual did not feel good about themselves.

1.4.7.4 Arousal

Arousal was the most prevalent trauma-related symptom discussed across the studies. Physiological reactions were perceived as observable jumpiness, tension, irritability, and sleep disturbances.

1.4.7.4.1 Hypervigilance

Numerous examples were provided by clinicians of how hypervigilance was expressed in different ways. A commonality across their accounts was anxiety and a heightened state of arousal. For individuals with limited verbal skills, clinicians perceived there to be a greater likelihood of this manifesting as challenging behaviour, including self-injury and aggression towards other:

“Their behaviour gets even more chaotic and incoherent. They react in a more primal, instinctive way, and they can't regulate their emotions.” (2)

Some clinicians referred to noticing a pattern of more subtle behaviours such as appearing on edge, alert, and expressing insecurity in others:

“He always had a sort of guarded readiness about him during any kind of social interaction” (3)

1.4.7.4.2 Irritability

Irritability was perceived to occur alongside hyperarousal. This was suggested to be a response to difficulties tolerating uncomfortable feelings. Altered reactivity was described as manifesting as anger out-bursts:

“A lot of anger and acting out ... but it was more connected to this sensitivity or guardedness.” (1)

Clinician's understood this behaviour as an expression of increased anxiety and therefore, a self-protective strategy. Clinicians described exercising caution around some individuals. It was felt that reactions could be disproportionate:

“If he was annoyed with a particular staff member, it would take days until he would talk to them again” (3)

1.4.7.4.3 Sleep problems

Issues with sleep were highlighted, with difficulties falling asleep and waking during the night perceived as relating to trauma, due to observable differences in arousal. Specifically, clinicians discussed witnessing traumatised autistic individuals waking abruptly and appearing immediately alert and restless:

“You often see that they suddenly wake up, and whether it’s nightmares or something else, I don’t know, but it’s very sudden. They sort of wake up and immediately on the way somewhere, but it’s not because they want something, it’s because of restlessness” (1)

1.4.7.5 Other trauma-related symptoms

Across studies, clinicians referred to expressions of trauma that were not easily classified by the DSM-5 criteria. A range of behaviours were commented on, including an increase in behaviours associated with autism, sexual preoccupations, and hallucinations.

1.4.7.5.1 Increases in behaviours associated with autism

Clinicians reported noticing an increase in some of the behaviours associated with autism following the incidence of trauma. Increases in repetitive behaviours and rigidity were cited:

“He has more intense repetitive behaviors.” (1)

“We often see increased rigidity.” (2)

Increases in these behaviours were perceived as an attempt to regain control, following an experience where the individual felt helpless. Other clinicians recognised increases in these behaviours to be a manifestation of increased anxiety resulting from the traumatic experience. For one individual this was expressed as increased echolalia and regression in language abilities:

“She has more echolalia now. She has less functional language, and asks for things repeatedly” (2)

1.4.7.5.2 Unusual sexual preoccupations

Unusual sexual preoccupations were highlighted as attempts of disclosure in autistic adults who had experienced sexual abuse. One clinician described this as a fixation on unusual sexual topics, alongside curiosity regarding other's reactions to this fixation:

"He talked about buying a big horse dildo. He wondered whether he could have it sent to the ward, and whether people would see that he had ordered it" (3)

For this individual, this behaviour was initially attributed to autism-related special interests, thus, was not explored by those around them. This reiterates the risk of diagnostic overshadowing for autistic individuals with trauma-related symptoms.

1.4.7.5.3 Sudden, unexpected episodes of aggression or self-injury

Increased or new self-injurious behaviour was also reported. This differed from the incidence of self-inflicted aggression, reported in re-experiencing, and was discussed as an expression of immense distress:

"The self-injurious behavior was new for him. It appeared following the abuse. He hit himself with his hand all over his body and slammed his head against the floor" (1)

Clinicians described how these expressions of distress did not tend to have any observable pattern or trigger, creating difficulties for those around the individual in effectively supporting them:

"We've seen peculiar and self-injurious behaviours that were difficult to find causes or triggers for" (2)

1.4.7.5.4 Possible hallucinations

Two case reports described autistic individuals who experienced vivid, visual images relating to the traumatic event. These experiences differed to the flashback symptoms reported as re-experiencing as they contained novel content. These experiences were perceived by clinicians to have a hallucinatory quality and were distressing to the individual:

"seeing the abuser as a "real" vision, but with novel content leading to a belief that the abuser was in her home and cooperating with a family member and staff in the unit" (6)

One clinician reported described how a teenager with mild ID reported “*seeing ghosts and clowns*” (10) following the experience of physical, emotional, and sexual assault by peers. Although these images did not directly relate to the traumatic experiences, the clinician perceived these images to represent auditory and visual hallucinations triggered by the traumatic experience.

1.5 Discussion

The current systematic review has provided an overview of the literature concerning traumatic events and trauma-related symptomology in autistic individuals. Overall, the results of this review imply that trauma-related symptoms, from all DSM-5 PTSD symptom groups, are reported in autistic individuals, with and without co-occurring ID. Numerous studies used the DSM-5 definition of PTSD to describe trauma symptomology. Therefore, the DSM-5 provided a useful framework for this review in integrating findings across studies and highlighting where the DSM-5 definition of PTSD may differ from the trauma-related experiences of this population.

The narrative synthesis indicated that autistic individuals report finding similar experiences traumatic to the general population, suggesting that assessment of trauma using the DSM-5 may be appropriate for identifying traumatic events in autistic people. Some common PTSD precursors, such as military trauma, were not mentioned in the literature, and other events, including car accidents, were scarcely reported. It is hypothesised that these differences are likely to be due to lack of opportunity for autistic people to have these experiences, rather than a psychological difference related to autism. The incidence of vicarious trauma (McCann & Pearlman, 1990), i.e. trauma symptomology resulting from repeated or extreme exposure to aversive details about traumatic events (DSM-5, Criterion A.4), was also absent from the reviewed studies. This type of trauma is typically reported in individuals who work in mental health, social services, and the criminal justice sector (Ashley-Binge & Cousins, 2020; Bercier & Maynard, 2015; Iversen, & Robertson, 2020). Therefore, this difference could be owing to less autistic people populating such roles, thus, reflecting a lack of opportunity to have these experiences. However, it is possible that autistic individuals may be less affected by these types of experiences due to social communication differences associated with autism. Future research into vicarious trauma in autistic people is warranted to explore these hypotheses.

The current definition of trauma within the DSM-5 remains controversial within the literature (Bryant, 2019). This review identified several ‘non-DSM-5 traumatic events’ in autistic individuals. Such events

have been identified as catalysts to trauma-related psychological sequelae in the general population (Adrian & Stitt, 2017; Idsoe et al., 2012; Van Hooff et al., 2009). However, the current review indicates that autistic individuals report several potentially unique traumatic events. Although these experiences were only reported by a few individuals in a small number of studies, further exploration of these events in autistic individuals is needed. In particular, insufficient adaptation of the environment to autism challenges and inappropriate management of challenging behaviour are likely to be common experiences for individuals with co-occurring ID. Communication difficulties may impact on ability to report trauma and access trauma-related support (Kildahl et al., 2019), thus, identifying whether these experiences are frequently perceived as traumatic in this population may improve clinicians' ability to assess trauma in this group. Furthermore, the findings that psychological therapy and the ASD diagnostic process could be perceived as traumatic is concerning. This should be explored further to determine how clinicians can reduce the risk of traumatising their autistic clients. Interestingly, this review identified that the experience of ABA may be perceived as traumatic by some autistic individuals. Further research is needed to determine the significance of this finding, however, the fact that ABA has not been reported to be a traumatic event in TD populations is unsurprising, given that ABA interventions are much more commonly experienced by autistic individuals.

There is a body of research regarding the experience of bullying and subsequent PTSD in TD individuals (Idsoe et al. 2021). This review found that bullying and peer victimisation were also frequently reported to be perceived as traumatic by autistic people. Autism increases the risk of experiencing peer victimisation (Hoover, 2015), with autistic children suggested to be three-times more likely to experience bullying than their TD peers (Maiano, et al., 2016). Therefore, it may be particularly important for clinicians to carefully consider these experiences in assessing for trauma in their autistic clients. Childhood emotional abuse and neglect were also commonly reported in the included studies. Research has proposed that the current conceptualisation of PTSD may not fully encapsulate the trauma sequelae resulting from traumatic interactions between children and caregivers during critical developmental stages, as such interactions are postulated to influence the development of the internal working model of the self (Schore, 2003). Literature regarding this experience in the general population has led to the formalisation of a distinct 'sibling' disorder in the Classification of Diseases (ICD-11) defined as Complex Post-Traumatic Stress Disorder (CPTSD; Herman, 1992). Individuals presenting with CPTSD experience the core symptoms of PTSD, alongside 'disturbances in self-organisation', involving affect dysregulation, negative self-concept, and relationship difficulties

(Maercker et al., 2013). Therefore, it is plausible that broader trauma-related symptomology reported by some autistic individuals may be better understood as CPTSD.

It is also possible that the experiences of less typical traumatic events may be due to autism affecting perception or interpretation of events. It is widely reported that autistic individuals experience some stimuli more intensely (Peterson et al., 2019). For instance, sensory differences such as heightened sensitivity to touch and over- or under-sensitivity to pain may increase the amount of distress experienced by autistic people in different situations. It is also possible that rigidity in behaviour and cognition, associated with autism, may mean that autistic individuals are more rigid about morals, boundaries, and expectations of the world. Consequently, autistic peoples' sense of self or schemas about a 'just world' may be more easily 'shattered' by events (Ulman, 2013), increasing their susceptibility to becoming traumatised. This review hoped to identify literature with richer descriptions, which may have gleaned insight into whether these processes are involved in trauma and trauma sequelae in autistic individuals, however, this evidence does not exist. Exploration of the role of these processes in trauma in autistic people may facilitate richer descriptions of trauma sequelae in this population, thus, would be a worthwhile endeavour for future research.

The findings of this review imply that trauma in autistic individuals manifests as re-experiencing, avoidance, negativism, and arousal, in line with the symptomology reported in the general population. The narrative and thematic synthesis found that descriptions of avoidance were not as prevalent as the other symptom groups. This finding is interesting, as avoidance behaviour is suggested to be common in autistic people, due to typically high levels of anxiety (Bejerot et al., 2014). Therefore, it is possible that trauma-related avoidance in autistic individuals may be being missed by clinicians, particularly, if the avoidance is not clearly related to traumatic experiences. In line with previous research in autistic individuals with ID (Kildahl et al., 2019), this review found that trauma-symptomology in autistic people with co-occurring ID manifests more behaviourally than is indicated in the general population. Therefore, clinicians should routinely consider trauma when formulating about new, unusual behaviours in these individuals, as such behaviours could be signs of trauma or abuse.

The narrative and thematic synthesis revealed several potentially unique trauma-related symptoms in autistic individuals. As reported in previous research (Peterson et al, 2019; Kildahl et al., 2019), autism associated difficulties including rigidity, echolalia and repetitive behaviours may be exacerbated in

traumatised autistic children and autistic adults with ID. This finding was not identified in autistic adults without ID. One explanation for this may be that this group report frequent masking, thus, may attempt to 'camouflage' autism-related behaviours (Hull et al., 2017). A further notable finding of the thematic synthesis was the incidence of hallucinations in traumatised autistic individuals. Although an interesting finding, hallucinations were only mentioned in two case reports, thus, this finding is tentative and should be explored further.

Moreover, the findings of this review suggest autistic individuals without co-occurring ID only report trauma-related symptomology relating to the DSM-5 symptom groups. This may indicate that trauma is expressed differently in this group, compared with autistic children and individuals with co-occurring ID. However, this finding may reflect the fact that numerous studies in this review employed the DSM-5 framework to conceptualise trauma-related symptoms in their samples, potentially missing broader symptomology. Autistic individuals without co-occurring ID frequently experience diagnostic overshadowing and difficulties in accessing appropriate mental health support (Camm-Crosbie et al., 2019). Therefore, it is important that potential differences in the trauma-related psychological sequelae of this group are not overlooked.

1.5.1 Strengths and limitations of included studies

The large heterogeneity in the study designs and participant characteristics affected the ability to collectively synthesise the data across studies. Consequently, sub-group comparisons were made on several levels (e.g. case/qualitative/group designs, child/adult samples, ID/no co-occurring ID). The data richness of the included studies varied, with several case reports only providing brief descriptions of trauma symptomology and most group studies neglecting to provide details of trauma presentations. Numerous studies omitted details regarding the intellectual functioning of their samples, thus, it is difficult to answer the review question pertaining to the similarities and differences between the traumatic experiences and trauma manifestation in autistic individuals, with and without ID. The high level of quality of the IPA studies was a relative strength of the included research. Additionally, several case studies met the standards for questions 3a and 4a on the adapted JBI, thus, contained rich data that was relevant to this review.

1.5.2 Strengths and limitations of this review

Much of the research on trauma in autistic people has used ID as an exclusion criterion (Rumball, 2018). Therefore, the synthesis of the literature on both, individuals with and without ID, was a strength of this review. Additionally, to systematically collate all the available evidence relevant to the review questions, broad inclusion criteria were employed, identifying studies with diverse methodology. A further strength of this review was the inclusion of studies reporting broader trauma-related experiences than those classified by the DSM-5. Limiting data extraction to the DSM-5 PTSD symptom groups would have constrained the scope of this review. Several limitations of this review should be noted. The findings of the qualitative synthesis are significantly limited due to a lack of data richness in the studies. Richer descriptions in the literature may have allowed for more insightful conclusions about aspects of events that may be traumatic, and how traumatic symptoms are perceived by people with autism, thus, assisting identification of psychological reasons why autistic people might be more vulnerable to trauma. Notwithstanding the limitations, the emerging themes in the thematic synthesis were reflected within the narrative synthesis and align with previous research (Hoover, 2015; Kildahl et al., 2019; Rumball, 2019). Additionally, all the studies included in the thematic synthesis reported from the clinician perspective. Accordingly, the interpretations presented in this review reflect the author's understandings of the clinicians' interpretations of autistic individuals' experiences, limiting the validity of the findings. Many of the clinicians appeared to perceive their clients through a DSM-5 lens, therefore, constraining what can be inferred about the experiences that they were not looking for. Descriptions of re-experiencing illustrate what this looks like from an observer perspective, rather than the lived experience. Furthermore, trauma-related symptoms may have been hidden in these studies due to diagnostic overshadowing. This highlights a necessity for qualitative studies to explore the experiences of traumatic events and trauma-related symptomology with autistic people themselves. Employing participatory methods, such as IPA, may be helpful in gleaning insight into the lived experiences of this population.

1.5.2.1 Clinical implications and directions for future research

The research relating to trauma and autism is still in its infancy. As discussed, studies are heterogeneous, and the quality of the evidence is varied. To date, one systematic review explored the identification of PTSD in autistic individuals with ID (Kildahl et al., 2019) and a review by Rumball

(2019), synthesised the research relating to the assessment and treatment of PTSD in autistic individuals. To the authors knowledge, this is the first systematic review to synthesise the literature pertaining to broad traumatic events and trauma-related symptomology in autistic individuals across the lifespan, both with and without co-occurring ID. The summary of the literature provided by the current review suggests important implications for clinicians in building expertise in identifying trauma in autistic individuals. Clinicians should be aware that autistic individuals with trauma-related symptomology typically have complex presentations. In assessing and formulating traumatic sequelae in autistic people, additional time, and consideration of a broader range of trauma catalysts and symptoms may be necessary. Clinicians should be particularly mindful of diagnostic overshadowing. This is pertinent in relation to autistic children and individuals with co-occurring ID, as this review indicates that trauma may manifest differently in these individuals, requiring curiosity in interpreting behavioural presentations.

Several research avenues are suggested that could translate to improved trauma-focused support for autistic individuals with trauma-related symptoms. High quality research is needed to better characterise trauma presentation in autistic individuals. The current review reported potentially unique traumatic events in autistic adults (without co-occurring ID). None of the studies used a measure of trauma that has been validated with autistic individuals and many relied on clinician interpretation of trauma presentation. Therefore, development of tools to accurately assess broad trauma presentation, validated for use with this population is essential. Furthermore, in light of the review findings, research is needed to explore the lived experiences of autistic individuals of engaging in psychological support for trauma-related symptoms, to determine whether current psychological treatments for trauma are appropriate for targeting trauma sequelae in autistic individuals.

1.5.3 Conclusion

As discussed, despite the heterogeneity in the existing research, preliminary accounts from the reviewed studies suggest that autistic individuals perceive a similar range of experiences as traumatic, and experience similar trauma-related symptomology to the general population. Thus, suggesting that the DSM-5 may be an appropriate framework for clinicians to use in assessing and formulating trauma with their autistic clients. This review highlights several potentially unique traumatic events

and indicates that, in autistic children and autistic adults with ID, a broader range of trauma-related symptoms are reported, including an exacerbation of autism-related behaviours. Additionally, trauma-related symptoms may present more behaviourally in autistic individuals with co-occurring ID. Future research in this field should seek to explore the lived-experiences of trauma with autistic people, and employ empirically robust methodology to examine the mechanisms related to autism that may impact on what experiences are perceived as traumatic and the resulting traumatic sequelae in this population.

Chapter 2 ‘You need to find the right therapy that’s going to fit you’: Autistic Adults Experiences of Seeking and Engaging in Psychological Support for Trauma-related Symptoms

This paper has been prepared in the format required for the journal *Autism*.

2.1 Abstract

Autistic individuals have an increased risk of experiencing potentially traumatic events and developing trauma-related symptomology. Knowledge of the efficacy of interventions for treating traumatic sequelae in autistic individuals is limited. This study aimed to explore the experiences of autistic adults who have engaged in psychological support for trauma-related symptoms. Eight autistic adults (2 females) aged between thirty and fifty years old completed semi-structured interviews. Interpretative phenomenological analysis was used to analyse the data. Four superordinate themes were identified: ‘Accessing support that fits my needs’, ‘Recognising trauma in autistic adults’, ‘Clinician understanding of the context of autism’, and ‘Not just doing therapy at me but working with me to do therapy’. The findings provide insight into the barriers experienced by autistic adults in accessing appropriate trauma-focused psychological support, potentially important clinician qualities and meaningful adaptations to therapeutic mechanisms. The findings indicate that changes to current practices may be necessary in meeting the therapeutic needs of autistic adults. Potential implications for psychological support providers are discussed.

2.2 Lay Abstract

Autism can be a risk factor for experiencing potentially traumatic events and trauma-related symptoms. However, it is unknown how well psychological trauma therapies work for autistic people. Eight autistic adults were interviewed about their experiences of therapy for trauma-related symptoms. Participants experiences were represented by four main themes: ‘Accessing support that fits my needs’, ‘Recognising trauma symptomology in autistic adults’, ‘Clinician

understanding of the context of autism', and 'Not just doing therapy at me, but working with me to do therapy'. The study found that autistic adults face many barriers finding appropriate therapy for trauma. The participants suggested specific adjustments to communication and therapeutic exercises that they found helpful. Future research with autistic people should explore what types of adapted psychological support for trauma-related symptoms could improve mental health outcomes for autistic adults.

2.2.1 Keywords

Autism, trauma, post-traumatic stress disorder, interpretative Phenomenological Analysis, therapy

2.3 Introduction

Autistic individuals² are at disproportionate risk of experiencing co-occurring mental health problems (Hollocks, et al., 2019). Interventions addressing Post-Traumatic Stress Disorder (PTSD) and trauma-related symptoms in autistic people have been relatively overlooked by research. PTSD is defined by the Diagnostic and Statistical Manual, Fifth Edition (DSM-5), as a sequelae to experiencing potentially traumatic events such as exposure to death, threatened death, actual or threatened serious injury, or actual or threatened sexual violence (Criterion A; American Psychological Association (APA), 2013). PTSD is characterised by altered arousal, re-experiencing of trauma, avoidance, negative changes in cognition and mood and an impact on social and/or occupational functioning (APA, 2013). It is posited that most individuals are exposed to potentially traumatic events within their lifetime (Kessler et al., 2017), however, only an estimated 3-8.9% of the general population develop PTSD (Atwoli, et al., 2015; McManus et al., 2009).

Autism may increase the risk of experiencing potentially traumatic events and revictimisation (Haruvi-Lamdan et al., 2018; Kerns et al., 2015; Rumball et al., 2020). Autistic individuals may also

² I use identity-first language purposefully. The participants who contributed to the study prefer identity first language that does not separate their experience of autism from who they are.

have greater susceptibility to the psychosocial consequences of exposure to trauma, including PTSD, impairment in adaptive functioning, problems with employment and independent living and reduced quality of life (Brewin et al., 2019; Fuld, 2018; Kerns et al., 2015; Rumball, 2019; Rumball et al., 2021). It has been proposed that this vulnerability may be due to an increased risk for autistic individuals of sensory hyper-reactivity to daily stimuli, social confusion and incomprehension and rejection by others (Roberts et al., 2015; Wood and Gadow, 2010).

Despite indications that the core characteristics of autism present unique predispositions to experiencing potentially traumatic events and developing trauma-related symptoms, knowledge of trauma sequelae in autistic individuals is limited. A study with autistic youth has suggested that impairment in neurological and affect regulation associated with autism may increase individuals' distress levels and negatively impact on ability to process trauma due to slower information processing (Brenner et al., 2018). Additionally, studies have reported that autistic individuals may be more susceptible to experiencing trauma-related symptoms in relation to experiences outside of those defined as 'Criterion A traumas' (APA, 2013) due to heightened stress reactivity and altered perceptual experiences associated with autism (Brewin et al., 2019).

Autistic adults requiring psychological intervention for trauma-related symptoms frequently fall through the gaps in mental health services (Maddox et al., 2020) due to 'diagnostic overshadowing' (i.e. mental health symptoms inaccurately being attributed to the diagnosis of autism) (Grubaugh et al., 2008). Clinicians have reported hesitancy in addressing trauma-related memories in autistic individuals owing to a lack of confidence regarding their skills in working effectively with this population (Frueh et al., 2006). Little is known about the suitability of trauma-focused interventions for autistic adults (Peterson et al., 2019). For most populations, the National Institute for Health and Care Excellence (NICE) (2018) recommend validated exposure-based therapies, specifically, Trauma-Focused Cognitive Behavioural Therapy (TF-CBT) or Eye Movement Desensitisation and Reprocessing (EMDR), for alleviating trauma-related symptoms. Currently, the efficacy of these interventions in autistic adults cannot be assumed (Peterson et al., 2019). To date, one study has systematically studied the effectiveness of trauma-focused EMDR with a small sample of autistic adults; reporting a reduction in PTSD symptoms, alongside improvements in depression, somatization, social communication and social motivation (Lobregt-van Buuren et al., 2019). Case studies with autistic children have also suggested positive outcomes for EMDR including improvements in mood and social functioning (Ipci et al., 2017; Kosatka & Ona, 2014). A review by Peterson et al., (2019) proposed adaptations to TF-CBT would improve the utility of the approach

for autistic youth. Suggested modifications included alternative modes of communication, visual aids, increased time and repetition, incorporation of circumscribed or restricted interests and explicit teaching of socially appropriate behaviours (Peterson et al., 2019). Thus far, there has been one systematic review of psychological intervention outcomes for PTSD in autistic individuals. Rumball (2019) reviewed the outcomes of seven case studies and reported a reduction in PTSD symptomology following psychological intervention for six of the included studies. However, reflecting the dearth in the literature, these findings are limited due to the large heterogeneity within the study designs (Rumball et al., 2019).

Qualitative research is emerging offering insight into the experience of psychological support for autistic adults. Kildahl et al., (2020) explored mental health clinician's perceptions of trauma presentation and approach to intervention in autistic clients. Clinicians expressed that autism may affect how individuals experience and cope with traumatic events, impacting on PTSD symptom expression and presenting challenges for clinicians in identifying trauma. Camm-Crosbie et al., (2019) conducted an online survey exploring autistic adults' experiences of psychological support and found that respondents voiced a strong desire for support to be individually tailored. This was echoed by Crane et al., (2019) in their exploration of autistic adult's experiences. Crane et al., (2019) concluded that current psychological support services require significant improvements in meeting the needs of this population.

Therefore, despite indication of increased risk of exposure to potentially traumatic events, there is a scarcity of research into the lived experiences of trauma in autistic adults. Consequently, it is necessary to explore what constitutes effective and acceptable psychological support for treating trauma sequelae in collaboration with autistic adults themselves (Benevides et al., 2020; Fletcher-Watson et al., 2019). To the authors' knowledge, this is the first study seeking to illuminate autistic voices and their experiences of psychological support for trauma-related symptoms. In expanding the limited knowledge in this area, this study aims to explore the experiences of autistic adults of seeking and engaging in psychological support for trauma-related symptoms by answering the following research questions: What are the experiences of autistic adults of seeking, accessing and engaging in psychological support for trauma-related symptoms? How do autistic adults make sense of the trauma-focused psychological support they have received?

2.4 Methodology

A qualitative research design was employed using semi-structured interviews and an Interpretative Phenomenological Analysis (IPA) methodology. IPA seeks to understand and amplify the lived experience of the research participants by providing an interpretative account of their experiences in their unique context (Larkin & Thompson, 2012). This methodology was chosen as IPA is gaining momentum as a useful participatory tool in illuminating autistic perspectives (Macleod, 2019). In IPA, the researcher engages in a 'double hermeneutic' through which both the researcher and the participant attempt to make sense of the experiences described (Smith, Flowers & Larkin, 2009). I am a twenty-nine-year-old, white British, neurotypical woman, with experience of working with autistic adults as a Trainee Clinical Psychologist in the National Health Service (NHS). I acknowledge that my position may have influenced the interactions with the participants and the interpretation of the results. I kept a reflective diary pre- and post-interview and throughout the analysis, in an attempt to identify and 'bracket' my own preconceptions in my interpretation of the participants narratives of their experiences. Additionally, discussions about the data with my supervisors, a Clinical Psychologist with experience of working with autistic adults and a research director with an interest in emotional memory processing, will have contributed to my interpretations of participants' accounts.

2.4.1 Participants and recruitment

Eight autistic adults with a formal diagnosis of Autism Spectrum Disorder (ASD) were recruited via purposive sampling. A recruitment poster was used to recruit participants from across the United Kingdom (UK) through social media, word of mouth and private psychology services. Following participants enquiring about the study, an information sheet (appendix G) was provided by email and an interview was arranged to collect data via Microsoft Teams communication and collaboration platform (MS Teams). Consent was obtained in written format using a consent form (appendix H). Inclusion criteria for participation in the current study specified: (1) age 18 or over (2) formal diagnosis of ASD (3) no diagnosed intellectual disabilities (ID) (4) able to understand spoken and written English (5) a good level of verbal expression (6) experience of engaging in psychological support for trauma-related symptoms (7) Current CORE-10 (Barkham et al., 2013) score of less than 25 indicating no acute 'severe' psychological distress or suicidality. ASD diagnosis was confirmed by review of diagnostic report. Participants ranged from 30-50 years old (mean = 38.13, SD = 3.18)

and 75% of the sample were females (two males). All participants received a £25 Amazon voucher. Table 6 summarises details of individual participants. Some participants did not report ethnicity or education level. Pseudonyms have been used to protect the identity of the participants.

Table 6. Participant Demographics

Name	Age	Age of autism diagnosis	Ethnicity (self-identified)	Living status	Employment status	Co-occurring diagnoses (self-reported)	Education
Samantha	31	26	White British	Lives with partner	Unemployed	Depression, anxiety, Borderline Personality Disorder, PTSD	Undergraduate degree
Neil	42	10	White British	Lives with parent	Unemployed	Depression, anxiety, PTSD	-
Laura	50	50	-	Lives independently	Unemployed	Depression, anxiety, chronic physical pain, PTSD	-
Michael	48	46	White British	Lives with partner and children	Full-time employed, education sector	Depression, anxiety, PTSD	Undergraduate degree
Alice	39	38	Northern Irish	Lives with partner	Employed, Author	Depression, anxiety, Crohn's disease, PTSD	-
Rachel	35	32	White Welsh	Lives with partner and children	Carer, part-time student, volunteer director, charity sector	Anxiety, depression, ADHD, PTSD	Undergraduate degree (currently studying)
Jane	30	30	Scottish	Lives with partner	Employed, healthcare sector	Depression, PTSD	Master's degree

Ella	30	25	White British	Lives independently (visited by a support worker)	Unemployed	Anxiety states, depression, PTSD	-
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- = Information not provided

2.4.2 Procedure

Ethical approval was granted for the study by the Ethics and Research Governance Committee at the University of Southampton (appendix I). Virtual interviews were conducted in the context of COVID-19 restrictions. I interviewed participants via video call using MS Teams. The interview schedule (appendix J) was developed by myself and my supervisors based on the aims of the project and methodological guidance (Larkin & Thompson, 2012; Smith et al., 2009). No members of the autistic community were involved in the initial development of the interview schedule. However, a pilot interview was conducted with an autistic adult who was eligible for the study and changes were made to the phrasing of questions in response to their feedback. NICE (2012) recommend the use of written and visual information in supporting autistic individuals with communication. Thus, prior to the interview, participants were emailed a PowerPoint presentation containing the interview questions and prompts (appendix K). This enabled participants to consider the questions beforehand and refer to them throughout the interview. The interviews were recorded on an encrypted voice recorder and ranged from 53-106 minutes (M=88 minutes). Participants were debriefed verbally at the end of the interview and sent a debrief form. All interviews were transcribed verbatim prior to analysis by a professional transcription service.

2.4.3 Analysis

Following transcription, I analysed the interview data using the six steps of IPA analysis (Smith et al., 2009). The data analysis was completed by hand. Initially, the first transcript was read and reread and voice recordings were listened to, ensuring full immersion in the data. Comments about the descriptive and linguistic content and conceptual understanding were made in the left margin and identified themes were noted in the right margin (appendix L). This process was repeated for each transcript and an initial thematic map was created (appendix M). Initial themes were iteratively reviewed and reorganised and a list of superordinate themes and subthemes were produced with their corresponding verbatim quotations. Themes were discussed amongst the research team and reviewed before the final superordinate themes and subthemes were agreed. For a theme to be classed as recurrent, it needed to be present across at least 6 of the 8 participants.

To support the credibility of the analysis, I kept notes throughout the research process. This included collating feelings and thoughts evoked pre and post each interview. These notes were

reflected upon throughout the analysis, enabling me to ‘bracket’ my ideas and maintain openness to alternative meanings. The research team audited a subset of the data and made credibility checks of emerging themes and their interconnections to ensure that my interpretations were representative of the participants’ responses.

2.5 Findings

The eight semi-structured interviews were analysed using IPA and resulted in the identification of four superordinate themes and ten subthemes. Themes and their frequency across participants are illustrated in Table 7.

Table 7. Identified themes, subthemes, and frequency across participants

Theme	Subtheme	Frequency
‘Accessing support that fits my needs’	Navigating NHS care pathways	8
	The pros and cons of private therapy	6
Recognising trauma symptomology in autistic adults	Traumatic experiences	6
	Diagnostic overshadowing	6
Clinician understanding of the Context of autism	Experience with autistic clients	7
	Clinician assumptions	7
	Clinician communication style	6
	Authenticity	8
‘Not just doing therapy at me, but working with me to do therapy’	Psychoeducation	6
	Meaningful reasonable adjustments	8

2.5.1 Theme 1- ‘Accessing support that fits my needs’

The participants reported experiencing a range of therapeutic approaches including EMDR (37.5%) TF-CBT (37.5%), psychoanalytical therapy (25%), counselling (75%), art therapy (12.5%), dialectical behavioural-informed therapy (25%) and schematic therapy (12.5%). Psychological support was provided by Clinical Psychologists, counsellors, art therapists and psychotherapists. All participants discussed the challenge of fitting into a support system that is not designed around their needs. Most participants experienced difficulties in accessing psychological support for their trauma

symptoms. When asked about her experience of the process, Laura highlighted the challenge of finding psychological support targeting trauma symptoms that considered her needs in relation to being autistic.

“There’s all sorts of psychological therapies out there...you need to find the right therapy that’s going to fit you.”

The phrase ‘the right therapy’ suggests a preferred or ideal form of psychological support. The suggestion of finding a therapy to ‘fit you’ implies nuance in what may constitute the ‘right therapy’ for each individual, rather than an exact formula for supporting autistic adults with trauma-related symptoms.

2.5.1.1 Navigating NHS care pathways

All participants referenced the wider context of the NHS, in terms of under-funding and oversubscribed waitlists, as barriers to accessing effective and timely support. An overwhelming sense of frustration and ‘*lack of faith*’ (Neil) in NHS provision of psychological support was evident in their accounts. Many participants had found themselves ‘*bounced between services*’ (Alice), and were offered support that did not fit their needs due to the rigidity of care pathways. A sense of hopelessness is illustrated in Samantha’s account:

‘The NHS were starting to say, “We’re only offering you group work again,” and that just would not work for me whatsoever’.

Ella described how frustration can also be felt by the clinicians working within NHS psychological support services:

‘They told me “Oh I will refer you for six sessions of CBT, but I don’t think it will meet your needs. I think you need to go on a waiting list to see a psychologist, but it will take about two years, possibly more”’

This was juxtaposed with the experiences of four of the participants who emphasised feeling ‘*extremely lucky*’ (Laura) in terms of the NHS psychological support they received for their trauma-related symptoms. There was a commonality across their accounts, with the participants perceiving that their psychological support had been ‘*outside of the mould*’ (Alice). Rachel described the proactive approach taken by her psychologist:

‘She managed to wangle me far more sessions than I probably should have had on the NHS... and she wasn’t, like, “This is the book, this is how we do it,” that was really, really helpful’.

Rachel's use of the word 'wangle' emphasises a sense of the psychologist skilfully manipulating the system and demonstrating flexibility in order to meet her needs.

2.5.1.2 The pros and cons of private therapy

Challenges in accessing appropriate NHS psychological services led five participants to seek private support for their trauma-related symptoms. Although all alluded to the financial cost of private therapy, the participants valued the increased choice, flexibility and autonomy in the therapeutic process afforded by the private sector. These factors enabled some participants to finally access psychological support that considered both, their trauma-related symptoms, and their needs relating to their autism:

'Going private I feel like there's less pressure...it's knowing that I can go as long as I need to, I can take it as slow or as fast as I want, that because it's not NHS, I'm not going to be shoved out the door whenever they decide.' (Samantha)

Conversely, the participants highlighted a necessity to exercise caution in navigating the private sector. Challenges were discussed in ascertaining the professional background and qualifications of therapists and understanding therapeutic modalities. This was perceived as a downside to the autonomy involved in seeking psychological support privately. Unusual encounters with clinicians in private practice were common. Neil disclosed one of his unhelpful encounters:

'I have had multiple therapists, one of whom said if I took the bible into my heart, then magically it would resolve all the issues.'

2.5.2 Theme 2 – Recognising trauma symptomology in autistic adults

Several factors contributed to challenges for participants in having their symptoms recognised as trauma-related by healthcare professionals. This included their experiences leading to post-trauma symptomology not fitting with clinician's conceptualisation of a 'traumatic' event, and specific influences of autism.

2.5.2.1 Traumatic experiences

Of those interviewed, two participants reported trauma symptoms following a single incident, whereas, six participants disclosed prolonged or multiple incidences of victimisation. Whilst half of the participants described traumatic experiences conventionally associated with PTSD, four participants explicitly described having negative life experiences as a consequence of 'dealing with

the neurotypical world' (Alice). These experiences related to bullying, social difficulties and their surroundings being insufficiently adapted to their needs. This was alluded to by Neil:

'I was pretty traumatised from school experiences, being around other kids, they latch on to anybody they perceive as weaker in the pecking order... I was absolutely terrified of people'

Neil's use of the word '*terrified*' accentuates the extent of distress caused by his social interactions with peers. Participants expressed the importance of clinicians extending curiosity to the impact of navigating the neurotypical world for autistic individuals and considering a broader range of 'traumatic' events than those conventionally associated with trauma.

2.5.2.2 Diagnostic overshadowing

For several participants, the process of seeking support for their trauma-related symptoms was described as '*a battle*' (Ella), involving feeling '*dismissed and unheard*' (Rachel) by clinicians. In making sense of these difficulties, Ella discussed how '*trauma symptoms can blur with autism symptoms*'. Rachel conceptualised this further with her explanation:

'A lot of the external behaviours are often attributed to being autistic, so the lines aren't drawn.' (Rachel)

For these participants, autism was often assumed to explain their trauma-related symptoms, and this presented barriers in accessing appropriate psychological support. Participants gave examples involving apparent increases in the severity of autistic characteristics. Alice discussed the implications of clinicians assuming her symptoms of hypervigilance were an expression of anxiety and rigidity in behaviour in the context of autism:

'My medical team had the stereotype of me as being very anxious and often difficult ... it meant that they hadn't put together my unusual reactions to things.'

For some, the persistence of such experiences with professionals led to self-doubt, struggling to trust their own judgements of their experiences:

'I spent three or four sessions saying, "Could I have fabricated this" Because I started really not believing myself.' (Rachel)

2.5.3 Theme 3- Clinician understanding of the context of autism

This theme was prevalent across participants and captures the necessity for clinicians to seek knowledge and understanding of the context of autism. This was perceived as essential for positive therapeutic alliance with autistic people. Rachel advised:

'Understand that they might be frustrated, and they might have a distrust, they may have gone through five or six clinicians beforehand and have been given misdiagnoses...building the rapport and the trust can take time.'

2.5.3.1 Experience with autistic clients

Seven of those interviewed explicitly sought psychological support from a clinician with experience of working with autistic adults. The excerpt from Alice, illustrates a view that was dominant in their accounts:

'People can read the resources on autism but it's very different from having spent a lot of clinical hours with actual three-dimensional people.'

Participants made the distinction between 'just Googling autism' (Jane) and learning about autism from autistic sources, with the latter perceived as vital in increasing the chances of autistic adults having a positive experience of psychological support. The participants disclosed researching this information about their clinicians:

'I Googled his name plus "autism" ... and I was like, "Okay, he does actually have experience around autistic people...I can invest in this.'" (Alice)

This perception was shared by six participants. The knowledge that their clinician had experience with autistic clients appeared to evoke confidence that the psychological support would be of value to them.

2.5.3.2 Clinician assumptions

This subtheme captures the participant's emotive and powerful descriptions of the assumptions and stereotypes encountered throughout their psychological support journey. Examples centred on clinician's neglecting curiosity and attempting to understand them through a stereotypical lens of 'high function'. Autism-related difficulties were commonly minimised due to the outward appearance of 'high intelligence' and eloquence. This led participants to feel 'completely dismissed' (Laura). An excerpt from Samantha illustrates this experience:

'What really annoys me is, because I can talk like this, they assume, oh, I'm quite intelligent, I've got a degree, I'm well-educated... so they ask me questions that they'll probably assume I can answer, then I just ...I can't understand.'

Frustration was evident in these participant's accounts and many felt unable to voice these feelings with their clinicians. Those interviewed expressed that, in challenging stereotypes and misconceptions about autism, it is important for clinicians to extend '*genuine curiosity*' (Jane) to the autistic adult in front of them in understanding their autism.

2.5.3.3 Clinician communication style

This subtheme reflects the participants' experiences with neurotypical clinicians in terms of a felt disparity in understanding and feeling for one another due to their differing world views and experiences. This was conceptualised as a case of mutual incomprehension, with participants perceiving a mismatch in the communication style between them and their therapist. Participants expressed a preference for a '*gentle but matter of fact*' (Rachel) style and their disdain for the '*customer service voice*' (Jane, Neil), '*head tilts*' (Samantha) and '*super fluffy*' (Rachel) communication style. Participants described how this style of communication evoked suspicions of dishonesty and led them to revert to scripted responses and unauthentic behaviour with their clinician:

'When someone says 'oh, I'm here for you' or this kind of language...I just can't connect with that... I have to switch on and start masking.' (Jane)

For some, this manifested as confusion, misunderstanding and a breakdown in the therapeutic relationship:

'She tried to be nice enough ...that's what was upsetting to me, I felt like she was getting really frustrated with me, which was making me frustrated with me.'

Samantha positions the 'nice enough' therapist as well-intentioned and the fault with herself, internalising the shared frustration. The fear of '*getting therapy wrong*' (Jane), evoked by such experiences, was cited by some as a barrier to seeking future psychological support.

2.5.3.4 Authenticity

Specific qualities were discussed as crucial for clinicians working with autistic adults. '*Sincerity and genuineness*' (Neil) were mentioned by all of the participants in the context of their difficulties in reading intentions and navigating '*social game playing*' (Jane). The implications of these experiences was distrust in others and additional challenges in navigating relationships. Laura echoed the views of many participants regarding the therapeutic relationship:

'It took a long time to let her in and build that relationship'.

In the service of authenticity, participants appreciated demonstrations of honesty and transparency. Rachel illustrates this point:

'she did apologise and said that she should have spotted it sooner. The fact that she took ownership of that helped.'

There was a common dislike for the *'unnatural formality'* (Jane) of the therapeutic relationship. All of those interviewed voiced the importance of experiencing realness from their clinician for them to feel safe:

'I don't like that unnaturalness in which I share everything yet I don't know the basics about them... this therapist would tell me, if she was going somewhere at the weekend...I felt the connection we had was genuine, so I could open up' (Jane).

2.5.4 Theme 4- 'Not just doing therapy at me, but working with me to do therapy'

The participants discussed their experiences of therapeutic activities. All participants expressed a preference for tangible, concrete language and therapeutic tools. Those who perceived that their psychological support fit with their autistic thinking style referred to the value of visual resources, writing as a communication method, closed or choice-based questions and tangible, as opposed to abstract, therapeutic tools.

2.5.4.1 Psychoeducation

Half of the participants highlighted difficulties in recognising their trauma-related symptoms due to *'outdated and specific'* (Rachel) information regarding trauma found on websites such as MIND and the NHS. Several participants discussed a tendency to take these examples literally:

'Non-military examples were if you've been in a major car accident...single incidents, when I was reading those examples, I couldn't correlate that with what happened to me'. (Rachel)

Rachel's account evokes a sense of invalidation of her experiences and, for Rachel, this delayed her access to trauma-focused psychological support.

Six of the participants discussed a desire to be informed about the methodology and theoretical basis of the therapeutic approaches used to target trauma-related symptoms. An in-depth understanding of the underlying processes of trauma helped the participants to better *'understand the reason'* (Laura) for therapeutic tools such as grounding and mindfulness.

Participants disclosed reading peer-reviewed journal articles and books about the physiological mechanisms of trauma to thicken their understanding:

'I've had this going into shutdown but reading the book (When the body say's no, Dr Gabor Maté) I came to understand that as dissociation.' (Jane)

2.5.4.2 'Not just doing therapy at me, but working with me to do therapy'

This theme considers how autism may affect the appropriateness of therapeutic tools for the individual. Reference was made to sensory differences and how sensory sensitivities should be integrated into psychological support. This is illustrated by Rachel's explanation of grounding:

'I have some dissociative symptoms and grounding can be quite difficult as I've got really poor proprioception, I find it difficult to place my body in space. That was why we started using scents, because I'm hypersensitive to smell so that can almost bring me back quicker.'

For many, visualisation was a useful therapeutic tool. However, imagining abstract, unfamiliar concepts was suggested to be futile. An excerpt from Michael illustrates that, for him, it was important that the concept being visualised was both tangible, and familiar:

'Visualising roots growing out your feet...to me, that's such an alien concept...your feet don't grow roots. Focusing on something concrete, like a place I had actually been and could remember, where I felt safe, that was more effective.'

Creative and flexible adaptations to communication methods were also valued. Alice, an author, highlighted how altering the communication modality of a trauma reliving exercise improved her ability to engage in the therapeutic work:

'I can find it difficult to unpick things, but actually, when I'm writing, I can do it a lot better, we agreed together that I would write it.'

Alice's use of the phrase '*agreed together*' implies collaboration in making reasonable adaptations. Across the board, participants appreciated clinicians who recognised the importance of making

adaptations truly meaningful to them and *'Not just doing therapy at me but working with me to do therapy'*. (Rachel)

2.6 Discussion

The participants in this study reported both positive and negative experiences of accessing and engaging in psychological support for trauma-related symptoms. The majority encountered challenges in accessing appropriate NHS support. Barriers including long waitlists, inaccessible services and insufficient funding were described by participants, in line with previous qualitative findings (Camm-Crosbie et al, 2019; Crane et al., 2019). Fragmented mental health services and lack of autism mental health pathways in NHS services have been highlighted as particularly problematic for autistic people without co-occurring ID, as these individuals frequently fall through the gaps in mental health services (Camm-Crosbie et al., 2019; Crane & Davidson et al., 2019, Maddox et al., 2019). Interestingly, study participants explicitly cited the rigidity of care pathways that are designed around the needs of neurotypical people as the main obstacle to accessing support for their trauma-related symptoms.

The autistic adults in this study reported greater satisfaction and positive outcomes in alleviating their trauma-related difficulties when clinicians adopted a flexible and creative approach to the structure and content of psychological support. The diversity reported in the types of psychological support encountered by the study participants fit with a recent review of the case study literature. Rumball (2019), reported positive outcomes for a variety of psychological therapies (psychotherapy, behavioural therapy, EMDR & CBT) and intervention lengths (4–43 sessions) in alleviating PTSD symptomology in autistic people. These findings, alongside the heterogeneity within the autistic spectrum (Peterson et al., 2019), imply that there is no single preferred intervention approach for treating trauma in autistic adults. Research is emerging indicating that NICE (2018) recommended therapies for treating PTSD in the general population may also be effective for autistic individuals (Ipci, et al., 2017; Kosatka & Ona, 2014; Lobregt-van Buuren et al., 2019). However, the current study findings suggest that clinicians need to attend to the unique characteristics of the autistic person in front of them in planning and delivering trauma-focused psychological support (Mason et al., 2021; Peterson et al., 2019). This may present challenges for clinicians in navigating between evidence-based practice and practice-based evidence in meeting the needs of autistic individuals. In building the case for a flexible and creative approach to trauma-focused psychological support with autistic adults, it is vital that clinicians continue to document and disseminate what is working well and what is not working with their autistic clients (Rice & Lee, 2020).

Recent studies have posited that the range of traumatic life experiences specified by the DSM-5 may be narrower than those interpreted as traumatic, and possibly triggering PTSD symptoms, in autistic individuals (Brewin et al., 2019; Haruvi-Lamdan et al., 2018; Kerns et al., 2015). In this study, autistic adults perceived both DSM-5 (Criterion A events) and other events as catalysts to their trauma-related symptoms. Half of our sample identified traumatic experiences relating to cumulative stress from prolonged social victimization and bullying. This reflects previous research suggesting that bullying and social interactions can result in PTSD symptomatology in autistic individuals (Brewin et al., 2019; Haruvi-Lamdan et al., 2018; Shepler, 2016). The autistic adults in this study perceived that reporting a non-criterion A trauma in relation to their psychological symptoms hindered timely recognition of their difficulties. This highlights the importance of clinicians attending to the individual's subjective response to and interpretation of an event when defining trauma (Brewin et al., 2019).

The participants in this study reported that the impact of their autism had been downplayed or dismissed by clinicians owing to their 'high-functioning' appearance and the absence of co-occurring ID. Research has suggested that the term 'high-functioning' may underestimate the difficulties commonly experienced by autistic individuals (Kenny et al., 2016). Such misconceptions may lead clinicians to underestimate the extent to which their autistic client is struggling and overestimate abilities in coping (Kenny et al., 2016; Nicolaidis et al., 2019). The way we talk about autism is important (Bradshaw et al., 2021), thus, clinicians should maintain an awareness of their language use in working with autistic individuals.

There was a common perception amongst participants that diagnostic overshadowing and stereotypical assumptions were reflective of clinician's lacking understanding of the context of autism. A lack of knowledge of autistic adults' mental health among professionals has been widely posited (Raja, 2014). Clinician knowledge, confidence, and experience function as gatekeepers for autistic adults seeking psychological support, therefore, it is vital that this is addressed. Research implies that clinicians are gaining knowledge about the characteristics of autism, however, clinicians continue to report a lack of confidence in effectively supporting autistic individuals (Cooper et al., 2018; Frueh et al., 2006; Maddox et al., 2019). For NHS services, a clearer understanding of what autism can and does not look like could be facilitated through liaison with specialist autism teams. Our participants expressed the importance of learning about autism from, and with, autistic sources. This suggests implications for NHS trusts, services, and therapist training programmes. Societal knowledge about autism is continuously evolving (Bradshaw et al., 2021). Learning about

autism from the autistic community themselves may be critical for clinicians in developing accurate knowledge and confidence in supporting autistic clients.

The importance of the therapeutic relationship is widely acknowledged (Norcross & Wampold, 2011). Participants in this study discussed relational difficulties with clinicians reflective of the double empathy problem (Milton, 2012). The double empathy problem describes how autistic and neurotypical people have different social communication styles, creating difficulties for both groups in empathising with one another (Milton, 2012). Participants discussed how a mismatch in social communication between themselves and their clinician led them to engage in camouflaging and masking behaviours. This is problematic, as research with autistic people has indicated that masking is exhausting and stressful (Hull et al, 2017). Additionally, client honesty and willingness to disclose are important mechanisms within the therapeutic process (Love & Farber, 2019). The double empathy problem has been suggested to increase susceptibility to misinterpreting signals from autistic people and inaccurately inferring their thoughts, feelings, and intentions (Mitchell et al., 2021). These difficulties may explain the study findings that, in order to develop therapeutic alliance, autistic adults preferred a longer duration of psychological support than is typically offered. The current findings suggest that demonstrating authenticity, honesty, and genuineness in fostering therapeutic alliance with autistic adults may begin to bridge the communication gap.

The Autism Act (2009) stipulates that clinicians are required by law to make reasonable adaptations to interventions to enable autistic adults to effectively engage with the support that they require. The current study findings imply that it is necessary to develop an understanding of the individual person and their autism prior to commencing psychological interventions in thinking about reasonable adjustments (Camm-Crosbie et al., 2019). An interesting finding of this study was that autistic adults reported the value of focusing on their sensory differences in finding grounding strategies that worked for them. Research has highlighted the importance of attending to sensory aversions in working therapeutically with autistic individuals (Mason et al., 2019), however, the idea of using sensory sensitivities to improve the utility of psychological strategies has not yet been explored. Finally, our participants expressed a preference for clear, current, and scientifically based information about trauma sequelae and interventions. Thus, psychological support providers should ensure autistic clients have an accurate understanding of the relevant therapeutic approaches and a clear rationale for implementing them.

2.6.1.1 2.6.1 Strengths and limitations

The main strength of this study was the unique sample and in-depth exploration of their experiences afforded by the IPA methodology (Smith, 2011). Illumination of lived experiences is particularly valuable as autistic voices have been neglected by research (Nicolaidis et al., 2019). A

further, unanticipated strength was the use of online data collection. Although a necessity in the context of COVID-19, online participation enabled the inclusion of individuals from across the UK. This is advantageous as healthcare provisions vary considerably between regions, thus, the experiences reported are likely to be representative of a diverse geographical area. My commitment to the qualitative research quality principles (Yardley, 2000) was also a strength. In particular, considerable time and care were taken during the interviews to attend to the communication needs of each participant and to understand each individual's experience; demonstrating the quality principle of commitment (Yardley, 2000).

Although generalisability is not a priority of IPA, there are some limitations regarding the extent to which participant's experiences varied. Notably, this study featured a white, mainly female, middle-aged sample of unknown socio-economic status. Considering the likely impact of intersectionality and cohort effects on autistic lived experience (Cascio et al., 2020), future studies should include more diverse samples and collect detailed demographic information. There was considerable heterogeneity in the type of psychological support participants received and the amount of time elapsed since treatment. Additionally, although autistic individuals were consulted about the content of the interview, it was not possible to involve the autistic community at the planning stage, thus, it is unclear whether this research reflects the priorities of the autism community (Pellicano et al., 2014). Finally, the validity of the study findings could have been improved using member checking (Smith et al., 2009).

This study provides novel insight into the lived experiences of autistic adults who have sought psychological support for trauma-related symptoms. The findings highlight difficulties faced by autistic adults in navigating NHS care pathways and accessing appropriate psychological support for their trauma-related symptoms. The findings also indicate potentially important therapist factors and therapeutic mechanisms. As discussed, further qualitative exploration with diverse samples is required to develop a clearer picture of autistic adult's experiences of psychological support for trauma-related symptoms. Future quantitative research is necessary to determine what types of adapted psychological support for trauma-related symptoms could improve mental health outcomes for autistic adults. Future studies could also explore different time points post-intervention in developing our understanding of how autistic individuals make sense of the psychological support they have received over time. Additionally, the study findings regarding the potential importance of learning about autism from autistic sources warrants exploration with the

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autistic community in determining how autistic participation in training programmes is best achieved.

Appendix A DSM-5 Diagnostic Criteria

DSM-5 Diagnostic criteria for post-traumatic stress disorder (PTSD) (APA, 2013)

To meet the DSM-5 criteria for post-traumatic stress disorder the person must have:

- **Been exposed to actual or threatened death, serious injury, or sexual violence in one (or more) than of the following ways:**
 - Directly experiencing the traumatic event.
 - Witnessing, in person, the event as it occurred to others.
 - Learning that the traumatic event occurred to a close family member or friend. In cases of actual or threatened death of a family member or friend, the events must have been violent or accidental.
 - Experiencing repeated or extreme exposure to aversive details of the traumatic event (e.g. first responders collecting human remains; police officers repeatedly exposed to details of child abuse).
- **Persistently re-experience at least *one* of the following intrusive symptoms:**
 - Recurrent, involuntary, and intrusive memories.
 - Recurrent traumatic nightmares (children may have frightening dreams not related to the trauma).
 - Dissociative reactions (e.g. flashbacks) in which the person feels or acts as if the traumatic event is recurring. These reactions may occur as brief episodes or the person may lose consciousness (children may re-enact the traumatic event through play).
 - Intense or prolonged distress after exposure to traumatic reminders.
 - Marked physiologic reactivity after exposure to trauma-related stimuli.
- **Persistently avoid stimuli associated with the traumatic event such as:**
 - Trauma-related thoughts or feelings, or
 - Trauma-related external reminders (e.g., people, places, conversations, activities, objects, or situations).
- **Experience at least *two* of the following negative changes in mood or thoughts that began or worsened after the traumatic event:**
 - Unable to recall key features of the traumatic event.
 - Persistent (usually distorted) negative beliefs and expectations about themselves or the world.
 - Persistent distorted blame of self or others for causing the traumatic event, or for resulting consequences.
 - Persistent negative emotional state (e.g. fear, horror, anger, guilt or shame).
 - Markedly diminished interest in (pre-traumatic) significant activities.
 - Feelings of detachment or estrangement from others.

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- Persistent inability to experience positive emotions (happiness, satisfaction, or love).
- **At least two of the following trauma-related alterations in arousal and reactivity that began or worsened after the traumatic event:**
 - Irritable or aggressive behaviour (with little or no provocation).
 - Self-destructive or reckless behaviour.
 - Hypervigilance.
 - Exaggerated startle response.
 - Problems in concentration.
 - Sleep disturbance.
- **The above symptoms should:**
 - Cause significant distress or functional impairment (e.g. social, occupational).
 - Not be caused by medication, substance use, or other illness.
 - Be persistence for more than one month.

Appendix B Sample characteristics of qualitative studies

Sample characteristics of qualitative studies

Number of study	First author (year)	Study type and data collection	Country of study	Number of respondents	Sampling technique	Female %	Professional background of respondents	Reporting on autistic individuals with ID?	Clinical context
1	Kildahl, Helverschou, Bakken & Oddli (2020)	IPA, interviews	Norway	N = 18	Convenience	77%	Specialist psychologist (N = 3), psychologist (N = 1), learning disabilities (LD) nurse (N = 7), psychiatrist (N = 2), nurse practitioner (N = 2), psychiatric nurse (N = 2), special educator (N = 1)	Yes (mild, moderate, severe and profound)	Informants were recruited from six hospitals in Norway and were employed in inpatient or outpatient mental health units supporting people with autism and ID
2	Kildahl, Helverschou, Bakken & Oddli (2020)	IPA, interviews	Norway	N = 18	Convenience	77%	Specialist psychologist (N = 3), psychologist (N = 1), LD nurse (N = 7), psychiatrist (N = 2), nurse practitioner	Yes (mild, moderate, severe and profound)	Informants were recruited from six hospitals in Norway and were employed in inpatient or outpatient mental

Number of study	First author (year)	Study type and data collection	Country of study	Number of respondents	Sampling technique	Female %	Professional background of respondents	Reporting on autistic individuals with ID?	Clinical context
3	Kildahl, Helverschou & Oddli, (2020)	IPA	Norway	N = 5	-	60%	(N = 2), psychiatric nurse (N = 2), special educator (N = 1) Clinical psychologist (N = 1), psychiatrist (N = 1), LD nurse (N = 2) psychiatric nurse (N = 1)	Yes	health units supporting people with autism and ID Specialised psychiatric ward

*Studies 1 and 2 report on the same sample

Appendix C Sample characteristics of the case reports and quantitative studies included in the review

Sample characteristics of the case reports and quantitative studies included in the review

Number of study	First author	Study type	Country of study	Autistic participants (with traumatic experiences / symptoms)	Comparison group	Age (case reports) and age range and mean (group studies)	Gender (case reports) or Female %	Ethnicity	Co-occurring conditions	Reporting on autistic individuals with ID?	ASD diagnosis	Relevant measures used
4	Carrigan & Allez (2017)	Case report	UK	(N = 1)	N/A	26	Male	Not stated	PTSD	Mild ID	Childhood diagnosis of ASD	-
5	Cook et al., (1993)	Case report	USA	(N = 1)	N/A	12	Male	-	PTSD	-	Psychiatrist evaluation using DSM-III-R criteria, Autistic Diagnostic Interview (ADI; Le Couteur et al., 1989) algorithm, and Childhood Autism Rating Scale (CARS; Schopler et al., 1988)	-
6	Fazel et al., (2020)	Case report	UK	(N = 1)	N/A	15	Female	-	Psychosis	-	Not stated	-

7	Gerhardt & Smith. (2020)	Case report	UK	(N = 1)	N/A	11	Male	-	ADHD, Unspecified Trauma and Stressor Related Disorder	None	ASD diagnosed by psychiatrist interview	-
8	Guest & Ohrt (2018)	Case report	USA	(N = 1)	N/A	5	Male	-	ADHD	None	ASD diagnosis confirmed prior to study	-
9	Ipci et al., (2017)	Case report	Turkey	(N = 1)	N/A	6	Male	-	PTSD, Selective mutism, OCD	None	ASD diagnosed by psychiatric interview	-
10	King & Desaulnier (2011)	Case report	Canada	(N = 1)	N/A	15	Male	Eastern European	PTSD	Mild ID	ASD diagnosis confirmed prior to study	-
11	Kosatka & Ona (2014)	Case report	USA	(N = 1)	N/A	21	Female	White	PTSD, Anxiety disorder not otherwise specified	None	Diagnosed by psychological testing at 18 years of age	-
12	Reese & Deutsch (2020)	Case report	Germany	(N = 1)	N/A	16	Female	-	None stated	None	ASD diagnosis confirmed prior to study	-

13	Robinson (2018)	Case report	Scotland	(N = 1)	N/A	30's	Male	-	None stated	None	ASD diagnosed by specialist ASD clinician within diagnostic team according to Diagnostic and Statistical Manual-IV	-
14	Trelles Thorne et al., (2015)	Case report	USA	(N = 1)	N/A	9	Male	Mexican American	ADHD; PTSD	borderline ID	Screened for ASD using the Autism Mental Status Examination (Grodberg et al. 2012)	-
15	Weiss & Lunsky (2010)	Case report	Canada	(N = 1)	N/A	30's	Female	-	Past major depressive episode, PTSD	None	ASD diagnosis confirmed prior to study, screened against criteria for Aaperger syndrome using the AAA	-

(Baron-Cohen
et al., 2005)

16	Brenner et al., (2018)	Case control	USA	N = 350 (99 with trauma)	None	4-21 (M = 12.9)	21.2%	Non- Hispanic/ Latino (n = 292 of 350)	-	IQ 37-125 (M = 77.46)	Specific items from the Child and Adolescent Symptom Inventory, Fifth Edition (CASI-5) (Gadow and Sprafkin 2013); caregiver report of the participati 's abuse history was collected via the
										Autism Disorder Observation Schedule-2nd Edition (ADOS-2; Lord et al., 2012); Social Communicati on Questionnaire (SCQ) (Rutter et al., 2003)	

											Demographic and Medical Intake Form created by AIC researchers.
17	Haruvi-Lamdan et al., (2020)	Case control	Israel	N = 25 (probable PTSD n = 8)	Typically developing (TD) peers (n = 25)	18–35 (M = 22.8)	40%	Most participants were Jewish, and born in Israel	ADHD (20%), depression and anxiety (8%), OCD (4%)	-	Life Events Checklist for DSM-5 (LEC-5; Weathers et al., 2013), PTSD Checklist for DSM-5 (PCL-5), Specific Version, a list of negative interpersonal situations that were based on a bullying
											ASD diagnosis confirmed prior to study, recognition of the diagnosis by the Israel Ministry of Welfare and the National Insurance service

													questionnaire (Sourander et al., 2010)
18	Hoch & Youssef (2020))	Case control	USA	N = 7695 (ASD + Trauma n = 1166) (Annual Assessment, 44.2%, Evaluations, 55.7% and Neuropsychological Assessments , 0.1%).	None	Children -	-	White (23%)	Not stated	-	Diagnostic information was extracted from the EMR system and included DSM-IV and ICD 9 (World Health Organization 1978), and 10 (World Health Organization 1992) systems of classification	-	
19	Hoover & Romero (2019)	Cohort study	USA	N = 20 (diagnosable PTSD n = 5)	None	8–14 (M = 11.0)	43%	African American (42.9%), (38.1%) White,	-	-	Screened for prior medical diagnosis of ASD	Interactive Trauma Scale (ITS) Prototype UCLA Post Traumatic	

	et al., (2019)	Cohort study						Personality disorder (N = 3)		Adapted Anxiety Disorders Interview Schedule- Children (ADIS-C) section PTSD version for adults with mild to borderline intellectual disabilities (Mevisen et al. 2016), The Impact of Event Scale- Revised (IES-R) (Weiss et al., 1997)
23	McDonne ll et al., (2019)	Case control	USA	N = 607 (ASD only with maltreatmen t = 99; ASD+ID with	TD peers n = (3101)	6-18, (M = - 11.6)	Non- Hispanic White (62.1%, ASD	Not stated	ID (N = 291)	Abstracted records were reviewed, and clinician reviewers

maltreatment n =138)

only;
42.8%,
ASD +
ID),
Non-
Hispanic
African
American
n
(30.1%,
ASD
only,
52.4%,
ASD +
ID),
Hispanic
(4.5%;
ASD
only,
3.1%,
ASD +
ID), Non-
Hispanic
Other
(3.2%,
ASD only
1.7%,
ASD + ID)

determined whether the child met criteria for ASD based on a coding scheme using DSM-IV-TR criteria

24	Mehtar & Mukaddes (2011)	Cross-sectional within-groups	Turkey	N = 69 (with trauma n = 18)	None	6-18 (M = 11.7)	23.2%	-	Previous comorbid psychiatric disorder (59.4%)	IQ 70–135; borderline-normal range IQ (27.5%), mild ID (7.2%), moderate ID (39.1%), and severe ID (26.1%)	Diagnosed and assessed carefully by experts on admission to the autism clinic and in follow-up visits	Schedule of Affective Disorders and Schizophrenia for School Aged Children (K-SADS-PL) PTSD scale (Kaufman et al. 1997), Trauma symptoms Investigation Form in Autistic Spectrum Disorders (TIF-ASD, Mehtar, et al 2011) Current and lifetime episodes using DSM-IV criteria;
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												completed with child where possible
25	Okazaki et al., (2020)	Cohort study	Japan	N = 21	TD peers (n = 22)	- (M = 27.0)	28.57%	Japanese	-	None	Confirmed prior to study- all patients re-evaluated using the ADOS-2 (Lord et al., 2012)	Japanese version of the Child Abuse and Trauma Scale (CATS; Sanders et al., 1995) to assess trauma history
26	Paul et al., (2018)	Case control	France	N = 39	TD peers (n = 53)	8-18 M = 13.23	15.38%	-	ADHD (53.8%)	-	Patients diagnosed by an ASD expert centre in Bordeaux, France, ASD diagnosis validated by a threshold score on the ADI-R Le Couteur et al. 1989) and the	Post-traumatic stress disorder Check List-Scale (PCL-S), Juvenile Victimization

Autism Diagnostic Observation Schedule- Generic (ADOS-G; Rutter et al., 1999)

Questionnaire— Screener Sum Version (JVQ) (Hamby et al., 2004). Authors created a questionnaire to assess the clinical and forensic consequences of the victimisations

27	Rumball et al., (2020)	One-time online survey	UK	N = 59 (reporting traumatic experiences N = 53)	None	19-67 (M = 39) 60.38%	White (89.8%), Asian (3.4%), African/Caribbean/Black	-	None	Verbal report from participants, definitive confirmation of ASD diagnosis was	-
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								British (1.7%), mixed ethnicity or other (5.1%).			obtained for 48/59 participants	
28	Taylor & Gotham (2016)	Cross sectional within-groups	USA	N = 36	None	17-22 (M 18.7)	16.70%	White non-Hispanic (91.7 %)	major depression (N = 5), obsessive-compulsive disorder (N = 2), dysthymia (N = 2), simple phobia (N = 1), bipolar disorder (N = 1), generalized anxiety disorder (N = 2), bipolar disorder, depressive disorder NOS (N = 1)	IQ 40-137; had IQ of 70 or less (27.8 %), 71- 85 (11.1%); 86- 100 (27.8 %), greater than 100 (33.3%)	Prior ASD diagnosis from a health professional that was confirmed through a laboratory evaluation	(K-SADS-PL; Kaufman et al. 1997), Current and lifetime episodes using DSM-IV criteria

29	Valenti et al., (2012)	Case control	Italy	N = 18	Peers not exposed to the earthquake (n = 42)	<18 (not stated)	16.70%	-	Not stated	IQ of 75 or lower) (71.6%)	Prior standardised assessment with the Autism Diagnostic Observation Schedule (ADOS)— Italian version (Lord et al. 2005) ASD diagnoses were made according to ADI-R Le Couteur et al. (1989) and ADOS scores and ICD-10 criteria.	Vineland Adaptive Behaviour Scales (Sparrow et al., 2008)
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Key: - = Not reported in study; N/A =not applicable

Appendix D CASP ratings for included qualitative IPA studies

CASP ratings for included qualitative IPA studies

Study number	First author (year)	Q1. Clear aims	Q2. Appropriate methodology	Q3. Appropriate design	Q4. Appropriate recruitment strategy	Q5. Appropriate data collection	Q6. Adequate consideration of relationship between researcher and participants	Q7. Ethical considerations	Q8. Rigorous data analysis	Q9. Clear statement of findings
1	Kildahl, Helverschou, Bakken & Oddli (2020)	✓	✓	✓	✓	✓	✓	✓	✓	✓
2	Kildahl, Helverschou, Bakken & Oddli (2020)	✓	✓	✓	✓	✓	✓	✓	✓	✓
3	Kildahl, Helverschou & Oddli, (2020)	✓	✓	✓	✓	✓	✓	✓	✓	✓

Appendix E Adapted JBI ratings for included case reports

Adapted JBI rating for included case reports

Study number	Q1. First author (year)	Q2. Clear description demographics	Q3. Clear description patient's history and timeline	Q3a. Rich description trauma sequelae	Q4. Clear description current clinical conditions	Q4a. Quotations from autistic individual illustrating trauma symptoms	Q5. Clear description diagnostic tests or assessment methods and result of these	Q6. Clear description of the intervention or treatment procedure	Q7. Clear description post-intervention clinical conditions	Q8. Were any adverse reactions, unanticipated events or necessary modifications described	Q9. Does the case report provide takeaway lessons regarding assessment and treatment of PTSD in ASD
4	Carrigan & Allez (2017)	✓	✓	✓	✓	✓	? PTSD = Yes ASD = No	✓	✓	✓	✓
5	Cook et al., (1993)	✓	? History = no Post- assessment = yes	✓	✓	✓	✓	? Psychopharmacology = yes Psychotherapy = no	? Psychopharmacology = yes Psychotherapy = no	? Psychopharmacology = yes Psychotherapy = no	? Assessment and systemic issues = yes

Study number	Q1. First author (year)	Q2. Clear description demographics	Q3. Clear description patient's history and timeline	Q3a. Rich description trauma sequelae	Q4. Clear description current clinical conditions	Q4a. Quotations from autistic individual illustrating trauma symptoms	Q5. Clear description diagnostic tests or assessment methods and result of these	Q6. Clear description of the intervention or treatment procedure	Q7. Clear description post-intervention clinical conditions	Q8. Were any adverse reactions, unanticipated events or necessary modifications described	Q9. Does the case report provide takeaway lessons regarding assessment and treatment of PTSD in ASD
6	Fazel et al., (2020)	✓	✗ ✓	✓	✗	✓	?	✓	✗	?	?
7	Gerhardt & Smith (2020)	✓	✓	✓	✓	✗	?	?	✓	?	✓
8	Guest & Ohrt (2018)	✓	✓	✓	✓	✗	?	✓	✓	?	✓
9	Ipci et al., (2017)	?	✓	✓	✓	✗	✗	?	?	✗	?
10	King & Desaulni	✓	✓	✓	✓	✗	?	?	?	?	?

Treatment = no

Study number	Q1. First author (year)	Q2. Clear description demographics	Q3. Clear description patient's history and timeline	Q3a. Rich description trauma sequelae	Q4. Clear description current clinical conditions	Q4a. Quotations from autistic individual illustrating trauma symptoms	Q5. Clear description diagnostic tests or assessment methods and result of these	Q6. Clear description of the intervention or treatment procedure	Q7. Clear description post-intervention clinical conditions	Q8. Were any adverse reactions, unanticipated events or necessary modifications described	Q9. Does the case report provide takeaway lessons regarding assessment and treatment of PTSD in ASD
11	er (2011) Kosatka & Ona	✓	✓	✓	?	✗	✓	✓	✓	✓	✓
12	(2014) Reese & Deutsch	✓	?	✗	✓	✓	✗	✓	✗	✓	✓
13	(2020) Robinson (2018)	?	✗	✗	✓	✗	✓	✓	✓	?	✓
14	Trelles Thorne et al., (2015)	✓	✓	✓	✓	✗	✓	?	✗	?	?
								Pharmacology= yes Psychological and school = no		Pharmacology= yes Psychological and school = no	Treatment = no, Assessment = yes

Study number	Q1. First author (year)	Q2. Clear description demographics	Q3. Clear description patient's history and timeline	Q3a. Rich description trauma sequelae	Q4. Clear description current clinical conditions	Q4a. Quotations from autistic individual illustrating trauma symptoms	Q5. Clear description diagnostic tests or assessment methods and result of these	Q6. Clear description of the intervention or treatment procedure	Q7. Clear description post-intervention clinical conditions	Q8. Were any adverse reactions, unanticipated events or necessary modifications described	Q9. Does the case report provide takeaway lessons regarding assessment and treatment of PTSD in ASD
15	Weiss & Lunsky (2010)	✓	✓	✓	✓	✗	✓	✓	?	PTSD = no depression and anxiety = yes	?
											Assessment = no Treatment = yes

Key: ✓ = yes, ? = can't tell, ✗ = no

Appendix F EPHPP ratings for included quantitative studies

Study number	First author (year)	Rating Confounders	Aware of research Q	Rating blinding	Tools reliable	Tools valid	Rating data collection method	Unit of analysis	Appropriate statistics	GLOBAL RATING
16	Brenner et al., (2018)	3	3	3	3	3	3	Individual	Yes	3 (weak)
17	Haruvi-Lamdan et al., (2020)	1	3	3	1	1	1	Individual	Yes	3 (weak)
18	Hoch & Youssef (2020))	3	3	3	3	3	3	Individual	Yes	3 (weak)
19	Hoover & Romero (2019)	3	3	3	1	1	1	Individual	Yes	3 (weak)
20	Howlin & Clements (1995)	3	3	3	3	3	3	Individual	Yes	3 (weak)
21	Kupferstein (2018)	3	3	3	3	3	3	Individual	Yes	3 (weak)

Study number	First author (year)	Rating Confounders	Aware of research Q	Rating blinding	Tools reliable	Tools valid	Rating data collection method	Unit analysis	of Appropriate statistics	GLOBAL RATING
22	Lobregt-van Buuren et al., (2019)	3	2	3	1	1	1	Individual	Yes	3 (weak)
23	McDonnell et al., (2019)	1	3	3	3	3	3	Individual	Yes	3 (weak)
24	Mehtar & Mukaddes (2011)	3	1	3	3	3	3	Individual	Yes	3 (weak)
25	Okazaki et al., (2020)	2	3	3	3	3	3	Individual	Yes	3 (weak)
26	Paul et al., (2018)	1	1	3	1	1	1	Individuals	Yes	2 (moderate)
27	Rumball et al., (2020)	3	3	3	1	1	1	Individual	Yes	3 (weak)
28	Taylor & Gotham (2016)	1	3	3	3	3	3	Individual	Yes	3 (weak)

Study number	First author (year)	Rating Confounders	Aware of research Q	Rating blinding	Tools reliable	Tools valid	Rating data collection method	Unit of analysis	Appropriate statistics	GLOBAL RATING
29	Valenti et al., (2012)	3	3	3	1	1	1	Individual	Yes	3 (weak)

Key: 4 = Case-control study, 5 = Cohort study, 7^a = Questionnaire, 7^b = Survey, 7^c = Interview cross-sectional within groups; 1 = strong, 2 = moderate, 3 = weak

Appendix G Participant information sheet

Participant Information Sheet

Study Title: An interpretative Phenomenological Analysis: The Experiences of Adults with Autism Spectrum Condition (ASC) of Accessing and Engaging in Psychological Support following trauma symptoms

Researcher: Charlotte Scrivens

ERGO number: 55779

- You are being invited to take part in a research study. This is because you have a diagnosis of ASC and have received some psychological support for symptoms relating to a difficult experience that has happened to you in your life.
- This information sheet is to help you understand why this research is being completed. By reading this information sheet you can decide if you would like to take part in the study. Please take your time reading the information below. You can email the researcher, Charlotte Scrivens, questions if anything in this information sheet is unclear.
- You may like to discuss it with others, but it is up to you to decide whether or not to take part.
- If you are happy to participate you will be asked to sign a consent form.

What is the research about?

The researcher is a Trainee Clinical Psychologist studying at the University of Southampton. This research is a student project and will be written up as part of the researchers Doctorate in Clinical Psychology. The researcher would like to find out:

- What has it been like for adults with ASC looking for and getting psychological support for symptoms related to traumatic life experiences?
- How do adults with ASC make sense of the psychological support they have received?

Finding out about people's experiences of trying to find and engaging in psychological support for trauma symptoms will help us to understand what this process is like for adults with ASC and how well current psychological support provisions are doing in supporting this group of people.

Why am I receiving this Participant Information Sheet?

You are receiving this Participant Information Sheet because you have contacted the researcher to say you would be interested in taking part.

What will happen to me if I take part?

- The researcher will arrange to meet with you virtually (via MS Teams video platform).
- Before the meeting, you will have the chance to email the researcher to ask any questions that you may have about participating in the study. If you want to take part, you will then be sent a consent form to sign and email back to the researcher. If you do not have a scanner you can take a clear picture of your signed consent form and attach this to an email to the researcher. If you are unable to email the consent form, you will be asked to give verbal consent once the Dictaphone recording has been started, prior to beginning your interview.
- The researcher will then ask you to send them your medical report. The researcher will check your report. This will be to confirm you have a diagnosis of an Autism Spectrum Disorder.
- At the meeting, the researcher will explain the study to you. You can then decide if you want to take part in the study. The researcher will ask you to answer some questions about yourself (questions like, how old are you? Who do you live with?).
- The researcher will then start the interview. The researcher will use a voice recorder and will ask you one interview question at a time.
- You will have a PowerPoint presentation emailed to you before starting the interview. This will have all of the interview questions and prompts so that you can refer to them during the interview to help you to answer the questions. if you wish to. You can take a break at any point during the interview by asking the researcher to pause the recording.
- Once the researcher has asked her questions, the interview will stop. The researcher will thank you for taking part. You will receive a £25 Amazon voucher to reimburse you for your time.
- The interview should take up to a maximum of 90 minutes.

Are there any benefits in my taking part?

There are no direct benefits to you, however, after finishing the interview, you will receive a £25 Amazon voucher to reimburse you for your time. .

Are there any risks involved?

Talking about your personal experiences may cause you some distress. If this happens, the researcher will work with you to decide what support you may need. This support could include:

- Stopping the interview
- The researcher supporting you to feel better during the interview

- Finding a service that can help you with how you are feeling

What data will be collected?

- Consent form and ASC diagnostic medical report. These documents are necessary for you to take part in the study. This information will be kept safe on a password protected computer only accessible to the researcher and their supervisor. Your ASC diagnostic medical report will then be destroyed once eligibility for the study has been confirmed.
- Your contact details including your name, email address, telephone number and the address where you will be when the interview takes place. This information will be collected to help the researcher arrange the interview with you. This information will be kept safe on a password protected computer only accessible to the researcher and their supervisor. After you have completed your interview, this information will be destroyed.
- Demographic information – You will answer some questions about yourself. This will include your gender, current age, age you received a diagnosis of Autism Spectrum Disorder, who you live with, employment status and mental health diagnoses. This information is important for the researcher in forming a clear picture of who the participants are. This information will be kept safe on a password protected computer, separate to the location of your contact details, ASC diagnostic medical report and consent form. The researcher will keep this information until her university coursework has been assessed. After the researcher's university coursework has been marked this data will be held in line with the Data Protection Act (2018). The data will be anonymised and kept for a period of five years after project completion.
- Video and Voice recordings – During the interviews, our voices will be recorded by a Dictaphone. There will also be a video recording of our faces. After the interview, the researcher will upload the video and voice files to a password protected computer. The audio file will be deleted from the Dictaphone. The researcher will be the only person who has access to this computer. The audio file will be destroyed after the interview has been transcribed.
-

Will my participation be confidential?

- Your involvement and any information the researcher collects about you will be confidential. The researcher will remove any information that could help others work out who you are. The researcher will do this before the project is handed in as university coursework.

- The researcher will need to share a small amount of information with the people helping her with the study (the project team). The project team must also keep your information confidential.
- Only members of the research team and responsible members of the University of Southampton may be given access to data about you for monitoring purposes and/or to carry out an audit of the study to ensure that the research is complying with applicable regulations. Individuals from regulatory authorities (people who check that we are carrying out the study correctly) may require access to your data. All of these people have a duty to keep your information, as a research participant, strictly confidential.
- The researcher will share the date, time and place of your interview with one member of the project team. The researcher will tell the person where they can find your contact information (in the locked cabinet). This is in case they cannot contact the researcher after the interview.
- If the researcher is worried about something you have said she will need to tell someone who can help you stay safe. This could be information about hurting yourself, someone hurting you or you hurting other people. The researcher will talk to you about this. Together you can think about any extra support you might need. If the researcher believes someone may be in imminent danger this could include calling the emergency services.
- Your participation and the information we collect about you during the course of the research will be kept strictly confidential.

Do I have to take part?

No, it is entirely up to you to decide whether or not to take part. If you decide you want to take part, you will need to sign a consent form to show you have agreed to take part.

What happens if I change my mind?

You can change your mind about taking part at any time. You do not have to give a reason. If you decide you do not want to continue, you can tell the researcher. The researcher will delete the audio recording. You will still receive a £25 amazon voucher to reimburse you for your time. You might change your mind after the interview. If you do change your mind, you can contact the researcher by email. It may not be possible to remove your interview from the study if it has been prepared for analysis.

What will happen to the results of the research?

Your personal information will remain confidential. The researcher will submit the results of the study as her university coursework. After the university work has been marked, the researcher hopes to write up the project for a research journal. This will be to help others find out about the results of this study. You can ask for a copy of this work if you would like.

Where can I get more information?

If you would like more information about this study, you can contact the researcher, Charlotte Scrivens, or the lead supervisor, Dr Melanie Hodgkinson by email.

What happens if there is a problem?

If you have a concern about any part of this study, you should speak to the researcher, Charlotte Scrivens or the lead supervisor, Dr Melanie Hodgkinson by email.

If you remain unhappy or have a complaint about any part of this study, please contact the University of Southampton Research Integrity and Governance Manager (023 8059 5058, rgoinfo@soton.ac.uk).

Data Protection Privacy Notice

The University of Southampton conducts research to the highest standards of research integrity. As a publicly funded organisation, the University has to ensure that it is in the public interest when we use personally-identifiable information about people who have agreed to take part in research. This means that when you agree to take part in a research study, we will use information about you in the ways needed, and for the purposes specified, to conduct and complete the research project. Under data protection law, 'Personal data' means any information that relates to and is capable of identifying a living individual. The University's data protection policy governing the use of personal data by the University can be found on its website (<https://www.southampton.ac.uk/legalservices/what-we-do/data-protection-and-foi.page>).

This Participant Information Sheet tells you what data will be collected for this project and whether this includes any personal data. Please ask the research team if you have any questions or are unclear what data is being collected about you.

Our privacy notice for research participants provides more information on how the University of Southampton collects and uses your personal data when you take part in one of our research projects and can be found at <http://www.southampton.ac.uk/assets/sharepoint/intranet/Is/Public/Research%20and%20Integrity%20Privacy%20Notice/Privacy%20Notice%20for%20Research%20Participants.pdf>

Any personal data we collect in this study will be used only for the purposes of carrying out our research and will be handled according to the University's policies in line with data protection law. If any personal data is used from which you can be identified directly, it will not be disclosed to anyone else without your consent unless the University of Southampton is required by law to disclose it.

Data protection law requires us to have a valid legal reason ('lawful basis') to process and use your Personal data. The lawful basis for processing personal information in this research study is for the performance of a task carried out in the public interest. Personal data collected for research will not be used for any other purpose.

For the purposes of data protection law, the University of Southampton is the 'Data Controller' for this study, which means that we are responsible for looking after your information and using it properly. The University of Southampton will keep identifiable information about you for five years after the study has finished after which time any link between you and your information will be removed.

Contact information:

Charlotte Scrivens (researcher) - C.A.Scrivens@soton.ac.uk

Dr Melanie Hodgkinson (lead supervisor) - M.J.Hodgkinson@soton.ac.uk

Thank you!

Thank you for taking the time to read the information sheet and considering taking part in this study.

Appendix H Participant consent form

CONSENT FORM

Study title: An interpretative Phenomenological Analysis: The Experiences of Adults with Autism Spectrum Condition (ASC) of Accessing and Engaging in Psychological Support following trauma symptoms

Researcher name: Charlotte Scrivens

ERGO number: 55779

Please initial the box(es) if you agree with the statement(s):

The researcher has explained the project to me.	
I have read and understood the information sheet (14.09.2020/ version 3) and have had the opportunity to ask the researcher questions about the study.	
I agree to take part in this research project and agree for my data to be used for the purpose of this study.	
I understand my participation is voluntary and I may withdraw (at any time up until 2 weeks after my interview). I can do this at any point and for any reason without my participation rights being affected.	
I understand the researcher will ask me questions and the answers will be recorded using video and a voice recorder.	

<p>I understand that the researcher is a student and my interview will help her complete a piece of coursework.</p>	
<p>I understand that I may be quoted directly in reports of the research but that my name or any other information that could identify me will be removed.</p>	
<p>I would like to take part in the interviews.</p>	
<p>I understand that I will receive a £25 Amazon gift voucher after finishing the interview to reimburse me for my time.</p>	
<p>I understand that everything I talk about in the interview is confidential unless the researcher believes there is an immediate risk of serious harm to the participant or someone else. If the researcher believes someone may be in imminent danger this could include calling the emergency services.</p>	

If you want to take part in the study, please write your name here (print name)

.....

Signature of participant.....

Date.....

Name of researcher (print name)

Signature of
researcher

Date.....

Appendix I Ethical approval

Approved by Research Integrity and Governance team - ERGO II 55779

The logo for the University of Southampton, featuring the text "UNIVERSITY OF" in a small, uppercase font above the word "Southampton" in a larger, serif font. The logo is white and is set against a dark teal background.

ERGO II – Ethics and Research Governance Online <https://www.ergo2.soton.ac.uk>

Submission ID: 55779

Submission Title: An interpretative Phenomenological Analysis: The Experiences of Adults with Autism Spectrum Condition (ASC) of Accessing and Engaging in Psychological Support Following Trauma Symptoms

Submitter Name: Charlotte Scrivens

The Research Integrity and Governance team have reviewed and approved your submission.

You can begin your research unless you are still awaiting specific Health and Safety approval (e.g. for a Genetic or Biological Materials Risk Assessment) or external review.

Appendix J Interview schedule

Interview schedule

Reminders to participants:

There are no right or wrong answers! Please take your time in answering. Sometimes I might ask shorter questions to make sure I understand what you told me (i.e., so are you saying...?) or if I need more information (i.e., Can you tell me more about that?) I also might return to a question if I feel the need.

It is really important that you have the chance to tell me about everything that you would like to during our interview. Therefore, there may be times when I will interrupt you or bring you back to the question. This is not because I am not interested in what you have to say, I just need to make sure that we have enough time to cover all of the questions. I hope this is ok.

I will be asking you about your traumatic experiences and trauma symptoms. You do not need to tell me any of the details about your traumatic life event(s) or details about what happened to you.

Example questions:

Part 1

1) Demographic questions

- Gender
- Ethnicity
- Age
- Age at Autism Spectrum Disorder diagnosis
- Who the participant is living with/relationship status
- Co-morbid mental health diagnoses
- Employment status

Part 2

Questions

2) I understand that you have experienced professional psychological support for a difficult/traumatic life experience. Please can you start by giving me an overview of the support you've had?

Prompts:

- Can you tell me more about the psychological support you have received?
- How did you find this professional psychological support?
- Did you access this support from the NHS or privately?
- Have you seen more than one therapist? How many?

Part 3

3) Please could you tell me about how you came to engage in psychological support for your trauma symptoms?

Prompts:

- Can you describe your difficulties you were experiencing that led you to seek psychological support for your traumatic experiences?
- Did you have any other trauma symptoms?
- How long had you been experiencing these symptoms?
- Did you recognise these symptoms as trauma symptoms? How did you notice them?
- Can you tell me about how you went about finding psychological support for your trauma symptoms?
- How did you feel about this process?

Part 4**Questions**

4) Can you tell me more about it was for you having that psychological support?

Prompts:

- What did your psychological support look like? (format/number of sessions/delivery)
- What was it like for you before your first session?
- How did you feel before/after your sessions?
- During the psychological support how did you feel?

5) Was there anything that was difficult or helpful about your psychological support?

Prompts:

- Overall, was this a positive or a negative experience for you? Can you explain why?
- Can you tell me more about the things that were difficult?
- Can you tell me about the things that were positive/helpful?
- Can you tell me anything about the sessions/appointments that was difficult?
- Can you tell me anything about the sessions/appointments that was helpful?
- Were your needs related to your Autism considered and met?

6) What was your relationship like with your therapist?

- Can you tell me about the positives?
- Was there anything that they did that was unhelpful?
- Was there anything that you would have liked them to have done differently?

Part 5

Questions:

7) Looking back, how do you feel about your experiences of having psychological support?

Prompts:

- Are there things that you learned during your psychological support?
- Are you glad you did it?
- Do you have any regrets about it?
- Would your experience of psychological support for trauma make you more or less likely to seek psychological support again in the future? Can you explain why?

8) What advice would you give psychological support services about supporting people with ASD?

Prompts:

- Do you have any advice specifically relating to trauma support?
- Is there anything you think they could do differently?

9) What advice would you give to someone with ASD who wants to get some support for coping with their difficult life experiences?

Final question:

10) Is there anything else you would like to tell me about or add before we end the interview?

Additional probe questions:

Can you tell me more about that?

Why is that important to you?

What does that mean to you?

What makes you think XXXX?

You used the word XXX, what does that mean to you?

You said XXX, can you tell me more about that?

What makes you think XXX?

You said XXX and XXX, is one more important than the other?

You said XXX has changed, how do you think it has changed?

Appendix K PowerPoint presentation containing interview prompts for participants

Reminders to participants

- There are no right or wrong answers!
- Please take your time in answering. Sometimes I might ask shorter questions to make sure I understand what you told me (i.e., so are you saying...?) or if I need more information (i.e., Can you tell me more about that?) I also might return to a question if I feel the need.
- It is really important that you have the chance to tell me about everything that you would like to during our interview. Therefore, there may be times when I will interrupt you or bring you back to the question. This is not because I am not interested in what you have to say, I just need to make sure that we have enough time to cover all of the questions. I hope this is ok.
- **I will be asking you about your traumatic experiences and trauma symptoms. You do not need to tell me any of the details about your traumatic life event(s) or details about what happened to you.**

Question 1:

- Please can you tell me about your...
 - Gender
 - Ethnicity
 - Age
 - Age at Autism Spectrum Disorder diagnosis
 - Who you live with/relationship status
 - Mental health diagnoses
 - Employment status

Question 2:

I understand that you have experienced professional psychological support for a difficult/traumatic life experience. Please can you start by giving me an overview of the support you've had?

You may like to consider:

- Can you tell me more about the psychological support you have received?
- How did you find this professional psychological support?
- Did you access this support from the NHS or privately?
- Have you seen more than one therapist? How many?

Question 3:

Please could you tell me about how you came to engage in psychological support for your trauma symptoms?

You may like to consider:

- Can you describe your difficulties you were experiencing that led you to seek psychological support for your traumatic experiences?
- Did you have any other trauma symptoms?
- How long had you been experiencing these symptoms?
- Did you recognise these symptoms as trauma symptoms? How did you notice them?
- Can you tell me about how you went about finding psychological support for your trauma symptoms?
- How did you feel about this process?

Question 4:

Can you tell me more about it was for you having that psychological support?

You may want to consider:

- What did your psychological support look like? (format/number of sessions/delivery)
- What was it like for you before your first session?
- How did you feel before/after your sessions?
- During the psychological support how did you feel?

Question 5:

Was there anything that was difficult or helpful about your psychological support?

You might like to consider:

- Overall, was this a positive or a negative experience for you? Can you explain why?
- Can you tell me more about the things that were difficult?
- Can you tell me about the things that were positive/helpful?
- Can you tell me anything about the sessions/appointments that was difficult?
- Can you tell me anything about the sessions/appointments that was helpful?
- Were your needs related to your Autism considered and met?

Question 6:

What was your relationship like with your therapist?

You may like to consider:

- Can you tell me about the positives?
- Was there anything that they did that was unhelpful?
- Was there anything that you would have liked them to have done differently?

Question 7:

Looking back, how do you feel about your experiences of having psychological support?

You may like to consider:

- Are there things that you learned during your psychological support?
- Are you glad you did it?
- Do you have any regrets about it?
- Would your experience of psychological support for trauma make you more or less likely to seek psychological support again in the future? Can you explain why?

Question 8:

Can you tell me about the process of seeking psychological support and how this was for you?

You may like to consider:

- How did you come to engage in psychological support for your trauma symptoms?
- Why did you decide to look for psychological support?
- Were you looking for a particular type of psychological support?
- How did you go about finding psychological support for your trauma symptoms?
- What made you decide to participate in the particular psychological support you chose to engage in?
- What was it like setting up the psychological support? How did you feel about this process?

Question 9:

What advice would you give to someone with ASD who wants to get some support for coping with their difficult life experiences?

Question 10:

Is there anything else you would like to tell me about or add before we end the interview?

Thank you!

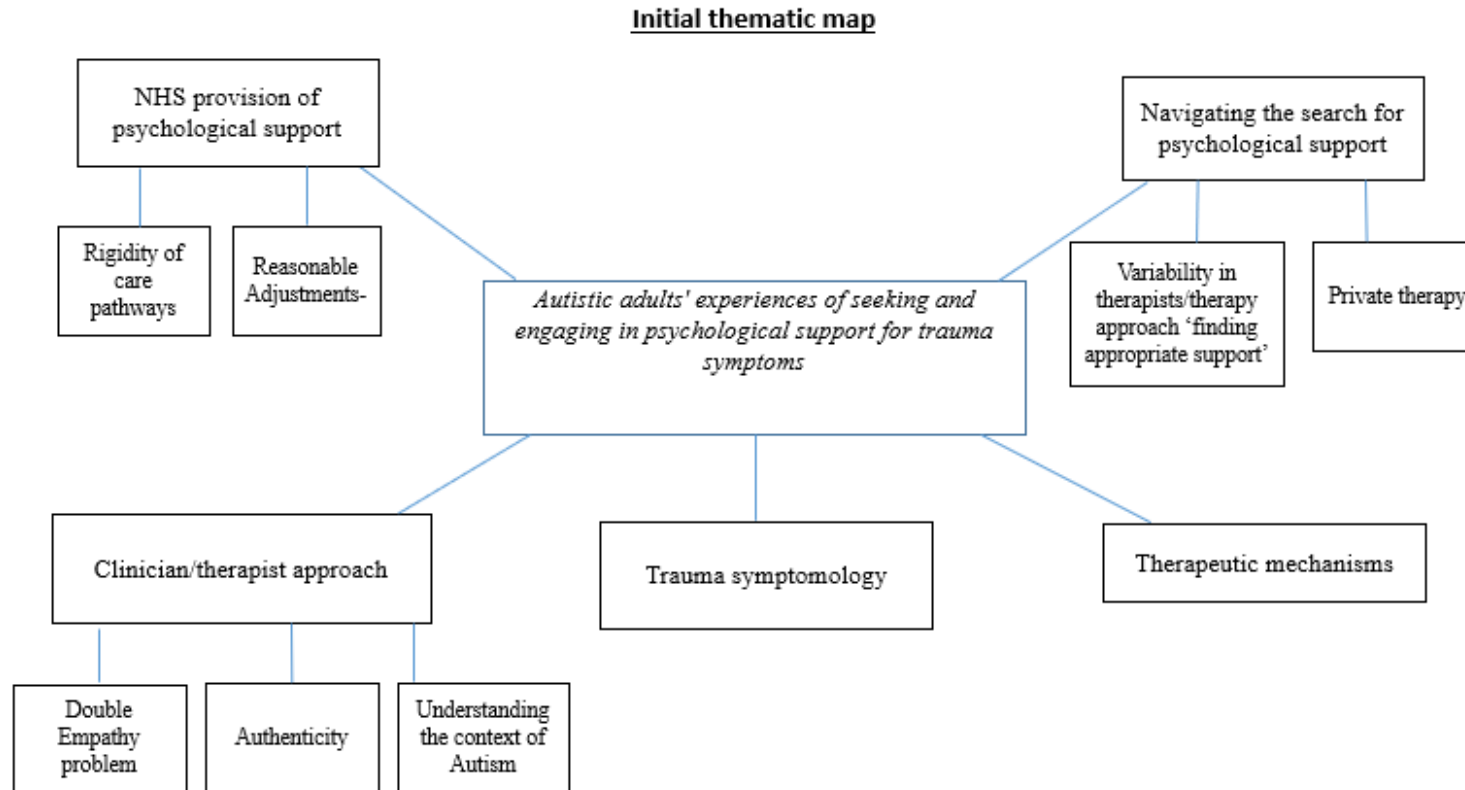
Appendix L Excerpt of IPA coding

Acknowledgements

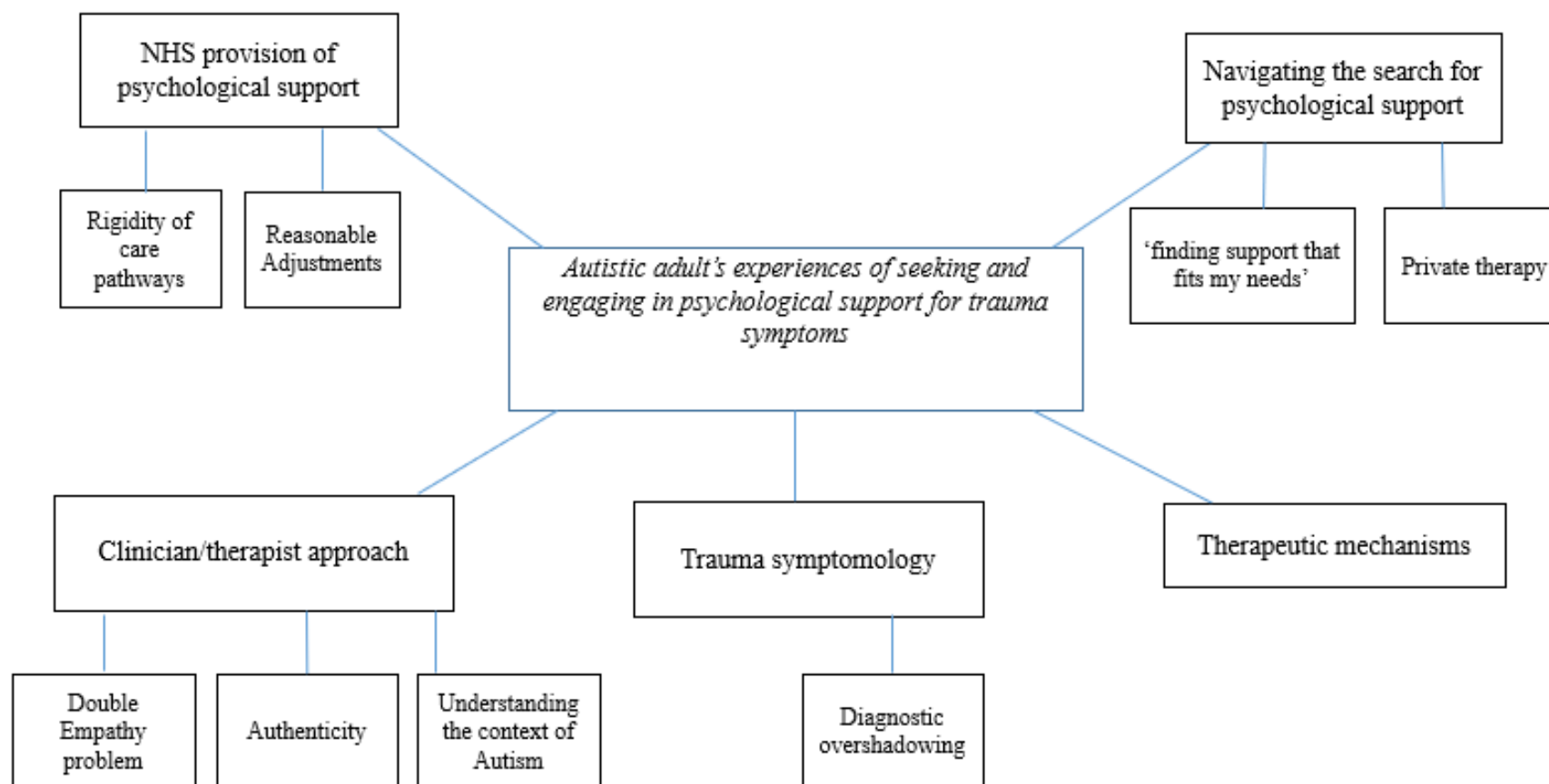
Exploratory comments	Transcript	Identified Themes
<p>PROMPT: overview of experiences?</p> <p>Describes details about the format of therapy –CBT, One to one Longer term therapy- significant? Sense of forced/reluctance- ‘tried’ ‘make me’</p> <p>PROMPT: tell me more</p> <p>‘We’ – indication of collaboration within the process P places fault/blame with themselves, their inability to understand the therapy</p> <p>PROMPT: unpacking mechanisms behind difficulties Confusion, complete lack of understanding <i>‘what the hell’ Emphasized confusion Difficulty articulating the difficulties – confusion in words</i> <i>Interchanging between use of ‘I’ ‘they’ and ‘we’ – confusion – possible lack of collaboration</i> Repetition of ‘I’- sense P felt at fault <i>hesitant repetition of ‘didn’t understand’</i> Sense of complete disconnect between therapist and P understanding of the therapy</p> <p>PROMPT: more information</p> <p><i>Repetition ‘we tried’ –effort entailed in process</i> Difficulty articulating experience- emphasizes discomfort in talking about their experience of EMDR?</p>	<p>Research: Can you give me a bit of an overview of the support you’ve had?</p> <p>Participant: Then I was referred to CBT therapy, which was one-to-one, and I did that weekly for a year. Oh, and before we tried CBT, they tried to make me do EMDR.</p> <p>Research: Can you talk a bit more about that and how that was for you?</p> <p>Participant: Yeah. I...we tried, like, two or three sessions, I couldn’t do it at all.</p> <p>Research: Do you know what it was about it that was difficult for you?</p> <p>Participant: I just didn’t understand what the hell we were doing, to be honest, so I had no idea what they...I didn’t understand a clue what the concept of what they were trying to do, or... I just didn’t understand what we were meant to be doing, to be honest.</p> <p>Research: And at the start of the EMDR, did the therapist try and do a little bit of explanation about the approach?</p> <p>Participant: She did try, yeah, she did try to explain it, and, like, I don’t know...like, we tried to do some of the, like, techniques and we tried practising it and stuff,</p>	<p>NHS Provision of psychological support</p> <p>Importance of psychoeducation Double empathy problem?</p>

<p><i>Speech is incoherent; Repetition 'I don't know' – Sense of trying to articulate and convey confusing and difficult feelings; overwhelming?</i></p> <p>Sense that the lack of success in therapy was due to her, her inability and lack of understanding – no mention of therapist's role</p> <p><i>Use of 'just' emphasizes struggle to explain. Tails off.</i></p> <p>PROMPT: visualisation?</p> <p><i>Firm tone – 'really'- emphasizes struggle with imagery</i></p> <p>Difficulty related to Autism – implications for therapy and use of visualisation</p> <p>EMDR therapy was an uncomfortable, negative, and unhelpful experience. <i>Use of 'a lot worse' – emphasizing severity/extent of impact of EMDR sessions</i></p> <p>Emotive – embarrassment? Trails off</p> <p>P clearly felt that she was at fault for confusing around therapy process- what are her expectations of therapy? Where did those develop from?</p> <p><i>Drawn out sigh- relating sense of frustration and hopelessness around that experience</i></p>	<p>like the visualisation part but I just...I don't know, I just couldn't grasp what we were meant to be doing or, like, I just couldn't get my head in the place where we were meant...I don't know why I couldn't, I just...it didn't make sense to me, like, what we were meant to be doing. I don't know why but...I just...I couldn't ...</p> <p>Research: Can you tell me a bit more about the problems you mentioned with visualisation in your EMDR sessions?</p> <p>Participant: I really can't do that, like, no, I just can't do that. I told her that, that I'm not very good at, like, imagining things and, like...that's one of the things that's actually in my, like, diagnostic report, I can't imagine things, like, I just can't do that. We carried on with it anyway and it just did not work. I just found the whole experience; I just remember it was very uncomfortable and it just didn't work at all well. Yeah, it just made everything a lot worse, to be honest. I'd always come away feeling like...I'd always come home, and, like, my behaviours would be worse, and I'd feel like...I don't know, a lot worse (SIGH).</p>	<p>Accessing support that fits my needs</p> <p>Double empathy problem? Clinician style</p> <p>Importance of meaningful reasonable adjustments to therapy tools</p>
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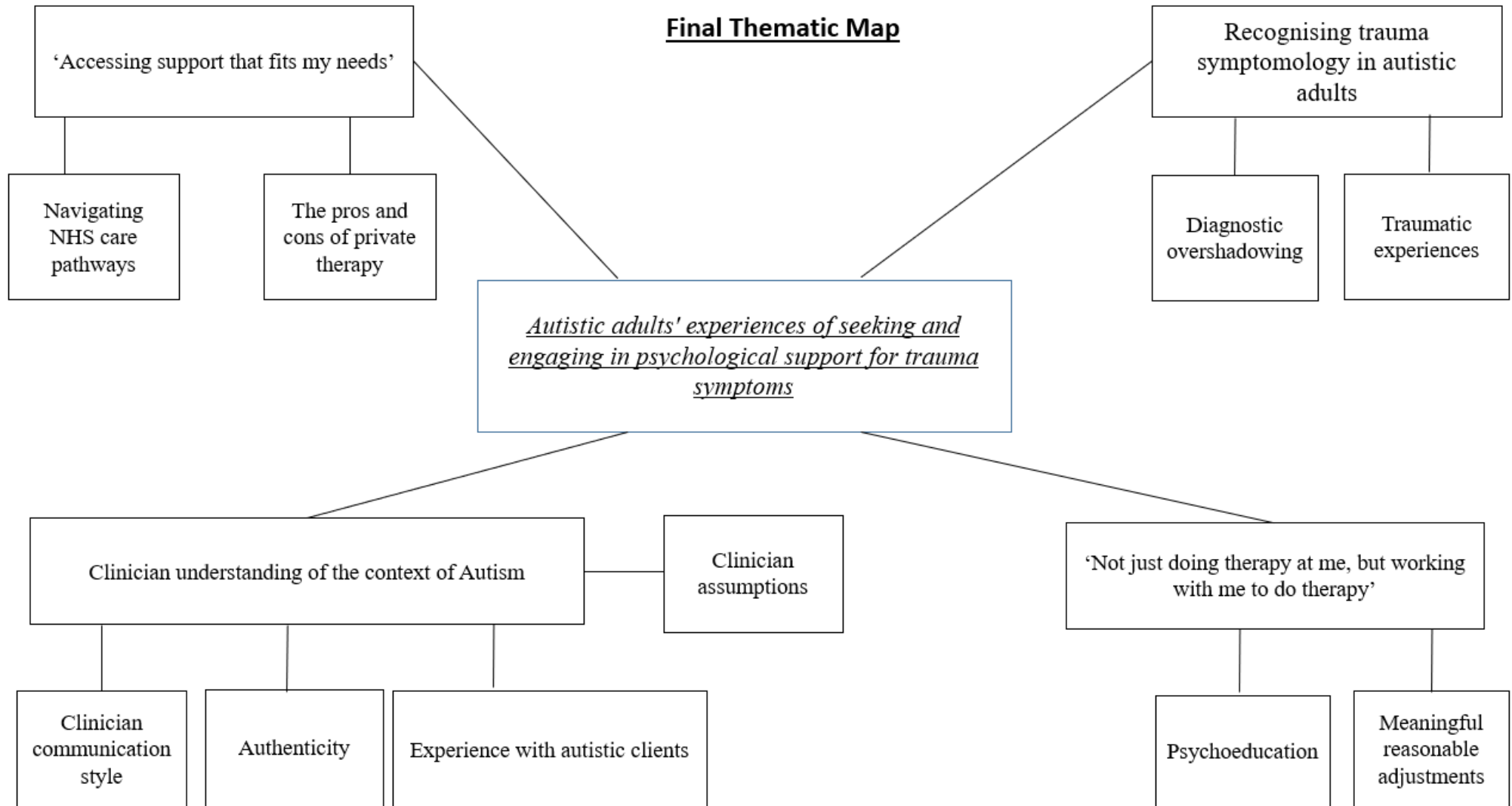
Appendix M Thematic maps illustrating theme progression



Developed Thematic Map



Final Thematic Map



List of References

- Adrian, J. A. L., & Stitt, A. (2017). Pet loss, complicated grief, and post-traumatic stress disorder in Hawaii. *Anthrozoös*, 30(1), 123-133.
- American Psychiatric Association. (1980). Diagnostic and statistical manual of mental disorders (3rd ed.). Washington, DC: Author.
- American Psychiatric Association (2013). Diagnostic and statistical manual of mental disorders (5th ed.). Arlington, VA: American Psychiatric Publishing.
- Ashley-Binge, S., & Cousins, C. (2020). Individual and organisational practices addressing social workers' experiences of vicarious trauma. *Practice*, 32(3), 191-207.
- Atwoli, L., Stein, D. J., Koenen, K. C., & McLaughlin, K. A. (2015). Epidemiology of posttraumatic stress disorder: prevalence, correlates and consequences. *Current opinion in psychiatry*, 28(4), 307.
- Autism Act (2009). Retrieved from <http://www.legislation.gov.uk/ukpga/2009/15/content>
- Barkham, M., Bewick, B., Mullin, T., Gilbody, S., Connell, J., Cahill, J., ... & Evans, C. (2013). The CORE-10: A short measure of psychological distress for routine use in the psychological therapies. *Counselling and Psychotherapy Research*, 13(1), 3-13.
- Baron-Cohen, S., Wheelwright, S., Robinson, J., & Woodbury-Smith, M. (2005). The adult Asperger assessment (AAA): a diagnostic method. *Journal of autism and developmental disorders*, 35(6), 807.
- Bejerot, S., Eriksson, J. M., & Mörtberg, E. (2014). Social anxiety in adult autism spectrum disorder. *Psychiatry research*, 220(1-2), 705-707.
- Benevides, T. W., Shore, S. M., Palmer, K., Duncan, P., Plank, A., Andresen, M. L., ... & Coughlin, S. S. (2020). Listening to the autistic voice: Mental health priorities to guide research and practice in autism from a stakeholder-driven project. *Autism*, 24(4), 822-833.
- Bercier, M. L., & Maynard, B. R. (2015). Interventions for secondary traumatic stress with mental health workers: A systematic review. *Research on Social Work Practice*, 25(1), 81-89.
- Bradshaw, P., Pickett, C., van Driel, M. L., Brooker, K., & Urbanowicz, A. (2021). 'Autistic' or 'with autism'? *Australian Journal of General Practice*, 50(3), 104-108.

List of References

Braun, V., & Clarke, V. (2006). Using thematic analysis in psychology. *Qualitative research in psychology, 3*(2), 77-101.

Brenner, J., Pan, Z., Mazefsky, C., Smith, K. A., & Gabriels, R. (2018). Behavioral symptoms of reported abuse in children and adolescents with autism spectrum disorder in inpatient settings. *Journal of autism and developmental disorders, 48*(11), 3727-3735.

Brewin, C. R., Rumball, F., & Happé, F. (2019). Neglected causes of post-traumatic stress disorder. *BMJ, 365*.

Cascio, M. A., Weiss, J. A., & Racine, E. (2021). Making autism research inclusive by attending to intersectionality: A review of the research ethics literature. *Review Journal of Autism and Developmental Disorders, 8*, 22-36.

Camm-Crosbie, L., Bradley, L., Shaw, R., Baron-Cohen, S., & Cassidy, S. (2019). 'People like me don't get support': Autistic adults' experiences of support and treatment for mental health difficulties, self-injury and suicidality. *Autism, 23*(6), 1431-1441.

Carrigan, N., & Allez, K. (2017). Cognitive behaviour therapy for post-traumatic stress disorder in a person with an autism spectrum condition and intellectual disability: A case study. *Journal of applied research in intellectual disabilities, 30*(2), 326-335.

Carter, S. (2009). Bullying of students with Asperger Syndrome. *Issues in Comprehensive Pediatric Nursing, 32*, 145-154.

Checklist, C. Q. (2018). Critical Appraisal Skills Programme. URL: <https://casp-uk.net/wp-content/uploads/2018/01/CASP-Qualitative-Checklist-2018.pdf> [accessed 2021-04-27].

Cook Jr, E. H., Kieffer, J. E., Charak, D. A., & Leventhal, B. L. (1993). Autistic disorder and post-traumatic stress disorder. *Journal of the American Academy of Child & Adolescent Psychiatry, 32*(6), 1292-1294.

Cooke, A., Smith, D., & Booth, A. (2012). Beyond PICO: the SPIDER tool for qualitative evidence synthesis. *Qualitative health research, 22*(10), 1435-1443.

Cooper, K., Loades, M. E., & Russell, A. (2018). Adapting psychological therapies for autism. *Research in autism spectrum disorders, 45*, 43-50.

- Crane, L., Adams, F., Harper, G., Welch, J., & Pellicano, E. (2019). 'Something needs to change': mental health experiences of young autistic adults in England. *Autism, 23*(2), 477-493.
- Crane, L., Davidson, I., Prosser, R., & Pellicano, E. (2019). Understanding psychiatrists' knowledge, attitudes and experiences in identifying and supporting their patients on the autism spectrum: online survey. *BJPsych open, 5*(3).
- CRD (2009). Systematic Reviews CRD's guidance for undertaking reviews in health care. York: Centre for Reviews and Dissemination (CRD), University of York.
- Estell, D. B., Farmer, T. W., Irvin, M. J., Crowther, A., Akos, P., & Boudah, D. J. (2009). Students with exceptionalities and the peer group context of bullying and victimization in late elementary school. *Journal of Child and Family Studies, 18*(2), 136–150.
- Fazel, M., Stratford, H. J., Rowsell, E., Chan, C., Griffiths, H., & Robjant, K. (2020). Five applications of narrative exposure therapy for children and adolescents presenting with post-traumatic stress disorders. *Frontiers in psychiatry, 11*, 19.
- First, M. B., Spitzer, R. L., Gibbon, M., & Williams, J. B. (1997). *User's guide for the Structured clinical interview for DSM-IV axis I disorders SCID-I: clinician version*. American Psychiatric Pub.
- Fletcher-Watson, S., Adams, J., Brook, K., Charman, T., Crane, L., Cusack, J., ... & Pellicano, E. (2019). Making the future together: Shaping autism research through meaningful participation. *Autism, 23*(4), 943-953.
- Fletcher-Watson, S., Brook, K., Hallett, S., Murray, F., & Crompton, C. J. (2021). Inclusive Practices for Neurodevelopmental Research. *Current Developmental Disorders Reports, 1-10*.
- Frueh, B. C., Cusack, K. J., Grubaugh, A. L., Sauvageot, J. A., & Wells, C. (2006). Clinicians' perspectives on cognitive-behavioral treatment for PTSD among persons with severe mental illness. *Psychiatric Services, 57*(7), 1027-1031.
- Fuld, S. (2018). Autism spectrum disorder: the impact of stressful and traumatic life events and implications for clinical practice. *Clinical Social Work Journal, 46*(3), 210-219.

List of References

- Gadow, K. D., & Sprafkin, J. (2013). The child & adolescent symptom inventory-5 (CASI-5).
- Grodberg, D., Weinger, P. M., Kolevzon, A., Soorya, L., & Buxbaum, J. D. (2012). Brief report: the autism mental status examination: development of a brief autism-focused exam. *Journal of Autism and Developmental Disorders, 42*(3), 455-459.
- Grubaugh, A. L., Cusack, K. J., & Zinzow, H. M. (2008). Trumping Rules affect diagnoses of persons with severe mental illness. *Psychiatric Services, 59*(10), 1219–1220.
- Guest, J. D., & Ohrt, J. H. (2018). Utilizing child-centered play therapy with children diagnosed with autism spectrum disorder and endured trauma: A case example. *International Journal of Play Therapy, 27*(3), 157.
- Hamby, S. L., Finkelhor, D., Ormrod, R. K., & Turner, H. A. (2004). The juvenile victimization questionnaire (JVQ): Administration and scoring manual. *Durham, NH: Crimes Against Children Research Center, 10-18*.
- Haruvi-Lamdan, N., Horesh, D., & Golan, O. (2018). PTSD and autism spectrum disorder: Co-morbidity, gaps in research, and potential shared mechanisms. *Psychological trauma: theory, research, practice, and policy, 10*(3), 290.
- Haruvi-Lamdan, N., Horesh, D., Zohar, S., Kraus, M., & Golan, O. (2020). Autism spectrum disorder and post-traumatic stress disorder: An unexplored co-occurrence of conditions. *Autism, 24*(4), 884-898.
- Helverschou, S. B., Bakken, T. L., & Martinsen, H. (2011). Psychiatric disorders in people with autism spectrum disorders: Phenomenology and recognition. In *International handbook of autism and pervasive developmental disorders* (pp. 53-74). Springer, New York, NY.
- Herman, J. L. (1992). Complex PTSD: A syndrome in survivors of prolonged and repeated trauma. *Journal of Traumatic Stress, 5*, 377–391.
- Hoch, J. D., & Youssef, A. M. (2020). Predictors of Trauma Exposure and Trauma Diagnoses for Children with Autism and Developmental Disorders Served in a Community Mental Health Clinic. *Journal of autism and developmental disorders, 50*(2), 634-649.

- Hollocks, M. J., Lerh, J. W., Magiati, I., Meiser-Stedman, R., & Brugha, T. S. (2019). Anxiety and depression in adults with autism spectrum disorder: a systematic review and meta-analysis. *Psychological medicine*, 49(4), 559-572.
- Hoover, D. W. (2015). The effects of psychological trauma on children with autism spectrum disorders: a research review. *Review Journal of Autism and Developmental Disorders*, 2(3), 287-299.
- Hoover, D. W., & Romero, E. M. (2019). The Interactive Trauma Scale: a web-based measure for children with autism. *Journal of autism and developmental disorders*, 49(4), 1686-1692.
- Hull, L., Petrides, K. V., Allison, C., Smith, P., Baron-Cohen, S., Lai, M. C., & nMandy, W. (2017). "Putting on my best normal": Social camouflaging in adults with autism spectrum conditions. *Journal of autism and developmental disorders*, 47(8), 2519-2534.
- Idsoe, T., Dyregrov, A., & Idsoe, E. C. (2012). Bullying and PTSD symptoms. *Journal of abnormal child psychology*, 40(6), 901-911.
- Idsoe, T., Vaillancourt, T., Dyregrov, A., Hagen, K. A., Ogden, T., & Nærde, A. (2021). Bullying victimization and trauma. *Frontiers in psychiatry*, 11, 1602.
- Ipci, M., Inci, S. B., Ardiç, Ü. A., & Ercan, E. S. (2017). A case of Asperger syndrome with comorbidity of posttraumatic stress disorder and selective mutism: Significant remission with the combination of aripiprazole and eye movement desensitization and reprocessing. *Journal of clinical psychopharmacology*, 37(1), 109-110.
- Iversen, S., & Robertson, N. (2020). Prevalence and predictors of secondary trauma in the legal profession: a systematic review. *Psychiatry, Psychology and Law*, 1-24.
- Kaufman, J., Birmaher, B., Brent, D., Rao, U. M. A., Flynn, C., Moreci, P., ... & Ryan, N. (1997). Schedule for affective disorders and schizophrenia for school-age children-present and lifetime version (K-SADS-PL): initial reliability and validity data. *Journal of the American Academy of Child & Adolescent Psychiatry*, 36(7), 980-988.
- Kenny, L., Hattersley, C., Molins, B., Buckley, C., Povey, C., & Pellicano, E. (2016). Which terms should be used to describe autism? Perspectives from the UK autism community. *Autism*, 20(4), 442-462.

List of References

- Kerns, C. M., Newschaffer, C. J., & Berkowitz, S. J. (2015). Traumatic childhood events and autism spectrum disorder. *Journal of Autism and Developmental Disorders*, 45(11), 3475-3486.
- Kessler, R. C., Aguilar-Gaxiola, S., Alonso, J., Benjet, C., Bromet, E. J., Cardoso, G., ... & Koenen, K. C. (2017). Trauma and PTSD in the WHO world mental health surveys. *European journal of psychotraumatology*, 8(sup5), 1353383.
- Kildahl, A. N., Helverschou, S. B., Bakken, T. L., & Oddli, H. W. (2020). "Driven and Tense, Stressed Out and Anxious": Clinicians' Perceptions of Post-Traumatic Stress Disorder Symptom Expressions in Adults with Autism and Intellectual Disability. *Journal of Mental Health Research in Intellectual Disabilities*, 13(3), 201-230.
- Kildahl, A. N., Helverschou, S. B., Bakken, T. L., & Oddli, H. W. (2020). "If we do not look for it, we do not see it": Clinicians' experiences and understanding of identifying post-traumatic stress disorder in adults with autism and intellectual disability. *Journal of Applied Research in Intellectual Disabilities*, 33(5), 1119-1132.
- Kildahl, A. N., Helverschou, S. B., & Oddli, H. W. (2020). Clinicians' retrospective perceptions of failure to detect sexual abuse in a young man with autism and mild intellectual disability. *Journal of Intellectual & Developmental Disability*, 45(2), 194-202.
- Kildahl, A. N., Bakken, T. L., Iversen, T. E., & Helverschou, S. B. (2019). Identification of post-traumatic stress disorder in individuals with autism spectrum disorder and intellectual disability: A systematic review. *Journal of Mental Health Research in Intellectual Disabilities*, 12(1-2), 1-25.
- King, R., & Desaulnier, C. L. (2011). Commentary: Complex Post-Traumatic Stress Disorder. Implications for Individuals with Autism Spectrum Disorders--Part II. *Journal on Developmental Disabilities*, 17(1).
- Kosatka, D., & Ona, C. (2014). Eye movement desensitization and reprocessing in a patient with Asperger's disorder: Case report. *Journal of EMDR Practice and Research*, 8(1), 13.
- Kupferstein, H. (2018). Evidence of increased PTSD symptoms in autistics exposed to applied behavior analysis. *Advances in Autism*, 4(1), 19-29.

Lai, M. C., Lombardo, M. V. & Baron-Cohen, S. (2014). Autism. *Lancet*, 383(8), 896-910.

Larkin, M., & Thompson, A. R. (2012). Interpretative phenomenological analysis in mental health and psychotherapy research. *Qualitative research methods in mental health and psychotherapy*, 101-116.

Le Couteur, A., Rutter, M., Lord, C., Rios, P., Robertson, S., Holdgrafer, M., & McLennan, J. (1989). Autism diagnostic interview: a standardized investigator-based instrument. *Journal of autism and developmental disorders*, 19(3), 363-387.

Lobregt-van Buuren, E., Sizoo, B., Mevissen, L., & de Jongh, A. (2019). Eye movement desensitization and reprocessing (EMDR) therapy as a feasible and potential effective treatment for adults with autism spectrum disorder (ASD) and a history of adverse events. *Journal of autism and developmental disorders*, 49(1), 151-164.

Lord, C., Rutter, M., & DiLavore, P. C. (1999). Autism Diagnostic Observation Schedule--Generic. *Dissertation Abstracts International Section A: Humanities and Social Sciences*.

Lord, C., Rutter, M., DiLavore, P. C., & Risi, S. (2005). Autism diagnostic observation schedule. In R. Tancredi, M. Sacconi, A. M. Persico, B. Parrini, R. Iglizzi, & R. Faggioli (Eds.), *Edizione Italiana*. Firenze: Giunti O.S.

Lord, C., Rutter, M., DiLavore, P., Risi, S., Gotham, K., & Bishop, S. (2012). Autism diagnostic observation schedule--2nd edition (ADOS-2). *Los Angeles, CA: Western Psychological Corporation*, 284.

Love, M., & Farber, B. A. (2019). Honesty in psychotherapy: Results of an online survey comparing high vs. low self-concealers. *Psychotherapy Research*, 29(5), 607-620.

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

Maddox, B. B., Crabbe, S., Beidas, R. S., Brookman-Frazee, L., Cannuscio, C. C., Miller, J. S., ... & Mandell, D. S. (2020). "I wouldn't know where to start": Perspectives from clinicians, agency

List of References

leaders, and autistic adults on improving community mental health services for autistic adults. *Autism*, 24(4), 919-930.

Maercker, A., Brewin, C., Bryant, R., Cloitre, M., van Ommeren, M., Jones, L,...Reed, G. (2013). Diagnosis and classification of disorders specifically associated with stress: proposals for ICD-11, *World Psychiatry* 12 (3), 198–206.

Maiano, C., Normand, C. L., Salvas, M. C., Moullec, G., & Aimé, A. (2016). Prevalence of school bullying among youth with autism spectrum disorders: A systematic review and meta-analysis. *Autism research*, 9(6), 601-615.

Mason, D., Ingham, B., Birtles, H., Michael, C., Scarlett, C., James, I. A., ... & Parr, J. R. (2021). How to improve healthcare for autistic people: A qualitative study of the views of autistic people and clinicians. *Autism*, 25(3), 774-785.

McCann, I. L., & Pearlman, L. A. (1990). Vicarious traumatization: A framework for understanding the psychological effects of working with victims. *Journal of traumatic stress*, 3(1), 131-149.

McCarthy, J., Blanco, R. A., Gaus, V. L., Razza, N. J., & Tomasulo, D. J. (2017). Trauma-and stressor-related disorders. In R. J. Fletcher, J. Barnhill, & S.-A. Cooper (Eds.), 2. *Diagnostic manual – Intellectual disability: A textbook of diagnosis of mental disorders in persons with intellectual disability* (pp. 353–400). Kingston, NY: NADD-National Association for the Dually Diagnosed. *research*, 9(6), 601-615.

McDonnell, C. G., Boan, A. D., Bradley, C. C., Seay, K. D., Charles, J. M., & Carpenter, L. A. (2019). Child maltreatment in autism spectrum disorder and intellectual disability: Results from a population-based sample. *Journal of Child Psychology and Psychiatry*, 60(5), 576-584.

McManus, S., Meltzer, H., Wessely, S., McManus, S., Meltzer, H., Brugha, T., ... & Jenkins, R. (2009). Posttraumatic stress disorder. *Adult psychiatric morbidity in England, 2007 Results of a household survey*, 53.

Mehtar, M., & Mukaddes, N. M. (2011). Posttraumatic stress disorder in individuals with diagnosis of autistic spectrum disorders. *Research in Autism Spectrum Disorders*, 5(1), 539-546.

Methley, A. M., Campbell, S., Chew-Graham, C., McNally, R., & Cheraghi-Sohi, S. (2014). PICO, PICOS and SPIDER: a comparison study of specificity and sensitivity in three search tools for qualitative systematic reviews. *BMC health services research*, *14*(1), 1-10.

Mevisen, L., Didden, R., Korzilius, H., & De Jongh, A. (2016). Assessing posttraumatic stress disorder in children with mild to borderline intellectual disabilities. *European Journal of Psychotraumatology*, *7*, 29786. <https://doi.org/10.3402/ejpt.v7.29786>.

Milton, D. E. (2012). On the ontological status of autism: the 'double empathy problem'. *Disability & Society*, *27*(6), 883-887.

Mitchell, P., Sheppard, E., & Cassidy, S. (2021). Autism and the double empathy problem: Implications for development and mental health. *British Journal of Developmental Psychology*, *39*(1), 1-18.

Mlinarić, A., Horvat, M., & Šupak Smolčić, V. (2017). Dealing with the positive publication bias: Why you should really publish your negative results. *Biochemia medica*, *27*(3), 447-452.

Moher, D., Liberati, A., Tetzlaff, J., Altman, D. G., & Prisma Group. (2009). Preferred reporting items for systematic reviews and meta-analyses: the PRISMA statement. *PLoS medicine*, *6*(7), e1000097.

National Institute for Clinical Excellence. (2012). *Autism Spectrum disorder in adults: diagnosis and management*. <https://www.nice.org.uk/guidance/cg142/resources/autism-spectrum-disorder-in-adults-diagnosis-and-management-pdf-35109567475909>.

National Institute for Clinical Excellence. (2018). *Posttraumatic stress disorder: management*. Retrieved from <https://www.nice.org.uk/guidance/ng116>

Nicolaidis, C., Raymaker, D., Kapp, S. K., Baggs, A., Ashkenazy, E., McDonald, K., ... & Joyce, A. (2019). The AASPIRE practice-based guidelines for the inclusion of autistic adults in research as co-researchers and study participants. *Autism*, *23*(8), 2007-2019.

Norcross, J. C., & Wampold, B. E. (2011). Evidence-based therapy relationships: research conclusions and clinical practices. *Psychotherapy*, *48*(1), 98.

List of References

Okazaki, K., Ota, T., Makinodan, M., Kishimoto, N., Yamamuro, K., Ishida, R., ... & Kishimoto, T. (2020). Associations of childhood experiences with event-related potentials in adults with autism spectrum disorder. *Scientific reports*, *10*(1), 1-10.

Ouzzani, M., Hammady, H., Fedorowicz, Z., & Elmagarmid, A. (2016). Rayyan—a web and mobile app for systematic reviews. *Systematic reviews*, *5*(1), 1-10.

Paez, A. (2017). Gray literature: An important resource in systematic reviews. *Journal of Evidence-Based Medicine*, *10*(3), 233-240.

Paul, A., Gallot, C., Lelouche, C., Bouvard, M. P., & Amestoy, A. (2018). Victimization in a French population of children and youths with autism spectrum disorder: a case control study. *Child and adolescent psychiatry and mental health*, *12*(1), 1-13.

Pellicano, E., Dinsmore, A., & Charman, T. (2014). What should autism research focus upon? Community views and priorities from the United Kingdom. *Autism*, *18*(7), 756-770.

Perrin, S., Meiser-Stedman, R., & Smith, P. (2005). The Children's Revised Impact of Event Scale (CRIES): Validity as a screening instrument for PTSD. *Behavioural and Cognitive Psychotherapy*, *33*(4), 487-498.

Peterson, J. L., Earl, R. K., Fox, E. A., Ma, R., Haidar, G., Pepper, M., ... & Bernier, R. A. (2019). Trauma and autism spectrum disorder: review, proposed treatment adaptations and future directions. *Journal of child & adolescent trauma*, *12*(4), 529-547.

Petticrew, M., & Roberts, H. (2006). *Systematic reviews in the social sciences*. In Malden, MA. Oxford: Blackwell Publishing

Pino, M., & Mortari, L. (2014). The inclusion of students with dyslexia in higher education: a systematic review using narrative synthesis. *Dyslexia*, *20*(4), 346–369.

PROSPERO: centre for reviews and dissemination. University of York, UK. [online] Available from: [<http://www.crd.york.ac.uk/PROSPERO/>] (accessed 27 April 2021).

Quality Assessment Tool for Quantitative Studies. Accessed December 28, 2020. <https://www.ehphp.ca/quality-assessment-tool-for-quantitative-studies/>

Raja, M. (2014). Suicide risk in adults with Asperger's syndrome. *The Lancet Psychiatry*, *1*(2), 99-101.

- Rayyan QRCI. [online] Available from: <https://rayyan.qcri.org/welcome> (accessed 27 April 2021).
- Reese, S., & Deutsch, S. A. (2020). Sexual assault victimization among children and youth with developmental disabilities: responding with trauma-informed care. *Journal of forensic nursing, 16*(1), 55-60.
- Rice, C. E., & Lee, L. C. (2017). Expanding the Global Reach of Research in Autism. *Autism: the international journal of research and practice, 21*(5), 515-517.
- Roberts, A. L., Koenen, K. C., Lyall, K., Robinson, E. B., & Weisskopf, M. G. (2015). Association of autistic traits in adulthood with childhood abuse, interpersonal victimization, and posttraumatic stress. *Child Abuse & Neglect, 45*, 135-142.
- Robinson, A. (2018). Emotion-focused therapy for autism spectrum disorder: A case conceptualization model for trauma-related experiences. *Journal of contemporary psychotherapy, 48*(3), 133-143.
- Rodgers, M., Sowden, A., Petticrew, M., Arai, L., Roberts, H., Britten, N., & Popay, J. (2009). Testing methodological guidance on the conduct of narrative synthesis in systematic reviews: effectiveness of interventions to promote smoke alarm ownership and function. *Evaluation, 15*(1), 49-73.
- Rodriguez, N., Steinberg, A., & Pynoos, R. S. (1998). UCLA post traumatic stress disorder reaction index for DSM-IV, child, adolescent, and parent versions. *Los Angeles, CA: University of California at Los Angeles.*
- Rotheram-Fuller, E., Kasari, C., Chamberlain, B., & Locke, J. (2010). Social involvement of children with autism spectrum disorders in elementary school classrooms. *Journal of Child Psychology and Psychiatry, 51*, 1227–1234.
- Rowley, E., Chandler, S., Baird, G., Simonoff, E., Pickles, A., Loucas, T., & Charman, T. (2012). The experience of friendship, victimization and bullying in children with an autism spectrum disorder: Associations with child characteristics and school placement. *Research in Autism Spectrum Disorders, 6*(3), 1126–1134.
- Rumball, F. (2019). A systematic review of the assessment and treatment of posttraumatic stress disorder in individuals with autism spectrum disorders. *Review Journal of Autism and Developmental Disorders, 6*(3), 294-324.
- Rumball, F., Brook, L., Happé, F., & Karl, A. (2021). Heightened risk of posttraumatic stress disorder in adults with autism spectrum disorder: The role of cumulative trauma and memory deficits. *Research in Developmental Disabilities, 110*, 103848.

List of References

- Rumball, F., Happé, F., & Grey, N. (2020). Experience of Trauma and PTSD Symptoms in Autistic Adults: Risk of PTSD Development Following DSM-5 and Non-DSM-5 Traumatic Life Events. *Autism research: official journal of the International Society for Autism Research*, 13(12), 2122-2132.
- Rutter, M., Bailey, A., & Lord, C. (2003). *The social communication questionnaire: Manual*. Western Psychological Services.
- Sanders, B., & Becker-Lausen, E. (1995). The measurement of psychological maltreatment: Early data on the child abuse and trauma scale. *Child abuse & neglect*, 19(3), 315-323.
- Schopler, E., Reichler, R. J., & Renner, B. R. (1988). *The childhood autism rating scale*. Los Angeles: Western Psychological Services.
- Schore, A. N. (2003). *Affect Dysregulation and Disorders of the Self*. Norton & Company.
- Shepler, T. L. (2016). *Assessing posttraumatic stress disorder in persons with autism spectrum disorder* (Doctoral dissertation, Alliant International University).
- Smith, J. A., Flowers, P., & Larkin, M. (2009). Interpretative phenomenological analysis: Theory, method and research.
- Smith, J. A. (2011). Evaluating the contribution of interpretative phenomenological analysis. *Health psychology review*, 5(1), 9-27.
- Sourander, A., Brunstein, K. A., Ikonen, M., Lindroos, J., Luntamo, T., Koskelainen, M., Ristkari, T., & Helenius, H. (2010). Psychosocial risk factors associated with cyberbullying among adolescents: A population-based study. *Archives of General Psychiatry*, 67(7), 720–728.
- Sparrow, S. S., Balla, D. A., & Cicchetti, D. V. (2008). Vineland adaptive behavior scales. In G. Balboni & L. Pedrabissi (Eds.), *Intervista, forma completa*. Firenze: Giunti O.S.
- Storch, E. A., Sulkowski, M. L., Nadeau, J., Lewin, A. B., Arnold, E. B., Mutch, P. J., ... & Murphy, T. K. (2013). *The phenomenology and clinical correlates of suicidal thoughts and behaviors in youth with autism spectrum disorders*. *Journal of autism and developmental disorders*, 43(10), 2450-2459.

Taylor, J. L., & Gotham, K. O. (2016). Cumulative life events, traumatic experiences, and psychiatric symptomatology in transition-aged youth with autism spectrum disorder. *Journal of Neurodevelopmental Disorders, 8*(1), 1-11.

The Joanna Briggs Institute. (2016). *Checklist for Case Reports*.

<http://joannabriggs.org/research/critical-appraisal-tools.html>. (Accessed 28 March 2021).

Thomas, B. H., Ciliska, D., Dobbins, M., & Micucci, S. (2004). A process for systematically reviewing the literature: providing the research evidence for public health nursing interventions. *Worldviews on Evidence-Based Nursing, 1*(3), 176-184.

Thomas, J., & Harden, A. (2008). Methods for the thematic synthesis of qualitative research in systematic reviews. *BMC medical research methodology, 8*(1), 1-10.

Ulman, R. B., & Brothers, D. (2013). *The shattered self: A psychoanalytic study of trauma*. Routledge.

Valenti, M., Ciprietti, T., Di Egidio, C., Gabrielli, M., Masedu, F., Tomassini, A. R., & Sorge, G. (2012). Adaptive response of children and adolescents with autism to the 2009 earthquake in L'Aquila, Italy. *Journal of autism and developmental disorders, 42*(6), 954-960.

Van Hooff, M., McFarlane, A. C., Baur, J., Abraham, M., & Barnes, D. J. (2009). The stressor Criterion-A1 and PTSD: a matter of opinion?. *Journal of Anxiety Disorders, 23*(1), 77-86.

Weathers, F. W., Blake, D. D., Schnurr, P. P., Kaloupek, D. G., Marx, B. P., & Keane, T. M. (2013). The clinician-administered PTSD scale for DSM-5 (CAPS-5). *Interview available from the National Center for PTSD at www.ptsd.va.gov, 6*.

Weathers, F. W., Blake, D. D., Schnurr, P. P., Kaloupek, D. G., Marx, B. P., & Keane, T. M. (2013). The life events checklist for DSM-5 (LEC-5). Instrument available from the National Center for PTSD.

Weathers, F. W., Litz, B. T., Keane, T. M., Palmieri, P. A., Marx, B. P., & Schnurr, P. P. (2013). The PTSD checklist for DSM-5 (PCL-5). *Scale available from the National Center for PTSD at www.ptsd.va.gov, 10*.

Weiss, D. S. M. C. R. (1997). Impact of Event Scale (IES-R). *The Impact of event Scale-Revised: assessing psychological trauma and PTSD*.

Weiss, J. A., & Lunsky, Y. (2010). Group cognitive behaviour therapy for adults with Asperger syndrome and anxiety or mood disorder: a case series. *Clinical Psychology & Psychotherapy, 17*(5), 438-446.

List of References

Wood, J. J., & Gadow, K. D. (2010). Exploring the nature and function of anxiety in youth with autism spectrum disorders. *Clinical Psychology: Science and Practice, 17*(4), 281-292.

World Health Organization. (1978). *International classification of procedures in medicine* (Vol. 1).

World Health Organization.

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

Yardley, L. (2000). Dilemmas in qualitative health research. *Psychology and health, 15*(2), 215-228.