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# Psychosocial Influences on the Health and Wellbeing of Autistic Individuals

Paul Reynolds-Cowie (BA Hons, MSc)

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School of Health and Wellbeing

College of Medical, Veterinary and Life Sciences

University of Glasgow

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**Note:** It is important to highlight that research indicates a preference from the autistic community for person or identity first language to be used when discussing autism, and so the term autistic person or individual will be used throughout this review. Indeed, autistic is now the recognised diagnostic label and preferred by many within the autistic community.

# Chapter 1: Autistic Individuals' Experiences and Perceptions of Victimisation: A Systematic Review and Meta-Ethnography

Prepared in accordance with the author requirements for [Research in Autism Spectrum Disorders; <u>https://www.sciencedirect.com/journal/research-in-autism-spectrum-disorders/publish/guide-for-authors</u>]

#### Abstract

#### Background

Autistic people are at an increased risk of being victimised across the lifespan. Existing research has generally adopted a quantitative approach, aiming to establish prevalence rates and risk factors. There has been an emergence of qualitative research seeking to understand the lived experience of victimisation among autistic people.

#### Aims and objectives

This systematic review and meta-ethnography aimed to synthesise qualitative evidence related to autistic peoples' experiences and perceptions of victimisation, and to theorise about how this may impact upon their mental health.

#### Design and Methods

A systematic search for qualitative research on autistic peoples' victimisation experiences was conducted in May and June 2024 across five databases: ASSIA, CINAHL, Medline, PsychInfo, and Web of Science CC. A proportion of titles and abstracts, as well as full text papers were screened by a second reviewer to enhance reliability. The modified CASP quality appraisal tool was used to assess the methodological quality of articles. Meta-ethnography was used to generate interpretative themes.

#### Results

27,093 items were retrieved prior to screening and eleven eligible papers were included in the review. Four third-order themes were identified: 'Normalisation and Expectation of Victimisation', 'Internalisation of Stigma', 'Impact of Victimisation Experiences and Stigma', and 'Responses to Victimisation Experiences, Stigma and Their Impact'.

#### Conclusions

The normalisation of victimisation and the internalisation of stigma were found to have a significant impact on autistic peoples' mental health. People often felt alone in coping with their experiences and resorted to coping strategies such as masking and compliance in an attempt to avoid further harm. These approaches were demonstrated to confer further risk to victimisation and impact on mental health. Implications for prevention and intervention were highlighted, particularly the need

for systemic change with regards to education and attitudes toward autistic and neurodivergent people more generally, and promising legislative and policy initiatives in relation to this were outlined.

Keywords: autism; victimisation; perceptions; experiences; qualitative; meta-ethnography

#### Introduction

Victimisation involves acts in which an individual is subject to cruel or unjust treatment, including bullying (intentional and repeated physical, verbal, and/or relational acts in situations wherein there is a difference in power) (Olweus, 1993), maltreatment (including neglect and physical and emotional abuse), sexual victimisation, (e.g. rape and sexual assault), and crime (e.g. robbery, theft and assault; Trundle et al., 2023). Autistic individuals report higher rates of violence and victimisation experiences than non-autistic individuals (Weiss & Fardella, 2018).

Disproportionate victimisation of autistic people relative to the general population has also been reported in other studies, e.g., adverse interpersonal interactions (63.25% vs. 32.33%; Haruvi-Lamdan et al., 2020), and sexual violence (78% vs. 47.4%; Brown-Lavoie et al., 2014). Elevated prevalence rates have also been reported in a recent systematic review (Trundle et al., 2023). This found that 40% of people reported sexual victimization, 16% reported being abused as a child and 84% of autistic adults reported having been victimised in more than one of the potential categories. Many of these experiences have been reported to be perpetrated by people whom they should have been able to trust such as friends, family members or carers (Forster & Pearson, 2020). The impact of victimisation on autistic people been associated with poorer emotional wellbeing and distress (Botha & Frost, 2020), and a range of mental health problems including depression and PTSD (Pearson et al., 2023).

Autism has traditionally been viewed as a neurodevelopmental condition that affects the way that a person interacts with, and experiences the world around them (Pellicano & den Houting, 2022). Within the conventional medical model the emphasis is generally on individual pathology; considering biological and physiological influences on health, with less attention paid to psychosocial factors which may also have an impact (Walker, 2012). Within this model autism has generally been perceived as a disability that resides within an individual (Pellicano & den Houting, 2022), and has often been deficit focused; highlighting what autistic individuals can't, rather than can do (Pellicano & den Houting, 2022). In more recent years the concept of neurodiversity has emerged, referring to the wide-ranging diversity that exists in human neurobiology (Kapp et al, 2019). This incorporates the entire spectrum of neurodevelopment, and rejects the notion that any divergence from what is perceived to be the norm is a defect requiring correction (Walker, 2012). However, this paradigm also recognises the very real challenges autistic individuals may experience. Proponents of neurodiversity argue that these difficulties are often the result of a social and environmental mismatch, rather than deficits intrinsic to the individual (Robertson, 2010; Kapp et al., 2013). For

instance, sensory sensitivities, communication differences, and mental health challenges are frequently reported by autistic individuals, and are acknowledged within the neurodiversity framework as areas requiring support and accommodation (Milton, 2012). Rather than denying the existence of impairments or needs, the neurodiversity perspective reframes them within the context of the social model of disability (Bagatell, 2010), emphasising that disabling experiences often stem from systemic barriers and a lack of societal inclusion (Kapp et al., 2013). In this way, neurodiversity promotes both the acceptance of autism as a valid identity, and the importance of targeted supports to improve quality of life, wellbeing, and autonomy.

Aligned with the neurodiversity paradigm, the double empathy problem (Milton, 2012) offers a revised perspective on how we understand communication difficulties between autistic and neurotypical people, reframing them as mutual, rather than one sided. For example, Milton (2012), argues that more traditional views would frame perspective taking difficulties solely as an autistic area of deficit, without considering that neurotypical people also struggle to understand the autistic perspective, due to fundamentally different perceptual and communicative frameworks. Indeed, Milton (2012), highlights how these differences can resemble cross-cultural interactions, where both groups must actively engage in bridging communication gaps. The implications of this reframing are that support and interventions for autistic people should shift away from solely teaching autistic individuals to conform to neurotypical norms and promote reciprocal understanding and inclusivity (Crompton et al., 2020). It is suggested that emphasising mutual adaptation and shared responsibility in communication can contribute to greater social inclusion and challenge deficit focused models of autism (Milton, 2012). Ultimately, it supports a culture in which diversity in communication styles is respected and accommodated, rather than pathologised (Milton, 2012).

Varying explanations have been articulated for the increased prevalence of victimisation among autistic people, with many positioning themselves within the traditional, and more deficit focused medical model. These have proposed an inherent vulnerability to victimisation among autistic people, and suggested that hypothesised deficits reading social cues, understanding others' emotions or intentions, literal interpretation of language, and restricted and repetitive behaviours make individuals stand out from their peers and be more easily targeted (Gibbs & Pellicano, 2023; Trundle et al., 2023).

In opposition to this notion of any pre-determined or innate vulnerability to victimisation, the interaction between person and environment has been emphasised (Pearson et al., 2022). Botha and Frost (2020) proposed the Minority Stress Model (Meyer, 2003) as a framework for

understanding the increased prevalence of adverse life events and outcomes from these for autistic people. This model posits that autistic people are a minority group within a society that discriminates against, and marginalises them (Gibbs & Pellicano, 2023), and suggests that increased exposure to adversity is not as a result of any inherent flaws, as emphasised in the neurodiversity and double empathy paradigms.

It is important to take a biopsychosocial perspective when seeking to understand the relationship between victimisation and being autistic. Most research thus far has focused on establishing prevalence rates via quantitative methodologies, particularly among child and adolescent populations, with a limited focus on autistic adults. More recently there has been an emergence of qualitative research exploring the lived experience of victimisation among autistic people. The autistic community has emphasised the need for research to focus on areas that could impact their daily lives, rather than 'neurotypical priorities regarding us' (Pellicano et al., 2014). The current review sought to address such priorities and build on a recent doctoral thesis which conducted a thematic synthesis of autistic adults' experiences of interpersonal victimisation (Smethurst, 2023). This review considered victimisation experiences across the lifespan, in addition to perceptions of why these occurred, while reflecting on the implications for peoples' mental health.

A methodological approach utilising meta-ethnography was planned as this involves an interpretative, rather than simply aggregative approach (Noblit & Hare, 1988). In comparison to other qualitative synthesis methods, meta-ethnography permits the reinterpretation of themes from primary studies using a systematic approach (Sattar et al., 2021). Consequently, it is particularly useful for the generation of new theory (Sattar et al., 2021). Meta-ethnography was selected over other possible methods, such as narrative synthesis, because it seeks to develop a more in-depth theoretical understanding of a phenomenon (Sattar et al., 2021). In contrast, a narrative approach tends to focus on delivering a coherent and accessible summary of qualitative findings (Cherry et al., 2024). As the rising rates of victimisation among autistic individuals are well-documented, it was considered crucial to explore and theorise the underlying contributing factors. This theoretical insight is intended to guide the development of more effective prevention and intervention strategies, ultimately aiming to mitigate the harmful effects of victimisation on the health and wellbeing of autistic people. This meta-ethnography examined the following questions:

1. What are autistic individuals' experiences and perceptions of victimisation, and how do they respond to such experiences?

2. What are the implications from the intersectionality between being autistic and experiencing victimisation for the mental health of autistic people?

#### Methods

#### Design

This qualitative systematic review was registered on the international prospective register PROSPERO (reference: CRD42024560778) and followed qualitative reporting guidelines for metaethnography, i.e. eMERGe (France et al., 2019; Appendix A), and PRISMA 2020 reporting guidelines for systematic reviews (Page et al., 2021; Appendix B).

#### Search Strategy

The SPIDER (Sample, Phenomenon of Interest, Design, Evaluation, and Research Type) framework was used to develop and refine the review question and search strategy (Table 1).

#### Table 1.

Criteria	Description
Sample	Autistic People (Clinical diagnosis or self- identification).
Phenomenon of Interest	Experiences and perceptions of victimisation.
Design	Interviews, focus groups, and online surveys allowing free text responses to questions enquiring about experiences and perceptions of victimisation among autistic people.
Evaluation	Experiences and perceptions of victimisation and the implications of the increased prevalence of

SPIDER Framework Used to Inform Review Questions and Search Strategy.

victimisation of autistic people for their mental health.

Research TypeStudies utilising qualitative or mixed-methodsapproaches, provided that qualitative data couldbe extracted separately.

The search strategy combined key concepts from relevant, peer-reviewed systematic reviews to enhance validity. Specifically, Brignell et al., (2022) terms for autism, Trundle et al., (2023), and Cooke et al., (2024), victimisation terms, and Shaw et al., (2004), and Wong et al., (2004), terms for qualitative research. Qualitative search terms combined simple and complex free text terms, alongside broad based terms, as previous research indicated not doing so could miss potentially relevant records (Shaw et al., 2024). Search strategies were adapted accordingly depending on the different database parameters (Appendix C). The search strategy, terms, and databases were identified in conjunction with the specialist university librarian. Searches were completed by the lead researcher across five databases: Web of Science (Core Collection), PsycINFO, MEDLINE, CINAHL and ASSIA. The search used a combination of thesaurus/index terms (translated for each database) and free text words. Search terms were combined using Boolean operators "or" / "and". No date restrictions were imposed, and searches were limited to articles written in, or pre-translated to English. Final searches were conducted in May and June 2024.

#### Study Selection

Papers found via searches across all databases were imported into the EndNote reference manager, and duplicates were removed. Titles and abstracts were screened against the inclusion and exclusion criteria (Table 2).

#### Table 2.

Inclusion and Exclusion Criteria.

Inclusion Criteria	Exclusion Criteria
Studies which specifically focus on and explore the experience and/or perception of victimisation	Quantitative studies
(including bullying, peer victimisation, interpersonal victimisation, violence, sexual victimisation, conflict, mate crime, exploitation, and maltreatment) of autistic people.	Systematic reviews and meta-analyses, book chapters, or non-peer reviewed articles (e.g., conference papers, dissertations).
Studies employing qualitative methodology and analysis, including mixed method studies with a	Reports of victimisation from other informants only, e.g. parent, caregiver or teacher.
qualitative element.	Studies where themes related to victimisation emerge during analysis but where such
Studies are written or translated in the English language.	experiences were not the primary focus of the study.

The remaining studies were subject to full-text review, with those not meeting eligibility criteria removed. Forward and backward citation searches of included papers were conducted, with no additional papers being included in the review. A secondary reviewer (trainee clinical psychologist) screened a subset of 1000 titles and abstracts with a concordance rate of 98% prior to discussion. In addition, 10 full text articles were reviewed in order to enhance the reliability of study selection, with a concordance rate of 80% and again any disagreements were resolved by discussion.

#### Data Extraction

Data relevant to the review questions was extracted using a standardised extraction form on Microsoft Excel and included the author(s), year of publication, country of study, aims, available demographics, methods of data collection and analysis, and key findings.

#### Assessment of Quality

There are an array of quality appraisal tools available for qualitative research, with much deliberation about what constitutes 'quality' in this area. Studies were not excluded based on their quality rating; rather, less emphasis was given within the synthesis to findings from studies assessed as relatively lacking in methodological rigour, as also instructed in Meta-Ethnography guidance (Sattar et al., 2021). Indeed, as outlined in more detail below, the process of 'translating' primary studies into one another begins with the study with the highest quality rating and each study thereafter is considered for ways in which it either adds or deviates from earlier studies with higher quality ratings.

The quality of included studies was assessed using an adaptation of the Critical Appraisal Skills Programme qualitative research checklist (CASP, 2018; Long et al., 2020; Appendix D). The CASP tool is considered to be a user-friendly option for a novice qualitative researcher and is endorsed by Cochrane and the World Health Organisation for use in qualitative evidence synthesis (Long et al., 2020). Long and colleagues (2020), sought to optimise this tool and proposed an additional question to the original checklist related to whether a study's theoretical underpinnings (e.g. ontological and epistemological assumptions; guiding theoretical framework(s) are clear, consistent and conceptually coherent. As in other studies (e.g., Lin et al., 2023), a scoring system was utilised for the 11 questions on the adapted CASP tool to allow the studies to be analysed in order of their methodological quality rating (Sattar et al., 2021). Items rated as "no" scored zero, "partially met" scored one, and "yes" scored 2, resulting in a score out of 22. In relation to a study being rated as partially met on a specific CASP item, it would mean that the study meets some, but not all, of the criteria outlined in the item. For example, on item 7 of the CASP "Was the data analysis sufficiently rigorous?", if a study provided a basic description of the data analysis process, such as coding and thematic analysis, but did not offer a clear explanation of how the themes were developed, or whether the analysis was independently verified by multiple researchers, it would be rated as 1.

Allocating quality ratings in 'thirds' has been used in other studies (Lin et al., 2023), therefore, studies scoring 0-7 were rated as poor, 8-15 moderate, and 16-22 high quality. Using a 0–2 scoring system on the CASP Qualitative Research Appraisal Tool, has been argued to enhance consistency, transparency, and reproducibility in assessments (Lockwood et al., 2015). It has been suggested that such a scoring system maintains the tool's qualitative approach while improving inter-rater comparison, sensitivity analysis, and study weighting in qualitative evidence syntheses (Thomas & Harden, 2008). It is also proposed to accommodate nuanced judgments, especially when a definitive answer is unclear, preserving the reflective nature of qualitative appraisals (Noyes et al., 2018).

The second reviewer appraised four of the eleven (36.4%) eligible studies, selected at random. Initial inter-rater agreement was 84% (37/44), with the most common difference in opinion being related to sufficient information being provided about recruitment, and whether the researchers influence on a study had been sufficiently addressed. Disagreements were discussed until consensus was reached on all items.

#### Data Synthesis

Data was analysed using the step by step methodology for conducting a meta-ethnography outlined by Sattar and colleagues (2021). Their practical step by step guide was based on the original seven steps developed by Noblit & Hare (1998). Stages one to three of the process involve identifying an area of interest for review, defining the focus of the synthesis, locating relevant studies and deciding which to include, familiarisation with the included studies, and quality appraisal. Stage four involves determining how the key concepts and themes from each included study are related. These may be participants sharing their experiences and opinions (first-order constructs), or study author's interpretations of participants' experiences (second-order constructs) which are conveyed through themes. Stage five requires translating the studies into one another. During this phase, the themes and concepts from each paper are compared to explore for areas of commonality and discrepancy, starting with the paper given the highest quality rating, and continuing to the lowest. This process is utilised to help inform the development of the higher interpretations that move beyond the description of data from the various studies (third-order constructs). Stage six requires synthesis of the translations, which can be deemed to be reciprocal where similar concepts can be drawn together, or refutational, where contradictory or disconfirming concepts are noted. It is possible to conduct both types of synthesis if required. This leads to the creation of a line or argument synthesis which places similarities and differences in concepts into a new interpretative context. Finally, stage seven involves expressing the synthesis through a narrative and diagrammatic format.

#### **Reflexivity Statement**

The lead reviewer was a trainee clinical psychologist who identifies as a neurotypical white British male. They had predominantly worked in acute physical health settings, supporting adults to cope with, and adjust to living with long term health conditions. With limited clinical, and no personal experience of working with autistic individuals, they held an outsider perspective on the victimisation experiences of autistic people. Although as part of this review they had immersed themselves in literature related to adverse life experiences, neurodiversity, and theories related to

membership of, or identification with a minority group, they had not experienced life as an autistic person, and had no significant experiences of victimisation.

They had also worked in largely medically dominated settings where a more deficit focused view of autism still prevails. Supervision was utilised to reflect on any pre-existing assumptions, beliefs and feelings from prior clinical and research experiences, with the aim of enhancing reflexivity whilst undertaking the meta-ethnography. A reflective log was also developed to support this. Furthermore, this review was undertaken in parallel with a primary qualitative research project which was also guided by a critical realistic stance. It is acknowledged that the authors' background, positionality, experience, and epistemological stance will have influenced their interpretation of the data in this review (See Appendix E).

#### Results

#### Summary of Included Studies

Database searches identified 27,093 records, which were imported to EndNote. 8219 duplicates were removed. The remaining 18,874 records were screened by title and abstract by the lead reviewer. A second reviewer (trainee clinical psychologist) screened a subset of 1000 records to enhance reliability with a 98% concordance rate and any disputes resolved by discussion.

18,812 records were excluded, resulting in 62 studies remaining for full-text review. Two studies were excluded as they contained mixed samples of participants with developmental disabilities, e.g. learning disability, cerebral palsy, and autism. However, data could not be extracted for autistic individuals alone or who had co-occurring conditions. A further twenty nine studies were excluded as they did not explicitly focus on autistic peoples' experiences or perceptions of victimisation. Twenty studies were excluded as they were quantitative. Forwards and backwards citation searching, in addition to 'related articles' searches did not provide any further records for review. Figure 1, below provides an overview of the process.

### Figure 1.

PRISMA (Preferred Reporting Items for Systematic Reviews and Meta-analyses) Diagram of Study Selection Process.



Table 3 presents an overview of study characteristics.

Each study in Table 3 is numbered, and this numbering is used here to ensure transparency of referencing.

### Table 3.

Table of Study Characteristics and Quality Appraisal Rating.

Author(s) & Year	Country (Setting/Context of Study)	Aim	Sample (Age, Gender, Ethnicity, Autism Diagnostic Status)	Methods of Data Collection & Analysis	Key Findings	Quality Appraisal (Score = Max 22)
1. DeNigris et al. (2018)	United States	To explore the prevalence of bullying later in development and the impact on identity.	N= 22 autistic undergraduates. Aged 16-38 years (M= 20.7), 19 male, 3 female. 12 White, 2 Black, 1 Asian, 2 Hispanic/Latino, 5 Other. 22 clinical autism diagnosis.	Semi-structured interviews and 6 - word autobiography task. Thematic Analysis	Theme: Experiences of Victimization Sub-Themes: cognitive empathy, superficial perspective taking, different. Theme: Responses to Bullying Victimization Sub-Themes: retaliation & seek help.	Moderate (9/22)

2. Douglas & Sedgewick (2024) Australia, United Kingdom, United States. To explore autisticNpeople'saexperiences of6interpersonal1violence and sexual3abuse, explicitlyAincluding autistic(Ipeople of all2genders.2

N= 24 autistic adults 6 males, 15 females, 3 non-binary. Aged 25-61 (M= 39.15) 23 White, 1 Latino. 23 clinical autism diagnosis, 1 self-identified. Semi-structured interviews

Thematic Analysis

Experiences of Abuse Sub-Themes: sexual assault & rape, classic abuse tactics, & partner characteristics.

Theme:

Theme: Autism Used Against You. Sub-Themes: abusing through autistic traits, undermining the autistic victim, & misinterpreting harmful intentions.

Theme: Poor Family Models

Theme: Impact of/on friendships Sub-Themes: lack of protective friendships & losing friends due to disclosure

High (16/22)

Theme: Handling trauma Sub-Themes: shutting down, long-term impact on relationships.

Theme: Recommendations for Relationship and Sex Education( RSE)

High (16/22)

3. Fardella et al., (2018)

Canada

To identify risk and protective factors for interpersonal violence among autistic adults.

N= 22 autistic adults Aged 18-53, (M=30). 10 female, 12 male. 22 clinical autism diagnosis. Semi-Structured Theme: Individual Interviews Needs Sub-Themes: Thematic Analysis awareness of self and the environment, interpersonal knowledge/skills, & skill building strategies.

> Theme: Supportive Contexts Sub-Theme: Benefits of a trusted person, advocates, & fostering

# acceptance and inclusion.

4. Fisher & Taylor (2016)	United States	To gain insight into perceptions of peer victimisation by autistic youth.	N= 30 autistic adolescents. Aged 17-19, (M = 18.19) 27 males, 3 females. 27 White (Non- Hispanic), 3 African American. 30 clinical autism diagnosis.	Semi-structured interview using ADOS-4 "Social difficulties and annoyance" module Content Analysis	Theme: Type of Victimization Sub-Themes: verbal victimization, physical victimization, relational victimization, & unspecified victimization.	Moderate (14/22)
5. Forster & Pearson (2020)	United Kingdom	To explore social relationships and the concept of mate crime in a group of autistic adults.	N= 5 autistic adults. Aged 22-25 years. 2 women, 3 men. All self-reported autism diagnosis.	Semi-Structured Interviews Interpretative Phenomenological Analysis	Theme: Perceptions and 'Learning the Formula'. Sub-Themes: self- perceptions and labels, time and practice, & through the eyes of others. Theme: Socialising 'it's More Complicated Than That'. Sub-Theme: reading	High (20/22)

social signals, a lot of effort, reciprocity & like mindedness.

Theme: 'Taking advantage of you' Sub-Themes: worse than bullying & more vulnerable.

# 6. Gibbs & Pellicano Australia (2023)

To explore interpersonal violence experiences of autistic people during adulthood. N= 22 autistic adults. Aged 19-57 years (M=36.23). 13 women, 4 men, 5 non-binary. 19 White and 3 Mixed/ Other. 21 clinical autism diagnosis and 1 selfidentified.

Semi-Structured Interviews Reflexive Thematic Analysis Theme: Every one of my autistic friends has been abused in some way, shape or form'. High (17/22)

Theme: Feeling unlovable and feeling that I'm wrong, I'm broken Sub-Themes: mental health impact, guilt & shame, feeling dismissed by others, & losing trust in others. Theme: 'maybe we just seem like easy targets' Sub-Theme: difficulties reading the room, not confident about recognising danger or abuse, & tendency to take people at face value. Theme: 'you spend your whole life being told that you are wrong the way you are'. Sub-Theme: invalidation of feelings and instincts, & pressured to conform and fit in.

7. Humphrey & Symes (2010)

United Kingdom

Exploring the roleN= 36 autisticof social support inchildren andresponses toadolescents.bullying andAged 11-16.barriers to utilising32 males, 4

Semi-Structured Interviews Thematic Analysis. Theme: Pupil Moderate (15/22) responses to bullying Sub-Themes: Seeking help from

		such support.	females. 36 clinical autism diagnosis.		teachers, Support from friends and/or classmates, The role of parents/family, going it alone.	
					Theme: Relationships with potential advocates/ sources of support. Sub-Themes: relationship with teachers & peer relationships.	
					Theme: Barriers to the utilisation of social support. Sub-Theme: traits associated with ASD, lack of trust, desire for solitude.	
8. Libster et al. (2022)	United States	To examine levels of peer conflict and bullying victimisation in autistic compared to non-autistic	N= 58 autistic children. Age, M= 10.45. 28 boys, 28 girls. 58 clinical autism diagnosis.	ADOS Module 3 Interview Thematic Analysis	Theme: Reasons for peer victimization.	Moderate (8/22)

		children. Also examining if there were sex differences in victimisation experiences.				
9. Pearson et al., (2022)	United Kingdom	To explore the lived experience of interpersonal victimisation among autistic adults from a phenomenological perspective.	<ul> <li>N= 43 autistic adults.</li> <li>27 women, 13 men.</li> <li>2 non-binary,</li> <li>1 genderqueer.</li> <li>36 clinical autism diagnosis,</li> <li>7 self-identified.</li> </ul>	Online survey (open ended questions) Reflexive Thematic Analysis	Theme: Cycles of victimization. Theme: Perceptions of victimization Sub-Themes: problems with trust, recognizing victimization, & the role of compliance.	High (21/22)
10. Pearson et al. (2023)	United Kingdom	To examine the impact of interpersonal violence on autistic adults.	N = 102 autistic adults Age range = 19-73, (M= 37.8) 64 women, 21 men, 14 non- binary, 4 other/prefer not to say. 72 clinical autism diagnosis, 30 self-identified.	Semi-structured questionnaire; written (n=100) or in person interview (n=2). Reflexive Thematic Analysis	Theme: The usual for autism. Sub-Themes: 'I thought I deserved it' & 'What's wrong with you, then?' Theme: Personhood revoked: the cost of living.	High (20/22)

					Theme: Unpacking the baggage. Sub-Themes: Finding the right words.	
					Theme: If you want to make an apple pie from scratch, you have to invent the universe first'. Sub-Themes: an imbalance of power, acceptance and mutual respect, & finding a community.	
11. Saggers et al., (2017)	Australia	To explore autistic student's experiences of bullying and its impact.	N=10 autistic children and adolescents. 9 males, 1 female. 10 clinical autism diagnosis.	Semi-Structured Interviews Reflexive Thematic Analysis.	Theme: Understanding of Bullying. Theme: Experiences of Bullying Behaviour. Sub-Theme: situational factors. Theme: Responses	High (17/22)

to Bullying Sub-Theme: Responding to and reporting bullying, impact of bullying behaviour on victim. The eleven studies were published from 2010-2024. All were conducted in High Income Countries. Four studies were undertaken in the United Kingdom (5,7,9,10), three in the United States (1,4,8), two in Australia (6,11), and one in Canada (3). One study (2) included participants from Australia, the United Kingdom and the United States. Studies varied in their focus, with five (1,4,7,8,9) seeking to explore autistic peoples' experiences of peer victimisation such as bullying. Three (2,6,10), focused on autistic peoples' experiences of interpersonal violence including sexual abuse (2), with one study (3) examining risk and protective factors for these experiences. Two studies (5,9), focused on autistic peoples' experiences of interpersonal victimisation, including 'mate crime' (5).

In relation to study design, two studies (1,8) employed mixed methods approaches. The remainder of studies utilised qualitative methodologies. Nine studies used semi-structured interviews for data collection. The exceptions to this were one study (9) which used an online survey with open ended questions requiring a text response, and another which used a semi-structured questionnaire (10). 100 responses to this were via text, with 2 participants preferring an in-person interview. Data analysis utilised thematic analysis in five studies (1,2,3,7,8), reflexive thematic analysis in four studies (6,9,10,11), content analysis in one study (4), and interpretative phenomenological analysis (5) in another.

Across studies, there were 374 autistic participants in total; 335 (89.6%) had a clinical autism diagnosis, and 39 (10.4%) self-identified as autistic. There were 177 males (47.3%), 171 females (45.7%), 21 non-binary (5.6%), 1 genderqueer (0.3%) and 4 'other' or 'prefer not to say (1.1%). Only four studies (1,2,4,6), provided data on participants' ethnicity, and in these studies there were 62 White participants, 5 Black, 3 Hispanic/Latino, 1 Asian, and 8 Mixed/Other. The age range of included studies was 10-73, with the youngest mean age in any given sample being 10.45 (8) and the oldest being 39.15 (2).

#### Quality Assessment Results

All studies explicitly stated the aims of the research, and with one exception where insufficient information was provided to justify a qualitative/mixed methods approach (8), selected qualitative methods appropriately. Two studies (1,8), scored '0' on the explanation and justification of the study design. They did not provide sufficient information on why a mixed methods approach was chosen or was appropriate. One study (3), scored '1' as it discussed using semi-structured interviews and open ended questions, but did not provide sufficient detail on why this was deemed the most appropriate approach to take. Only three studies (5,9,10) discussed their theoretical underpinnings

and provided sufficient detail to establish whether these were clear, consistent, and conceptually coherent. The remaining eight studies, scored '0' on this item. Four studies (2,3,6,11), clearly outlined their recruitment strategy and scored '2'. Six did to some extent (1,4,5,7,9), and scored '1'. The reasons for this varied: insufficient information on why chosen participants were the most appropriate to take part (1,4,5,7); no information on why some people decided not to participate (9). One study (8) lacked any clear explanation and scored '0'. Two studies (1.7) scored '1' on their approach to data collection. One study (1) did not justify their rationale for choosing online surveys followed by interviews, while the other (7), provided insufficient information on what was asked during interviews. One study (8) lacked clear information and scored '0'. The remaining eight studies scored '2' on this item.

Only two studies (6,9) were felt to have adequately addressed the relationship between researchers and participants and scored '2'. Five studies scored '1' on this item (2,5,6,7,10) due to: insufficient critical examination of the researchers' role in formulation of the research questions and data collection (2); critical examination of researchers' role in formulation of the research question (5,7); limited information on reflexivity (10). Five studies scored '0' on this item (1,3,4,8,11). Ethical issues were clearly addressed in six studies (3,5,7,9,10,11), which scored '2'. Three studies scored '1', due to: insufficient information on how they handled the effects of the study on participants during or after the study (2,6,8); lack of information on informed consent (6). Two studies scored '0' on ethical issues (1, 4). Data analysis was deemed to be sufficiently rigorous in three studies (5,9,10). Four studies scored '1', due to: lack of reflexivity/critical examination of researchers' role, potential bias and influence during data analysis and selection of data for presentation (3,6); insufficient depth of discussion of data analysis process (4,11); insufficient data presented to support the findings (11). Four studies (1,2,7,8), scored '0' on this item. All studies provided a clear statement of their findings, and ten studies scored '2' on the value of the research. The only exception to this was one study (1), which provided insufficient information on future research directions. Table 4 provides an overview of quality ratings.

# Table 4.

### Quality Assessment Ratings.

Author (Year)	1. DiNigirs et al (2018)	2. Douglas & Sedgewick (2024)	3. Fardella et al (2018)	4. Fisher & Taylor (2016)	5. Forster & Pearson (2020)	6. Gibbs & Pellicano (2023)	7. Humphrey & Symes (2010)	8. Libster et al (2022)	9. Pearson et al (2022)	10. Pearson et al (2023)	11. Saggers et al (2017)
Clear Aims	2	2	2	2	2	2	2	2	2	2	2
Qualitative Methodology	2	2	2	2	2	2	2	1	2	2	2
Research Design	0	2	1	2	2	2	2	0	2	2	2
Theoretical Underpinnings	0	0	0	0	2	0	0	0	2	2	0
Recruitment Strategy	1	2	2	1	1	2	1	0	1	1	2
Data Collection	1	2	2	2	2	2	1	0	2	2	2

Relationship & Reflexivity	0	1	0	0	1	2	1	0	2	1	0
Ethical Issues	0	1	2	0	2	1	2	1	2	2	2
Data Analysis	0	0	1	1	2	1	0	0	2	2	1
Findings	2	2	2	2	2	2	2	2	2	2	2
Value	1	2	2	2	2	2	2	2	2	2	2
Quality Appraisal (Max=22)	9	16	16	14	20	18	15	8	21	20	17
Rating	Moderate	High	High	Moderate	High	High	Moderate	Moderate	High	High	High

Note: A rating of 0 was given when an item on the modified CASP tool was rated as 'No', a score of 1 was assigned when an item was rated as being partially met, and a score of 2 was given when an item was rated as 'yes'.

#### Results of Synthesis

First-order constructs from participant accounts of their experiences and second-order constructs (themes) from researchers' interpretations of accounts were extracted and compared across studies using the method described Sattar et al., (2021). Reciprocal translation was used to identify similar concepts across the studies that could be grouped together under either an existing or new concept. Refutational synthesis was used to explore contradictory concepts. Examples of the synthesis process can be found in Appendix F.

This process resulted in the development of four third-order constructs describing autistic peoples' experiences, perceptions and responses to victimisation, and the implications of these for their mental health. A line of argument synthesis was used to assimilate the third-order concepts together and determine how they were related. This synthesis highlights how the prevalence and pervasiveness of victimisation experiences across the lifespan leads to a normalisation and expectation of being victimised. It describes how the internalisation of stigma related to being autistic increases peoples' risk of being exposed to victimisation. Both of these factors have a considerable impact upon autistic peoples' mental health. Furthermore, the response to the impact of such experiences often leaves people trapped in a vicious cycle that confers risk of further exposure to victimisation, and has additional deleterious effects on their mental health. Individual resiliency and other protective factors in preventing and recovering from these experiences are also outlined. Figure 2 shows a diagrammatic representation of the synthesis.
## Figure 2.

Diagrammatic representation of the four third-order concepts and line-of-argument synthesis (represented by arrows) from the meta-ethnography.



#### Normalisation and Expectation of Victimisation

All studies (1-11) highlighted the prevalence of victimisation experiences. Five studies (2,5,6,9,10) reported these as pervasive across contexts and relationships, including strangers and people who should have been trusted such as family, friends, and professionals. Across studies (1-11) people reported wide ranging experiences including physical assault, sexual assault, stalking and harassment, school and workplace bullying, and verbal, emotional and psychological abuse. These experiences being commonplace were highlighted to result in people becoming 'desensitised to violence' in one study (6), which set a precedent for this being the norm within interpersonal and peer relationships as highlighted by another as study (10). The normalisation of such dehumanising experiences also led to a delay in people recognising this as abuse in two studies (2,10).

#### Internalisation of Stigma

Autistic people emphasised the role of personal risk factors in their experiences of victimisation. However, societal views of autism, in addition to the systemic invalidation many faced when disclosing their experiences were emphasised as significant precipitating and perpetuating factors:

*Attribution of Individual Risk*: In seven studies (1,3,4,5,6,8,9) autistic people highlighted personal attributes, or autistic traits as potentially contributing to victimisation experiences. Autistic communication style and difficulties in reading others and their intentions were highlighted as risk factors in five studies (2,3,5,6,9). A tendency to perhaps be too trusting, and wanting to see the best in others was reported in four studies (2,5,6,9). In addition, two studies highlighted that this was also felt to arise from loneliness and a desire for social connection (2,5). In four studies autistic people discussed assuming others would be like them and only say what they mean (2,5,6,9). The overwhelming nature of social interactions in a neurotypical world was felt to result in reduced danger awareness (2), while potentially upsetting others by saying the wrong thing was also highlighted by one study (2).

**Societal Views of Autism:** Societal conceptualisations of autism, particularly the deficit focused lens through which it is viewed, were emphasised in five studies (2,3,5,6,10), as significantly impacting upon autistic peoples' self-worth, and increasing the likelihood that they may be targeted by predatory individuals. Forster and Pearson (2020), highlighted how, within the literature autism is often framed as a 'personal tragedy', or something to be normalised. Five studies described autistic people being acutely aware that they were often perceived negatively, or as 'lesser than' by others

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(2,3,4,5,10). Indeed, in one study this was the case regardless of awareness of a diagnostic label (2), and more generally in eight studies was attributed to a prevailing sense of being viewed as different, or 'othered' by society (1,2,3,4,5,6,8,10).

Autistic people in four studies (2,3,6,10) referenced the experience of a 'lifetime' of being the one who 'got things wrong', and how this messaging would often lead to them feeling unable to trust their own judgement in dangerous situations or abusive relationships. In four studies (2,3,5,6) there was a prevailing sense of the emphasis being on autistic people having to change, or learn new skills to reduce their likelihood of being victimised; much like a lifetime of pressure to conform to neurotypical norms that was described in one study (6). In four studies (2,5,6,10) societal views of autism were highlighted as creating a culture of victim blaming, and reducing the emphasis on wider systemic change to influence the disproportionate victimisation of autistic people

*Perpetrator Actions*: There was an interaction between societal views of autism impacting peoples' ability to trust their own judgement about how they were being treated, and perpetrators deliberately targeting them because of this. For example, in one study (2) by emphasising that victims had historically had difficulty in social situations, they were able to strengthen and reinforce gas lighting tactics (psychologically manipulating someone into doubting their own recollections of events or their mental health; 2). Examples were cited of guilt tripping in two studies (2,10), and in one study deliberately triggering autistic meltdowns in front of other people in order to present the victim as unreasonable (2), and telling family or friends that the autistic person had misinterpreted what happened in some way (2) were reported; utilising the stereotype that autistic people are unreliable narrators of events. Although such tactics are commonly used by abusers regardless of the victim's neurotype, in the study by Douglas and Sedgewick (2024), in romantic relationships, abusers were generally aware that the victim was autistic and were felt to have intentionally targeted specific autistic traits to perpetuate their abuse.

**Invalidation of Experiences:** In five (2,5,7,9,11) studies where experiences of help seeking were explored in more depth, people were often faced with disbelief or blame from a variety of people, including family, friends or professionals such as police or therapists. In three studies (2,6,11) even when people were believed, they often found the response of others to be inadequate. Indeed, in one study (6) this was experienced as being worse than the abuse itself. It was highlighted in three studies (2,6,10) that such responses are likely to be influenced by preconceived ideas that others have about autistic people, e.g. that they commonly misinterpret situations, or are not credible narrators of events. The lack of validation for the often traumatic experiences people had been through was felt to further affirm feelings of self-blame, and the normalisation of victimisation and

violence in three studies (2,6,10). Furthermore, in the same three studies this resulted in people feeling that they had been left to cope with the impact of their experiences alone.

#### Impact of Victimisation Experiences and Stigma

The experiences of polyvicitmisation, and the invalidation of others had led autistic people in four studies (2,6,9,10) to believe that what had happened to them was deserved, and that they were the problem. Feelings of guilt and shame were expressed in three studies (5,6,10). This was especially the case in one study (5) where autistic people had been victimised by others, who had pretended to care about them, in order to take advantage of them (5). Such experiences were also reported to result in a loss of trust in four studies (2,6,9,10); in both peoples' own judgement, and others more generally, including people in authority. The mental health impact of victimisation was also reported in two studies (2,6), and included depression, anxiety and post-traumatic stress disorder (PTSD).

#### Responses to Victimisation Experiences, Stigma and Their Impact

The utilisation of 'survival responses' in an attempt to cope with the trauma of what had happened to people, as well as trying to avoid further harm were discussed. However, there was also reports of learning and growing from these adverse experiences:

*Masking/Camouflaging:* Masking involves an autistic person making deliberate efforts to disguise their visible autistic traits, and simultaneously mimicking traits deemed to be acceptable in a society dominated by neurotypicals (Cage et al., 2019). In one study (10), this approach was used in order to conceal aspects of an autistic identity that people felt elicited victimisation behaviours from others, and had been used by some since childhood (10). Masking as a response to traumatic experiences and invalidation from others was conceptualised as leading to burnout, which subsequently resulted in people being unable to mask further, and thus increased the risk of victimisation (10). A sense of grief at the loss of the person some felt they could have become was also shared (10). Although this response to victimisation and stigma experiences was derived from only one primary study (10), it was felt important to include this. This study was perceived as providing a deep and detailed insight into masking as a response to such experiences. This also aligns with the idea of "reciprocal translation," wherein the unique perspective of each study contributes to a more comprehensive understanding being developed of the phenomenon under investigation (Sattar et al., 2021).

**Compliance:** Closely linked to masking and camouflaging was the response of compliance to other's manipulations in three studies (2,3,9). The reasons for this varied, e.g., avoiding confrontation, not wanting to be perceived negatively by others, self-preservation in a dangerous situation, or not wanting to get others into trouble when the perpetrator was a family member, for example. This response led to long term emotional or financial implications in one study (9).

**Isolation and Withdrawal:** In four studies (2,6,7,9), the experiences of polyvictimisation and loss of trust in themselves, or others, had led autistic people to withdraw and isolate, as this was perceived as the only way to keep safe. Social isolation has been linked to poorer mental health and increased risk for victimisation (Fardella et al., 2018).

*Learning and Growing from Experiences:* In one study (10), access to good social support was particularly helpful in recovering from, and mitigating the impact of victimisation. Having good support networks or links to organisations who could help (10), in addition to access to neurodivergent affirming therapists was highlighted (10). In two studies, (3,5) people spoke of having family and friends who would draw their attention to people taking advantage of them, or whom they could consult with when they noticed themselves feeling unsure about a particular person or situation. In two studies (2,10), people highlighted their ability to learn from their experiences and recognise what a healthy relationship looks like; better protecting their boundaries and recognising 'red flags'. In one study (1), there was also a sense of these experiences helping to develop resilience, however, Douglas & Sedgewick (2024), highlighted the need for prevention strategies to ensure people do not need to 'learn' from such harrowing experiences.

#### Discussion

This systematic review and Meta-Ethnography sought to investigate autistic peoples' experiences and perceptions of victimisation, in addition to how they respond and cope with such treatment. It also aimed to explore the intersectionality between being autistic and the experience of victimisation, and the implications of this for the mental health of autistic people. The metaethnographic approach produced four third-order concepts, 'normalisation and expectation of victimisation', 'internalisation of stigma', 'impact of victimisation experiences and stigma', and 'responses to victimisation experiences, stigma and their impact'. The polyvictimisation of autistic people detailed in this review was similar to other recent quantitative reviews that have been conducted (Trundle et al., 2023). In addition, the impact of victimisation experiences on the mental health of autistic people was in keeping with previous research demonstrating an association with poorer psychological wellbeing (Botha & Frost, 2020). While in the studies reviewed, autistic people acknowledged some personal attributes that they felt could increase their risk of victimisation, e.g., being very trusting and taking people at face value, it is also possible this risk factor may have been overestimated due to the internalisation of autistic stigma. As previously highlighted, it seems more appropriate to frame the prevalence of victimisation among autistic people as an interaction between the person and their environment, rather than an innate vulnerability (Pearson et al., 2022).

The review findings emphasise the need for improved sex and relationship education from an early age, particularly from a prevention and intervention standpoint (Douglas et al., 2024). Educational and interventional approaches that focus on developing practical skills should shift away from framing autism in terms of perceived deficits. Instead, in keeping with the neurodiversity and double empathy paradigms, they should promote mutual understanding between neurodiverse and neurotypical individuals. These approaches should encourage autistic people to trust their instincts and validate their own emotions and feelings (Gibbs & Pellicano, 2023). Teaching assertiveness and the ability to engage in selective non-compliance is also crucial to help protect against victimisation (Douglas et al., 2024). In addition, there is an urgent need to improve access and adapt environments in both educational and workplace settings, especially given the merging link between over-compliance and diminished social, academic, and vocational opportunities (Cage et al., 2020; Smethurst et al., 2024).

In relation to coping with victimisation, the utilisation of masking and camouflaging strategies were conceptualised as a trauma response, and survival strategy to avoid further harm, rather than being viewed as a social strategy to try and 'fit in', as they have been in earlier research (Cage & Troxell-Whitman, 2019). Masking was linked to an increased likelihood of 'people pleasing' and compliance. This was found to leave people trapped in a vicious cycle where masking was used as a trauma response, but would eventually lead to burnout, and when people could no longer mask, there was an increased risk of victimisation. As discussed, whilst masking was referenced in only one study (10), and was felt to add depth and uniqueness to the analysis and review findings, it is important to acknowledge that it is preferable for third-order constructs within a meta-ethnography to be derived from multiple studies (Toye et al., 2014). Using only one study can limit the generalisability and robustness of this construct (Sandelowski, 2004). Furthermore, a single study may be subject to

biases, limitations in methodology, or contextual factors that may not be applicable to other settings or populations (Sandelowski, 2004).

The other response to victimisation many people were left with was to comply with perpetrators, which is also a risk factor for being victimised (Pearson et al., 2022). These responses appeared to be closely linked to the systemic invalidation and testimonial injustice (Williams & Jobe, 2024), people experienced when seeking support, alongside barriers to accessing services, which has previously been highlighted (Doherty et al., 2022). Some people also expressed that reduced social and vocational opportunities meant that they felt reliant on perpetrators to meet their basic needs. Indeed, recent research (Smethurst et al., 2024) has highlighted the unemployment and underemployment of autistic people. Significantly higher dropout rates from university and college have also been demonstrated (Cage et al., 2020). These systemic issues could increase the risk of exploitation, or make it more difficult for people to leave abusive relationships or situations.

The impact of victimisation experiences and stigma, as well as how autistic people respond to these, can also be understood with the framework of minority stress (Meyer, 2003). The experiences of autistic people across the studies in this review align with this framework and the perspective of being a minority group within a society that discriminates against, and marginalises them (Meyer, 2003), and that hermeneutical injustice is often one of the main driving forces in being exposed to adversity.

#### Weaknesses of the Literature

The extent to which the theoretical underpinnings of the different studies were clear, consistent and conceptually coherent was difficult to establish for most studies. Equally researcher reflexivity and their relationship to participants was often unclear, making it difficult to ascertain their influence on theme development. All studies were conducted in Western Countries, pre-dominantly the United Kingdom and United States and findings must be interpreted in light of this. Limited information on demographic variables such as ethnicity was provided across studies; for those where it was, participants were pre-dominantly white and cisgender. This is important to consider, particularly in light of research demonstrating heightened vulnerability to victimisation of people with multiple marginalised identities (Chakrabort & Garland, 2012; Cooke et al., 2024). In addition, only a few studies provided information on autistic community involvement in the design and analysis of their studies. This is important to consider in light of the double empathy problem (Milton, 2012), which could have an influence at all stages of the research process.

#### **Review Strengths and Limitations**

The utilisation of a meta-ethnographic approach to this issue permitted the development of theory related to a victimisation pathway to elevated levels of mental health difficulties among autistic people. This review also adopted a broad and sensitive search strategy, which combined key concepts from relevant, peer-reviewed systematic reviews related to key search terms for autism, victimisation and qualitative research. Furthermore, the adoption of a qualitative approach to this review permitted a detailed and richer understanding to be developed of the experiences, and potential reasons for the increased rates of victimisation experienced by autistic people in earlier quantitative reviews (Trundle et al., 2023).

In relation to limitations, the mixture of quality of included studies considerably varied and meant that, inevitably those studies rated as being more rigorous and with broader findings contributed more to the data synthesis. It should also be noted that the same research group were involved in several of the included studies, which could potentially introduce bias. However, each study included different samples, research questions, and themes based on the interpretations of participants' responses. There was also no second coder to increase reliability of the data analysis, and so this was based on the primary author's interpretations of the data.

#### Clinical, Policy and Research Implications

Clinically, given both the prevalence and impact of victimisation experiences that have been outlined, consideration of means by which more routine screening of these could be implemented into clinical practice seems warranted. In addition, services should raise awareness of the impact of the systemic invalidation many autistic people face when disclosing victimisation experiences. It is vital that services do not actively re-traumatise people who already face considerable barriers and inequalities when seeking mental health support. Indeed, one such means by which this could be addressed would be through consultation and co-working with autistic survivors of victimisation experiences. Furthermore, it is crucial to recognise how both internalised and externalised stigma can affect autistic individuals' willingness to engage with prevention and intervention strategies that promote autonomy, assertiveness, and resistance to compliance. As emphasised throughout this review, negative experiences and stigma can deeply impact the self-esteem and self-acceptance of autistic people. Supporting autistic individuals in building self-esteem and self-acceptance may enhance their engagement with preventative strategies designed to reduce the risk of victimisation.

Strengthening social connections and preventing isolation are also essential policy considerations. The need for autistic only spaces where people can meet and strengthen connections within their own community has been suggested (Pearson et al., 2023). In addition, some studies have demonstrated the benefits of peer support initiatives between neurodiverse and neurotypical peers (DeNigris et al., 2018). Lastly, and most importantly, steps need to be taken to increase and enhance neurodiversity affirming diagnostic, educational and therapeutic practices (Gibbs & Pellicano, 2023). This would be a vital step to creating a culture of acceptance of autism, and would emphasise the need for the system to change, rather than autistic people not being themselves in order to avoid victimisation and its consequences.

Efforts to promote greater autism awareness, education, and anti-stigma are increasingly reflected in national policy and legislation. The UK Government's National Autism Strategy (2021–2026) and the Scottish Government's proposed Learning Disabilities, Autism and Neurodivergence (LDAN) Bill (2023) represent significant national efforts to improve the lives of autistic and neurodivergent individuals. The UK strategy outlines a five-year plan for England focused on increasing public understanding of autism, improving access to education, healthcare, and employment, and ensuring better community and criminal justice support. It is backed by targeted funding and shaped through consultation with autistic people and stakeholders. In parallel, the Scottish LDAN Bill has many of the aforementioned objectives, but also seeks to establish legal definitions of learning disabilities and neurodivergence, mandate inclusive national strategies, and promote accessible communication, improved health outcomes, and data-driven service planning. Together, these initiatives reflect a growing commitment across the UK to advancing the rights, inclusion, and wellbeing of autistic and neurodivergent people through coordinated, rights-based approaches. Both also align well with the Transforming Psychological Trauma (NHS Education for Scotland, 2017) initiative being implemented in Scotland. Indeed, the importance of services being trauma informed is vitally important and was discussed in the clinical implication section of this review.

Future research should focus on, and encourage autistic community involvement at all stages of the research process. Greater consideration of intersectionality is also required, to help better understand how overlapping identities, such as race, gender, sexuality, and socioeconomic status shape experiences of harm and discrimination. Autistic individuals who belong to multiple marginalised groups may face compounded vulnerabilities that increase their risk of victimisation (Brown & Leigh, 2020). Masking could also be considered an intersectional factor and is something

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worthy of further exploration in any future research in this area. Lastly, the qualitative research literature has predominantly focused on the victimisation experiences of autistic adults, highlighting the need for more studies involving children and adolescents to strengthen prevention and intervention efforts at earlier stages of development.

## Conclusions

The findings show that the normalisation and expectation of victimisation experiences, along with the internalisation of stigma has a significant impact upon the risk of autistic people experiencing victimisation. The impact of these experiences and felt stigma, in conjunction with attempted coping strategies had a significant adverse effect on autistic peoples' mental health. Collectively, these findings allowed for the development of a theory related to a victimisation pathway being, in part, potentially responsible for the elevated rates of mental health difficulties observed in the autistic population. Protective factors such as good social support and understanding professionals were also identified. The need for a shift in societal attitudes and greater acceptance of autism and neurodivergence more generally, were highlighted as important prevention and intervention targets to reduce the victimisation experiences of autistic people, and the subsequent deleterious effects on their self-concept and mental health.

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# Chapter 2: An Exploration of Experiences of First-Episode Psychosis among Autistic Adults

Prepared in accordance with the author requirements for [Journal of Autism and Developmental Disabilities; https://link.springer.com/journal/10803/submissionguidelines#Instructions%20for%20Authors]

## Plain Language Summary

## Title

An Exploration of Experiences of First-Episode Psychosis among Autistic Adults

## Background

Autism is defined medically by difficulties with social communication and restricted or repetitive behaviours, present since childhood. In psychosis, people experience reality differently from those around them and may hear or see things that are not there (hallucinations) and believe things that are not true (delusions). Autism and psychosis have been found to often present together.

Research seeking to explain this link has been dominated by medical studies attempting to highlight autism as a risk factor for the development of psychosis because of biology or thinking style differences.

Other research has highlighted the potential role of difficult life experiences in the development of psychosis. Autistic individuals are exposed to more difficult life experiences such as bullying, discrimination or stigma. Despite this, little attention has been paid to the potential influence of psychological and social factors in the higher rates of psychosis found in autism.

Research into lived experience has the potential to shed new light on psychosis in autism and inform improved assessment and intervention.

## Aims and Questions

The main aim of this research is to focus on the lived experience of psychosis among autistic people. The research questions seek to explore how people made sense of their experiences and the factors they believe were important in their recovery journey during first episode psychosis (FEP). We believe this is the first study to be carried out in this area.

## Methods

Clinicians from an early intervention in psychosis service (EIP) identified potential participants and provided them with information about the study. 6 autistic with a median age of 22 took part in semi-structured interviews about their life as an autistic person and their experiences of FEP. Reflexive Thematic Analysis was used to develop themes from across the interviews.

## Main Findings

Participants' experiences of FEP, such as hearing things that others could not, or being worried that other people meant to harm them were similar to other research that has been carried out in the general population. In addition, the factors that people believed may have played a role in developing FEP, such as stressful life experiences, e.g. exams, and the loss of a loved one, were also similar to other research. Participants discussed viewing being autistic as a 'positive difference', but they were aware that many people still hold negative views about autistic people. This resulted in people trying to hide that they were autistic in certain situations, which was often stressful. The potential role this could play in the higher rates of psychosis in autistic people was discussed. The importance of support and connecting with others was a key finding.

## Conclusions

This study provides insight into the lived experience of FEP in autistic adults. The study identified intervention and prevention strategies at individual, service, and governmental level to support people with such experiences.

## Abstract

#### Purpose

Autistic people are disproportionately affected by mental health problems relative to the general population. Recently, the increased prevalence of psychosis among autistic people has been gathering increasing attention. Neurobiological accounts have dominated in efforts to understand this relationship, often overshadowing the need for research that explores autistic peoples' lived experience. This study aimed to be the first to address this gap in research and provide an insight into experiences of first-episode psychosis (FEP) and factors which are important in navigating recovery among autistic adults.

#### Methods

Reflexive Thematic Analysis (RTA) was used to investigate the lived experience of autistic adults. Six autistic adults with experiences of FEP participated in semi-structured interviews.

## Results

Four themes were identified: 'Experiences and Impact of Psychosis'; 'Adverse Experiences as a Pathway to Psychosis';' The Nuances of an Autistic Identity'; and 'The Importance of Interpersonal Support'.

#### Conclusion

The experiences of psychosis and perceived factors contributing to its development were consistent with other qualitative studies in the general population. The impact of internalised stigma related to an autistic identity, and the impact of this on wellbeing was highlighted. Key factors in recovery, particularly in relation to peer support were emphasised. The implications of these findings in supporting positive autistic personal and social identities and how to support autistic people experiencing psychosis more generally are discussed.

#### Introduction

The co-occurrence of autism and psychosis has been gathering increasing research attention (Gesi et al., 2024). Based on findings from numerous meta-analyses an approximate threefold to tenfold increased prevalence of psychosis in autistic people relative to the general population has been suggested (Gesi et al., 2024), which may even be an underestimate (Schalbroeck et al., 2023). Neurobiological explanations have dominated in efforts to explain this relationship, often overshadowing the need for research that explores autistic peoples' lived experience.

The majority of explanations articulated to account for the aforementioned prevalence rates have been situated within the conventional medical model (Walker, 2012), which focuses on biological and physiological influences on health. This perspective views the 'problem' as residing within the affected individual (White et al., 2023), and has resulted in neurobiological explanations dominating, where autism and psychosis are seen as distinct conditions caused by shared risk factors, e.g., shared genetic risk, or that one condition predisposes a person to the other (Schalbroeck et al., 2023). Overlap in the presentation of both conditions, such as perceived difficulties in social interaction and social cognition have been cited as evidence to support the neurobiological account (Ferrara et al 2024).

Models derived from autism research have also been conceptualised in an attempt to further understand this relationship. In particular, it has been suggested that schizophrenia is predominantly a deficit in theory of mind, and that perceived impairments in social cognition associated with autism are responsible for misreading the mental states of others, resulting in increased paranoia or persecutory beliefs (Frith, 1992). Indeed, it has been suggested that a deficit in social cognition can represent the clinical manifestation of a neurobiological vulnerability to psychosis (Ferrara et al., 2024).

It has been highlighted that psychosis is a heterogeneous phenomenon which incorporates a variety of psychiatric diagnoses (Beards & Fisher, 2014). The implications of this, are that there is unlikely to be a single causal pathway, and different risk factors may influence the experience of different symptoms (Beards & Fisher, 2014). It has been proposed that any aetiological model seeking to conceptualise pathways to psychosis must 'broaden out' and adopt a biopsychosocial perspective (Beards & Fisher, 2014), which also applies to the co-occurrence of autism and psychosis. Indeed, there is a need to account for adverse life experiences and the influence of trauma, stress, and socio-developmental factors (Perez-Alvarez, 2016).

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Explanations of the co-occurrence of autism and psychosis that have been rooted in the aforementioned perspectives, reflect an often prevailing view that being autistic somehow predisposes people to poorer mental health (Botha & Frost 2020). Attributing the cause of a person's difficulties to autism, whilst simultaneously giving little attention to other explanations, particularly negative social factors, is not uncommon (Kapp, 2019). From a social development perspective, research by the autistic community has highlighted that autistic people are generally more likely to experience a variety of stressors such as victimisation, violence, discrimination, rejection and felt stigma (Turnock et al., 2022). These experiences can be understood with reference to Minority Stress Theory, which posits that lower social status leads to stigmatised minority groups having exposure to more adverse life events, whilst at the same time having fewer resources to cope (Botha & Frost 2020). Minority stress has been proposed to have its own distinct and deleterious effect on health, beyond simply general stress (Botha & Frost 2020).

Social identity theory (Tajfel & Turner, 1979) is also helpful to consider as this contends that belonging to particular social groups informs a person's identity, and this process of identification happens when group membership is used to define a person. Defining the self as a group member is thought to improve wellbeing when the group is seen positively, or when a person experiences a sense of collective self-esteem (Botha & Gillespie-Lynch, 2022). As a minority group, autistic individuals may attempt to 'mask' their autistic identity and traits in an attempt to reduce their experiences of stigma and discrimination (Pearson & Rose, 2021). It has been suggested that such concealment may also be related to adverse outcomes such as late or missed autism diagnosis, mental health issues, burnout and suicidality (Pearson & Rose, 2021).

The co-occurrence of autism and psychosis has been linked to a range of adverse outcomes. There is evidence to suggest that autistic individuals who experience psychosis may experience a longer duration of untreated psychosis, greater symptom severity, and be less likely to respond to multiple antipsychotic medications, as well as being at an increased risk of suicidality and self-harm (Larson et al., 2017; Larson et al., 2020). This highlights the need for more research which provides insight into the lived experience of both psychosis and help-seeking/intervention among autistic people.

To the best of our knowledge, no research on the lived experience of FEP among autistic people has yet been conducted. This study aimed to generate insights into the experiences of psychosis in autistic people, and foreground their experiences of navigating recovery from FEP using semistructured interviews. Semi-structured interviews were chosen for this study due to their flexibility, which allows researchers to adapt and rephrase questions in response to participants' needs. This adaptability is especially valuable when working with autistic individuals, who may vary in their communication styles, processing speeds, and comfort with social interaction (Beresford et al., 2004; Harrington et al., 2014). The heterogeneity of autism and the diversity of lived experiences were also key considerations in the selection of this method. Semi-structured interviews enable a deeper exploration of personal narratives by encouraging participants to expand on topics that hold personal significance (Milton & Bracher, 2013). This depth is particularly important in autism research, where understanding individual perspectives requires capturing rich, subjective experiences (Milton & Bracher, 2013). Ultimately, this approach aimed to foster a more inclusive and accessible research environment, facilitating the collection of authentic and meaningful data. The interviews were conducted with two key questions guiding the research:

1. How did people understand and make sense of what they were experiencing when they first accessed support for FEP? Particular attention will be paid to the factors that people feel may have contributed to the development and maintenance of psychosis.

2. What elements do people feel are important in their recovery journey from psychosis? This will include consideration of the extent to which people incorporate aspects of their autistic identity as part of this process.

## Methods

This study was reported in accordance with Reflexive Thematic Analysis Reporting Guidelines (RTARG; Braun & Clarke, 2024; Appendix G). The original project proposal can be found in Appendix H.

## Design

A qualitative, cross-sectional design was utilised. This involved conducting semi-structured interviews to gather insights on the experiences of life as an autistic person and of first episode-psychosis. Reflexive Thematic Analysis (RTA; Braun & Clarke, 2019), adopting a critical realist stance, was considered appropriate as the present study sought to explore autistic people's experiences of first-episode psychosis, their perceptions of contributory factors, and the extent to which they incorporated aspects of an autistic identity into their explanations. As critical realism locates itself between positivist and constructionist paradigms (Byrne, 2022) it permits cautious interpretation of participant's experiences to be generated, whilst also acknowledging the context in which these are

being constructed (i.e. the researcher's interpretations of the participant's perceptions, mediated by cultural context and individual characteristics; Byrne, 2022).

#### Participants

Autistic adults (clinical diagnosis or self-identification), aged 16 and over, who were current service users of an Early Intervention in Psychosis (EIP) Service in NHS Greater Glasgow and Clyde Health Board were recruited between 1<sup>st</sup> May to 1<sup>st</sup> October 2025. They were made aware of the study by clinicians within the service who believed they may meet the eligibility criteria, and were provided with a study information leaflet (Appendix H). They were then contacted by the lead researcher to discuss participation further.

Exclusion criteria were insufficient English language skills to comprehend the study procedures, and no clinical diagnosis of autism or self-identification as autistic, e.g. a clinician suspecting someone may be autistic, but this never having been discussed with a potential study participant. A recent acute relapse of psychosis in the previous 4 weeks also meant that study involvement would be delayed.

Eleven potential participants were identified in the service with six autistic adults taking part in this study. Two participants declined participation after being approached by clinicians, two were deemed ineligible due to a recent acute relapse of psychosis, and one potential participant was not approached as it was not deemed an appropriate time for them to engage in the study by their clinician.

Minimal information was collected to preserve the confidentiality of participants, as the small sample size could have permitted jigsaw identification. To provide some contextual background for the study, brief demographic information was collected at interview via a questionnaire (Appendix H).

The median age of participants was 22, with four males and two females. Three participants identified as 'White British', and three as 'Black or Ethnic Minority Group'. Four participants had a clinical diagnosis of autism, and two self-identified. It was deemed appropriate and important to include those who self-identify as autistic in recognition of the many barriers to receiving a formal diagnosis (Wilson et al., 2023). There is also evidence that those who self-identify as autistic have similar self-conceptualisations and experiences of stigma as those with a formal diagnosis (MacDonald, 2020).

There has been intensifying debate within the qualitative research field with regards to sample sizes required to reach 'data saturation'. As a concept data saturation within thematic analysis is often considered as the point of 'information redundancy', that is when no new codes or themes emerge from the data (Braun & Clarke, 2021b). It has been argued that meaning is not hidden in data and waiting to be discovered, but rather that meaning is found at the intersection of the data and the researcher's contextual and interpretative practices (Braun & Clarke, 2021b). As meaning is generated through interpretation in reflexive thematic analysis, rather than being 'extracted' from the data, it is proposed that questions about sample size and when to stop data collection are subjective, and not possible to be determined in advance of data analysis (Braun & Clarke, 2021b). When considering the timeframe limitations of this study and the interpretative approach being taken to analysis, more focus was given to the concept of 'informational power' (Malterud et al., 2016). This approach posits that the more relevant information a sample holds, the fewer participants that are needed.

#### Materials

Semi-structured interviews gathered qualitative information about autistic adults' experiences of life as an autistic person and of FEP. An interview schedule (Appendix H) was informed by relevant literature and developed in conjunction with the Psychosis Research Patient and Public Involvement (PPI) group at the University of Glasgow. Two members of this group with lived experience of psychosis were consulted. The Adverse Childhood Experiences Research Group, who have members who identity as neurodivergent were also consulted. Consultation with these group was utilised to ensure that the interview questions were accessible, sensitive, and appropriate. A semi-structured format permitted flexibility, enabling the researcher to follow the participant's line of response. This has been demonstrated to promote rapport building between the researcher and participant, in addition to offering more agency to the participant with regards to the pace and direction of the interview (Howard et al., 2019). Reflective notes were made after each interview to aid reflexivity.

#### Procedure

All participants were recruited via the EIP Service. Clinicians were asked to approach any service users who they believed may meet study eligibility criteria, and provide them with a brief study information leaflet (Appendix H). If interested in participating consent was sought for study details to be passed to the researcher. After initial telephone contact the participant information sheet

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(Appendix H) and consent form (Appendix H) were emailed and a follow up call organised to decide on participation.

Options were given for interviews to be conducted online via MS Teams, or at EIP and University sites. Participants were offered to bring a support person to interview. Prior to the interview, informed consent was gained from all participants, and as outlined earlier, a demographic questionnaire was completed, in addition to a privacy notice (Appendix H). Interviews were recorded using an encrypted Dictaphone provided by the University of Glasgow. These lasted between 40-90 minutes (Mean= 63.3). Given the sensitive nature of the interviews, a debrief was offered at the end of the interviews to check on participants' wellbeing. Follow up 'check-in' telephone calls ('Script' in Appendix H) were also organised for one week after the interview to ensure the interviews had not caused any significant distress, and that participants' named clinician at the EIP would be notified and would liaise with them directly. Interview recordings were saved to the lead researchers NHS account and transcribed verbatim using computer software, with any potentially identifiable information removed.

#### Data Analysis

The qualitative data gathered by the interviews was analysed using RTA (Braun & Clarke, 2019). This approach emphasises the researcher's subjectivity as an analytic resource, and their reflexive engagement with theory, data and interpretation (Braun & Clarke, 2021a). Indeed, for this reason reflexive thematic analysis was deemed as most appropriate for this study as it was undertaken by a non-autistic researcher and involved analysis of data generated by autistic participants. The researchers social, cultural, historical, political and ideological positioning all impact on their interpretation and are all acknowledged and accounted for as part of the analysis process (Braun & Clarke, 2021a). Furthermore, RTA is proposed to be more appropriate for the heterogeneous sample expected in this study (Braun & Clarke, 2021a), as participants had different pathways into the service e.g., autism diagnosis then psychosis or vice versa.

As recommended by Braun and Clarke (2019), analysis moved from data familiarisation and initial coding to the development of themes and review. A predominantly inductive approach to coding was adopted, therefore, open coded and respondent/data-based meanings were given prominence. However, an element of deductive analysis was utilised to ensure that the coding process supported the development of themes, and respondent/data based meanings given prominence were relevant

to the research questions. Coding was undertaken by the lead researcher. After all interviews had been coded, the codes were then compiled alongside relevant data extracts which supported theme development (See Appendix I). Following this, transcripts were again reviewed in order to be satisfied with the validity of the theme development. This approach of repeatedly engaging with the data allowed for further refinement of themes in relation to both their title and content. Theme development was also supported through ongoing collaboration and reflexive discussions with the research supervisors (See Appendix J for excerpt from reflexive log). To maintain a reflexive approach there was no pre-determined end point to data collection or any aim to achieve data saturation. As outlined, the concept of informational power (Malterud et al., 2016), helped to guide decisions about both the richness and depth of data collected.

#### Reflexivity Statement

As a Trainee Clinical Psychologist, I recognised that within many of the services I had worked, the more medicalised and deficit view of autism remains dominant, and this previously influenced my own perceptions. I acknowledged my position as an 'outsider' to the autistic community, and although I attempted to immerse themselves in literature related to adverse life experiences, and theories related to membership of, or identification with a minority group, I was aware that I have not experienced life as an autistic person or had experiences of FEP. As outlined earlier, it was hoped that the use of semi-structured interviews could help in relation to this as they are designed to enable a deeper exploration of personal narratives by encouraging participants to expand on topics that hold personal significance

I was aware that many participants may have had difficult past experiences of working with health professionals and may have contrasting views on the diagnostic labels used to conceptualise their experiences. However, it was hoped that my training and work experiences have encouraged and enabled me to work in a collaborative manner with people, and to be curious about their own unique views and experiences in a non-judgemental manner.

This study has also considered wider political issues in relation to research being conducted with autistic people. There has been a lack of inclusion of autistic people in research and their experiences have often been framed by researcher's theories and interpretations of their experiences. The adaptations to this study's design which are discussed in more detail throughout the methodology sections hoped to address issues related to such power imbalances. The study was designed with collaboration and meaningful involvement in mind.

## Ethics

Ethical approval was granted from the West of Scotland Research Ethics Committee 3 (REC; IRAS330394; Appendix K), and managerial approval from NHS Greater Glasgow and Clyde's Research and Innovation Department (UGN24MH016; Appendix L).

## Results

## Reflexive Thematic Analysis

Table 1 provides an overview of the analytic outputs of RTA. Themes are discussed further below, alongside illustrative quotes. Pseudonyms are used throughout the results section on order to maintain the anonymity of participants. Further illustrative quotes can be found in Appendix M.

Table 1.

Overview of Themes Developed from RTA.

Themes	Brief Description
1. Experiences and Impact of Psychosis	Participants described a range of experiences that were consistent and familiar with FEP. The highlighted the impact of these experiences on themselves, whilst also empathising with the emotional impact on those closest to them.
2. Adverse Experiences as a Pathway to Psychosis	Participants reflected on their perceived pathways to FEP and identified what they felt were important contributory factors. Stressful experiences, and trauma and loss, were discussed as being perceived to be important precipitants to psychosis.
3.The Nuances of an Autistic Identity	This theme captured how people related to the autistic identity and the perceived strengths associated with being autistic. There was also discussion about the awareness of stigma and the challenges of navigating a neurotypical world.

## 4.The Importance of Interpersonal Support and Social Connection

The importance and positive experience of professional, peer, and family support were discussed in detail by participants. Some areas of difficulty with the support offered and suggestions for how best to support autistic people were also outlined.

## **Theme 1: Experiences and Impact of Psychosis**

All participants reported experiences of paranoia and/or persecutory delusions. These often consisted of concerns and paranoia about family or friends wishing to harm them, or more general concerns about 'something bad happening', as demonstrated by the participant excerpt below:

"I was accusing my friends and family of like really crazy things because I was, I was really struggling with what I was dreaming and what was reality." (Connie)

Auditory hallucinations and voice hearing were also experienced by four participants, with examples highlighted below:

"There was another voice in my head that could talk, that could have its own ideas, that could be themselves but it felt that, it maybe hated me." (Jack)

"I was staying at another friends and one of my friends was there and he left and I could still hear them." (Emily).

For two of the participants (Aaron and Jack), their experiences of psychosis had resulted in them becoming more withdrawn and isolated. Indeed, for Aaron he described becoming a "ghost" and "completely estranged" to the point where he had "lost interest in everything around me in life, in communicating". While for Jack the experience of voice hearing was "frightening" and he discussed how the voice would often "try and upset me as much as it could". However, he also reflected on some positive interactions with the voice, stating that "sometimes it wasn't bad like it was just conversations that I have, like there was always someone there to talk to, sometimes it made me feel less lonely". Emily reflected on her experiences being "extremely difficult because you lose your sense of self".

Participants highlighted being very aware, and empathising with the impact that their experiences had on those close to them, especially their family and friends. Cam and Jack discussed their parents

being "scared" and "worried". Cam described how his father had stated that it was "the worst day of his life when I went into hospital". He also shared how his parents "didn't know what was happening", while for Emily, there was a feeling that those closest to her had "trouble readjusting" because "they had never seen something like that and they didn't know what to do with that". Dylan also spoke of experiencing feelings "guilt" and "blame" about the impact his experiences had on his family:

"Yeah, I guess.....I don't know, I don't really, you know, you blame yourself that it happened to you, and you kind of caused it for your family and things like that".

The experiences and impact of psychosis among participants was consistent with other qualitative research that has been conducted in the general population (Cadario et al., 2011; Griffiths et al., 2019; Noiriel et al., 2020). However, participant's expressions of empathy for the impact psychosis had on those closest to them is important to note, especially given the stereotype of autistic people not being able to take another's perspective or lacking in empathy (Smith, 2009).

#### Theme 2: Adverse Experiences as Pathways to Psychosis

A range of stressful experiences were highlighted related to school, university, and work. In addition, transitional stages in life, such as beginning university, or a first graduate job were discussed. Stressful events leading to a period of sleep disruption which had a further deleterious impact on people's wellbeing were emphasised. For Cam, the transition to university and the new social demands associated with this were very stressful. He stated that *"I hadn't socialised in and a while and I got stressed out basically, and then over a few months it kind of got worse"*. He reflected on how the stress of these experiences *"just tipped me over the edge I think"*.

For both Dylan and Jack, the stress associated with exams at school were identified as important. Dylan discussed how stress associated with exams meant that he "didn't really sleep beyond this point, I wasn't getting any sleep and then I just kept spiralling and it was getting worse". While for Aaron and Connie, work related stress was identified as an important precipitant. Aaron described how the loss of a graduate job after three months "really knocked back my confidence and that is when things took a turn for the worst and that's where I kind of gradually went downhill off a slope". While for Connie, work related stress and poor treatment by her employer led to her "not sleeping so much and then ultimately having to go into hospital because of my psychosis". Traumatic experiences and loss were also discussed as important contributors to psychosis. For Dylan witnessing the sudden death of his father had been very traumatic and had a significant impact over a period of time, as he stated *"it was basically trauma from my house.....and it was mainly about my dad... a lot of stress and triggers from my dad's death"*. For Aaron, the loss of his best friend was highlighted as making *"things a hell of a lot worse"*. While for Emily, *"living below the poverty line"* and in *"an abusive household"* were discussed.

Participant accounts of their perceived pathways to psychosis being influenced by stress, trauma and loss were again consistent with other qualitative research that has been conducted in the general population (Cadario et al., 2011; Griffiths et al., 2019; Noiriel et al., 2020). They are also in keeping with the developmental psychopathology framework which is used to understand how psychological disorders emerge and evolve over the course of a person's development (Cicchetti & Rogosch, 2002). This perspective emphasises the interplay between neurodevelopmental, cognitive, and environmental factors, and their interaction in the development of difficulties such as psychosis (Cicchetti & Rogosch, 2002). Other research has suggested autistic individuals, who often experience atypical brain development, may face heightened vulnerability during adolescence when significant brain changes occur, increasing the risk for psychosis (Chisholm et al., 2015). Genetic predispositions and environmental stressors, such as social adversity, have been proposed to further exacerbate this risk (Van Os et al., 2010).

#### Theme 3: The Nuances of an Autistic Identity

All participants' expressed a generally positive, or neutral self-perception of their autistic identity. Three viewed themselves as "different" (Cam, Dylan, Jack), but this was not perceived negatively, with Cam describing himself as "quirky", and Dylan feeling that being autistic was "nothing to be ashamed of". Indeed, the general positive self-perception associated with being autistic was encapsulated well by Emily:

"It's just, I don't know, a different way of living. It's a different way of seeing the world. A different way of, it's just like being instead of being forced".

Being creative and having special interests were also perceived as positive elements of being autistic:

"Well, if, just... like when I get hobbies, I just like that one hobby, and I dedicate myself to it for a while, so I get really good at things quite fast from it." (Jack)

"I'm really good at photography, like I have a special interest in that." (Connie).

Despite their own generally positive perceptions of their autistic identity, all participants highlighted an awareness that this might not be perceived as such by others, and that stigma related to autism remained pervasive, and led to them being treated differently. Connie expressed feeling that "neurotypical people jump to conclusions that are the complete opposite of who I am." She also felt that "the majority of people don't understand me or don't get along with me." Jack discussed preferring most people to not be aware that he was autistic as "people might think of me different because of it, or might act or treat me a bit different, thinking they need to be different to talk to me. I, yeah, cause I just like them treating me normal." An awareness of stigma also meant that people often had to conceal aspects of their autistic identity in order to not be treated differently, as highlighted in the extracts below:

"But not in that like I won't tell them I'm autistic, but in that I have to hide all of my autistic traits. it's like I can tell them I'm autistic, it's like they just don't want me to present as autistic. It's like they're aw nice you are autistic, please don't do anything autistic." (Emily)

"If I'm in quite a big group, or a big crowd nearby that I need to go talk to, then I try to keep it hidden. Well I make sure just in case, if anyone who knows is with me, to tell them not to say and I kind of just try and mimic what everyone else is feeling, so they can't really notice anything different." (Jack)

The concept of autistic masking has been linked to a range of adverse mental health outcome including burnout (Cage & Troxell-Whitman, 2019), and again reflects the additional stress burden experienced in this sample. Indeed, the contrast between participants' view of themselves and how they believe society perceives them was consistent with findings from Botha et al., (2022), in a qualitative study exploring how autistic people make sense of stigma.

Research exploring how autistic identity develops is still in its infancy (Davies et al., 2024), partly due to prevailing stereotypes of autistic people as withdrawn and asocial (Botha & Gillespie-Lynch, 2022). As outlined earlier, Social Identity Theory (Tajfel & Turner, 1979), proposes that defining the self as a group member is thought to improve wellbeing when the group is seen positively, or when a person experiences a sense of collective self-esteem (Botha & Gillespie-Lynch, 2022). In relation to the autistic identity, if an autistic person grows up in a society where autism is perceived negatively, this may result in them being less likely to integrate autism into being a core part of who they are, i.e. their personal identity. If this is the case, it is proposed that people may be less likely to associate with other autistic people, which could diminish their autistic social identity (Botha & Gillespie-

Lynch, 2022). Indeed, McIntyre et al 2018., proposed that certain identities, such as migrant identities, may increase the risk of developing paranoia through reduced self-esteem. While in a more recent study (Greenaway et al., 2019), it was suggested that control and trust may mediate the relationship between paranoia and particular social identities; highlighting that stigma, prejudice and discrimination associated with certain identities might promote a lack of trust, and provide the foundations for suspiciousness, and the later development of persecutory ideas.

Having a positive personal autistic identity has been found to be positively associated with psychological wellbeing (Corden et al., 2021). Meanwhile, a positive autistic social identity has been associated with higher collective self-esteem (i.e., positive perceptions of group membership), which was, in turn, associated with higher personal self- esteem (i.e., positive perceptions of self) and, importantly, reduced traits of anxiety and depression (Cooper et al., 2021). In the present study, where autistic people were found to have a positive, or at least neutral autistic personal identity, their autistic social identity appeared to be more context dependent, with broader societal stigma being internalised by many. This finding could perhaps be best understood by the concept of identity compartmentalisation (Hogg et al., 2024), whereby keeping a stigmatised identity, such as being autistic, or someone who has experienced psychosis, separate within the self, and expressing this in a distinct group, may feel safer than identity integration in a stigmatising context (Hogg et al., 2024). Therefore, the intersection of autistic and psychosis experiences may uniquely challenge the integration of a stable and positive sense of self, while also providing potential pathways for resilience through positive group identification and self-acceptance (Cooper et al., 2021).

When discussing any perceived negatives, or challenges that may be associated with being autistic, participants often cited the demands and expectations of living in a neurotypical world, in particular that they adapt and alter their communication for others to understand them better. Cam and Jack spoke of finding social situations "*difficult*", while Connie spoke of the struggle of *"making myself find a place in the world"*. She also shared how overwhelmed she gets in social situations:

"I kind of I cry a lot. Like I don't, I don't know many people that kind of can't control their emotions like I can't".

These challenges were well summarised by Emily when she stated that "you've got to really analyse speech and learn how the person communicates. You've got to change your communication to their communication all the time".

In relation to this study, and when considering the influence of adverse life experiences and stress as risk factors for psychosis, the concept of minority stress is important to consider. As outlined earlier,

minority stress refers to the additional stress burden which minoritised individuals have to cope with, in addition to the daily life stresses everyone encounters (Botha & Frost, 2020). This was evident in many of the aforementioned participants' accounts.

#### Theme 4: The Importance of Interpersonal Support and Social Connection

Various aspects of professional support were valued and appreciated, with the availability and regular contact with their keyworker or community psychiatric nurse (CPN) cited as being very important, as demonstrated in the extracts below:

"I used the health professionals if I was worried about anything or just called them, but having that option available, even if you're not going to use it, is good." (Cam)

"She comes down to the house every couple of weeks, a CPN I think they are called. So if I'm having a bad week where I can't go out to anything there's always somebody you can talk to." (Jack)

For Dylan, working with psychology had been beneficial in developing a better understanding of emotions, as well as autism and how this may be linked to some of their experiences:

"just before I had psychology, I wasn't really in contact with my emotions, I wasn't really in touch with them, kind of everything was spilling out and, ......and loads of psychology meetings and over time you can kind of bridge the gap, but then I just learned to connect them and kind of control them as well, so I kind of find it hard to deal with emotions sometimes, it tends to spill out, but I've gotten a lot better due to psychology meetings and esteem in general." (Dylan)

For Emily and Connie, some aspects of professional support were perceived as more challenging. For Connie, being someone who is detailed oriented and not being given more information on the medications she had been prescribed was distressing. In addition, she also found the way in which people would communicate with her difficult at times, especially their use of language:

"I was quite reluctant to take my medication. They did prescribe me like 4 different things, and they wouldn't tell me exactly what they were and I'm quite like detail orientated so I wanted to know like what the drugs they were giving me were. But I wasn't in the right headspace to ask for the details so I just kind of really struggled to take it. I think I'd have ended up taking them a lot quicker if they'd just given me more information about what I was being given because when I did eventually ask they were like really common drugs that I would have related to."

"They would say like I'm going to turn into a butterfly, like I'm going to evolve into this new person.... so weird things like that."

For Emily, difficulties in communication with professionals, especially aspects of her autistic communication style being perceived to be misinterpreted as symptoms of psychosis, in addition to a perceived lack of understanding of the value of her special interests were highlighted:

"This is something I've said, that's in my medical records, in my first, in my first, in my first eh... admission, because I was saying things like this to describe what I was feeling. And I was like, I'm Spiderman right now, and they put down..... thinks she is Spiderman. And it's like no! I don't think I'm Spiderman, I'm using a metaphor. That, that's which is very, very funny. It's like I'm the autistic one, I'm meant to be black and white and mean to not understand that s\*\*\*."

"I understand the whole stress aspect but that was really unhelpful as well. Um... the lack of understanding for what is stress? And what is perceived as stressful? Like my internship. That was the most beautiful thing I have ever done, it was a calming environment, the best thing. I was explaining this to my doctor and he was like no! But work....work is a very stressful thing to do. I was like you need to take into account that what I'm working in is my special interest. That is something that has been taken away from me and that is something that got me down. He was like no working is stressful!"

The aforementioned communication challenges could perhaps be best understood by considering the double empathy problem (Milton, 2012). This highlights the complex and challenging nature of interaction and understanding between different groups, particularly neurotypical and autistic people, and that they may have difficulty empathising with each other's experiences and emotions. It situates difficulties in understanding as a reciprocal problem and emphasises the need for both sides to strive to understand each other better.

The support and provided by peers in the service and some friends was highly valued by participants. Social connection, as well as the groups and activities on offer providing a structure and routine to the week were highlighted:

"So Esteem played a massive role in you know, helping me get back on track. And you know, seeing a sense of normality and living a normal life. They arranged for a lot of activities. And they helped me revive my interests again, they really helped a revival in me, so it's really, Esteem have been absolutely fantastic in that sense." (Aaron)

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The benefits of shared experience and being able to connect and support each other was emphasised. Indeed, two people found they were even able to 'have a joke' with peers about their experiences, which was in contrast to interacting with family, who would often become worried when psychosis was discussed:

"I guess it's just the weekly visits and the clubs as well, meeting up with people and then they share their experiences, and you can share yours, and I guess you get to know people, and you can have this bond where you've all been through this experience, and you can all basically empathise with people as well, and that kind of helped me realise I wasn't alone, and other people have suffered through this, and it's not kind of stigmatised as well" (Dylan)

"I tried talking about it to my friends and family and they just think it sounds crazy, like they can't, they can't or I'll talk to my partner about it and he'll actually sometimes get worried I'm thinking about that again. But eh, if you tell the people who are like minded or who have had an episode, it's just kind of funny to talk about the stories, like you can see the fun in it" (Connie)

These findings are consistent with other research (Hogg et al., 2022), which has indicated that social connections are important to wellbeing in people experiencing psychosis; often referred to as the concept of the 'social cure' (Hogg et al., 2022). This phenomenon has arisen from an expanding area of research which has linked social identification (a felt sense of belonging in groups) to be beneficial for psychological health and overall wellbeing (Haslam et al., 2018). Indeed, the protective effects for health and wellbeing from the formation of social connections with others experiencing similar health problems has been demonstrated for people with depression (Cruwys et al., 2014), and psychosis (Hogg et al., 2022), among other health conditions The cognitive model for the development of social identification (Amiot et al., 2007), suggests that the integration of different social identifies reflects a more stable sense of self and is important for wellbeing.

The current study did not directly focus on participants' social identities as people who have experienced psychosis to the same extent as it did autistic identity. However, it was clear from some participants' accounts that it was easier to connect with others based on shared experiences of psychosis, than it was with family and friends. In particular, people seemed to find it easier to be their authentic self, based on identifying with the experiences of other service users, than they did expressing their autistic identity in many situations. These experiences are possibly reflective of identity compartmentalisation (Hogg et al., 2022),

The practical and emotional support provided by family was also very important for two participants as outlined below:

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"My mum was a big support for me, visiting me every day in hospital and it was quite far as well, really helped me a lot" (Dylan)

"Yeah, well my mum.....she took time off while I was in hospital and she took some time off and we did a bit of cycling together, and that was good and that encouraged me to exercise more because I felt unfit when I got out of hospital" (Cam)

Establishing links with autistic support organisations that people could be signposted to, being careful around the use of language and metaphors, and some further training on working with autistic people were all highlighted as important:

"I'm also part of this film club with autistic people, it's called the spectrum film club and they watch films once a month together and I volunteer there, something like that would be really useful" (Cam)

"I think more encouragement to be who I was before rather than being a new person. Em yeah that would have been better. Because I was fine before I got unwell, I didn't need to change me entire personality" (Connie)

"Understanding meltdowns. That's so important. That's not just from me. That's from talking across the board with autistic people in hospital. Um understanding meltdowns and really trying to get an idea of how the person is going to react and how you can work with them" (Emily).

## Discussion

To our knowledge this is the first qualitative study to explore experiences of first-episode psychosis among autistic adults. Participants offered rich accounts of their experiences and perceived pathways to FEP. They detailed the significant emotional impact on both themselves and those close to them. The complexity and nuance of relating to an autistic identity, particularly in a neurotypical world where people perceived and experienced stigma related to being autistic was an important, and central theme of this research. The other central theme related to the importance of social connection in navigating recovery from FEP, and demonstrated the positive impact of a supportive, stigma free environment which allowed people to relate to others and feel more like their authentic self. The implications for clinical practice and policy from these findings are discussed below.

#### **Implications of Findings**

There are a number of important implications from this study. Firstly, although the availability, validation and sense making offered by professional support was valued, some people also experienced certain aspects as challenging. Differences in communication styles between autistic people and clinicians should be considered, and as outlined the double empathy problem (Milton, 2012), could be helpful to incorporate into autism training and awareness raising in services. Consultation with the autistic community is also important in this area.

In relation to support and recovery, there are important implications both in terms of how people relate to their autistic identity, and how valuable the promotion and strengthening of social connections can be in recovery. Despite generally holding positive self-perceptions about being autistic, people in this sample were very aware of the prevalence of societal stigma. Although the compartmentalisation of identities can have beneficial effects for wellbeing, especially when such identities are stigmatised, in the longer term the literature would suggest that such concealment is not likely to be optimal for wellbeing. This would require the erosion of stigma related to autism, which can be tackled at the individual, service, and wider societal level.

In relation to individuals and services, given how valued social connection was for wellbeing and recovery, close links with autistic support organisations, and the implementation of autistic peer support programmes, where possible, could be highly beneficial. There is evidence to suggest that as a result of experiences of stigma and discrimination, autistic people experience a disconnect between the number of social connections they aspire for, and the number they have (Botha et al., 2022). As a consequence, autistic people may have more limited opportunities to develop a positive sense of self as it relates to being autistic (Davies et al., 2024). Services having close links with autistic support organisations could have the potential to support autistic people to develop connectedness with other autistic people, and strengthen their personal and social autistic identities, which have been outlined to be though to be conducive to wellbeing. Furthermore, peer support initiatives have also been endorsed in recent work by autistic people to support people to positively reframe their autistic identity (Crompton et al., 2022). Indeed, peer support groups have been shown to cultivate positive identity development and improve self-esteem and community belonging among people in other minority groups, e.g., LGBTQ+ people (Borthwick et al., 2020). It is also important to consider that autistic people may wish to connect with others in different ways, e.g., the internet and social media, or may not yet be at a stage in their identity development where
the aforementioned supports would be valued. Again it is important that there is autistic community involvement at all stages of the development of any such initiatives to make them work best for the people who may wish to utilise them.

#### Strengths, Limitations and Future Directions

This study provides insight into the lived experience of first-episode psychosis among autistic adults. Autistic people are disproportionately affected by mental health problems relative to the general population, and despite significantly higher prevalence rates of psychosis, they have thus far been underrepresented in the literature on this area. The use of a qualitative methodology with semistructured interviews allowed autistic voices to be heard on this important issue, and for future support needs specific to this population to be articulated. The use of reflexivity also enhanced the transparency of this research by acknowledging the influence of the researcher on the interpretation of participants' accounts. The researcher acknowledged his position as a neurotypical, and as someone who had not experienced psychosis, and established their position as an outsider perspective when conducting this research. The consultation with the psychosis research group at the University of Glasgow in helping to shape participant materials, including the interview topic guide was also a strength of this research. There is intersectionality within the members of this group, some of whom identify as neurodivergent and have had experiences of psychosis.

Recruitment was challenging for a number of reasons. As may be expected the fluctuating nature of psychosis meant that some potential participants were unable to take part due to an acute relapse. Others declined participation after being approached by clinicians and being provided with an overview of the study. Other studies with autistic adults (e.g., Pearson et al., 2023) have found value in offering a range of participation methods, such as open ended free text responses, in addition to face to face or video interviews. The utility of such methods may be worth considering in future research.

While the current study was able to consider intersectionality in relation to being autistic and experiencing psychosis, it did not have the scope to explore how having other identities, particularly other minority identities, e.g., sexual or gender identities may intersect and impact upon both pathways to psychosis, and recovery. It may be interesting to explore the compartmentalisation of identities in relation to such intersectionality, and the extent to which social identity and connection may buffer against such minority stress.

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#### Conclusions

The experiences of, and perceived pathways to FEP among autistic adults in this study were consistent with research conducted in the general population. These experiences were found to have a significant emotional impact on people and those close to them. Consideration of the intersectionality between being autistic and experiencing psychosis provided some novel insights into how navigating the complexities of an autistic identity may have contributed to such experiences. In addition, interesting findings related to the compartmentalisation of different personal and social identities was considered. Social connection was found to be an influential recovery factor, alongside professional and family support. Suggestions for ways autistic people can be supported to develop positive personal and social identities were considered. Whilst the contribution of services, government and society in general to promote greater autism awareness and acceptance were outlined as important factors in potentially reducing the co-occurrence of FEP in autistic people.

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# Appendices

# Appendix A: Improving Reporting of Meta-Ethnography: The eMERGe Reporting Guidance

Number	Criteria Headings	Reporting Criteria	Reported or Page(s)
	Phase 1—Selecting meta-eth	nography and getting started	
	Introd	luction	
1.	Rationale and context for the meta-ethnography.	Describe the gap in research or knowledge to be filled by the meta-ethnography, and the wider context of the meta- ethnography.	P13
2.	Aim(s) of the meta-ethnography.	Describe the meta- ethnography aim(s).	P13-14
3.	Focus of the meta-ethnography.	Describe the meta- ethnography review question(s) (or objectives).	P13-14
4.	Rationale for using meta- ethnography.	Explain why meta- ethnography was considered the most appropriate qualitative synthesis methodology.	P13
	Phase 2—Decidin	g what is relevant	
	Met	hods	
5.	Search strategy	Describe the rationale for the literature search strategy.	P14-15
6.	Search processes	Describe how the literature searching was carried out and by whom.	P14-15
7.	Selecting primary studies	Describe the process of study.	P15-16
	Find	lings	1
8.	Outcome of study selection	Describe the results of study searches and screening.	P19
	Phase 3—Reading	g included studies	l
	Met	hods	

9.	Reading and data	Describe the reading and data	P16
5.	_	extraction method and	. 10
	extraction approach	processes.	
	Fine	dings	
10.	Presenting	Describe characteristics of the	P21-31
	characteristics of	included studies.	
	included studies		
	Phase 4—Determining	how studies are related	1
	Met	hods	
11.	Process for	Describe the methods and	P18
	determining how	processes for determining how	
	studies are related.	the included studies are related:	
		- Which aspects of studies	
		were compared	
		AND	
		- How the studies were	
		compared	
	Find	lings	
12.	Outcome of relating	Describe how studies relate to	P35
	studies	each other.	
	Phase 5—Translating s	tudies into one another	1
	Met	hods	
13.	Process of translating	Describe the methods of	P18 & P98
	studies	translation:	
		- Describe steps taken to	
		preserve the context and	
		meaning of the relationships	
		between concepts within and	
		across studies – Describe how	
		the reciprocal and refutational	
		translations were conducted.	
		Describe how potential	
		alternative interpretations or	
		explanations were considered	
		in the translations.	
	Find	lings	
L			

14.	Outcome of translation	Describe the interpretive	P35-40
		findings of the translation.	
	Dhaco 6 Syntho	sizing translations	
	Phase 0—Synthes		
	Met	hods	
15.	Synthesis process	Describe the methods used to develop overarching concepts ("synthesised translations") Describe how potential alternative interpretations or explanations were considered in the synthesis.	P18
	Fina	lings	
16.	Outcome of synthesis process	Describe the new theory, conceptual framework, model, configuration, or interpretation of data developed from the synthesis.	P35-40
	Phase 7—Express	sing the synthesis	I
	Discu	ission	
17		Compared the second	D40.45
17.	Summary of findings	Summarize the main interpretive findings of the translation and synthesis and compare them to existing literature.	P40-45
18.	Strengths, limitations, and reflexivity.	Reflect on and describe the strengths and limitations of the synthesis: - Methodological aspects—for example, describe how the synthesis findings were influenced by the nature of the included studies and how the meta-ethnography was conducted. - Reflexivity—for example, the impact of the research team on the synthesis findings	P43 & 98
19.	Recommendations & Conclusions		P40-45

# Appendix B: PRISMA 2020 Checklist

Section and Topic	ltem #	Checklist item	Location where item is reported
TITLE	-		
Title	1	Identify the report as a systematic review.	P8
ABSTRACT	•		
Abstract	2	See the PRISMA 2020 for Abstracts checklist.	P9-10
INTRODUCTIO	N		
Rationale	3	Describe the rationale for the review in the context of existing knowledge.	P11-14
Objectives	4	Provide an explicit statement of the objective(s) or question(s) the review addresses.	P13-14
METHODS	<u>_</u>		-
Eligibility criteria	5	Specify the inclusion and exclusion criteria for the review and how studies were grouped for the syntheses.	P16
Information sources	6	Specify all databases, registers, websites, organisations, reference lists and other sources searched or consulted to identify studies. Specify the date when each source was last searched or consulted.	P15
Search strategy	7	Present the full search strategies for all databases, registers and websites, including any filters and limits used.	P15 & 88
Selection process	8	Specify the methods used to decide whether a study met the inclusion criteria of the review, including how many reviewers screened each record and each report retrieved, whether they worked independently, and if applicable, details of automation tools used in the process.	P15-16
Data collection process	9	Specify the methods used to collect data from reports, including how many reviewers collected data from each report, whether they worked independently, any processes for obtaining or confirming data from study investigators, and if applicable, details of automation tools used in the process.	P16
Data items	10a	List and define all outcomes for which data were sought. Specify whether all results that were compatible with each outcome domain in each study were sought (e.g. for all measures, time points, analyses), and if not, the methods used to decide which results to collect.	P16
	10b	List and define all other variables for which data were sought (e.g. participant and intervention characteristics, funding sources). Describe any assumptions made about any missing or unclear information.	P16

Section and Topic	ltem #	Checklist item	Location where item is reported
Study risk of bias assessment	11	Specify the methods used to assess risk of bias in the included studies, including details of the tool(s) used, how many reviewers assessed each study and whether they worked independently, and if applicable, details of automation tools used in the process.	P31-34
Effect measures	12	Specify for each outcome the effect measure(s) (e.g. risk ratio, mean difference) used in the synthesis or presentation of results.	N/A
Synthesis methods	13a	Describe the processes used to decide which studies were eligible for each synthesis (e.g. tabulating the study intervention characteristics and comparing against the planned groups for each synthesis (item #5)).	N/A
	13b	Describe any methods required to prepare the data for presentation or synthesis, such as handling of missing summary statistics, or data conversions.	N/A
	13c	Describe any methods used to tabulate or visually display results of individual studies and syntheses.	N/A
	13d	Describe any methods used to synthesize results and provide a rationale for the choice(s). If meta-analysis was performed, describe the model(s), method(s) to identify the presence and extent of statistical heterogeneity, and software package(s) used.	N/A
	13e	Describe any methods used to explore possible causes of heterogeneity among study results (e.g. subgroup analysis, meta-regression).	N/A
	13f	Describe any sensitivity analyses conducted to assess robustness of the synthesized results.	N/A
Reporting bias assessment	14	Describe any methods used to assess risk of bias due to missing results in a synthesis (arising from reporting biases).	N/A
Certainty assessment	15	Describe any methods used to assess certainty (or confidence) in the body of evidence for an outcome.	N/A
RESULTS			
Study selection	16a	Describe the results of the search and selection process, from the number of records identified in the search to the number of studies included in the review, ideally using a flow diagram.	P19-20
	16b	Cite studies that might appear to meet the inclusion criteria, but which were excluded, and explain why they were excluded.	P19-20
Study characteristics	17	Cite each included study and present its characteristics.	P21-31
Risk of bias in	18	Present assessments of risk of bias for each included study.	P31-34

Section and Topic	ltem #	Checklist item	Location where item is reported
studies			
Results of individual studies	19	For all outcomes, present, for each study: (a) summary statistics for each group (where appropriate) and (b) an effect estimate and its precision (e.g. confidence/credible interval), ideally using structured tables or plots.	N/A
Results of	20a	For each synthesis, briefly summarise the characteristics and risk of bias among contributing studies.	P21-34
syntheses	20b	Present results of all statistical syntheses conducted. If meta-analysis was done, present for each the summary estimate and its precision (e.g. confidence/credible interval) and measures of statistical heterogeneity. If comparing groups, describe the direction of the effect.	N/A
	20c	Present results of all investigations of possible causes of heterogeneity among study results.	N/A
	20d	Present results of all sensitivity analyses conducted to assess the robustness of the synthesized results.	N/A
Reporting biases	21	Present assessments of risk of bias due to missing results (arising from reporting biases) for each synthesis assessed.	N/A
Certainty of evidence	22	Present assessments of certainty (or confidence) in the body of evidence for each outcome assessed.	N/A
DISCUSSION			
Discussion	23a	Provide a general interpretation of the results in the context of other evidence.	P40-45
	23b	Discuss any limitations of the evidence included in the review.	P43
	23c	Discuss any limitations of the review processes used.	P43
	23d	Discuss implications of the results for practice, policy, and future research.	P43-45
OTHER INFOR	MATION		
Registration	24a	Provide registration information for the review, including register name and registration number, or state that the review was not registered.	P14
and protocol	24b	Indicate where the review protocol can be accessed, or state that a protocol was not prepared.	P14
	24c	Describe and explain any amendments to information provided at registration or in the protocol.	P14
Support	25	Describe sources of financial or non-financial support for the review, and the role of the funders or sponsors in the review.	N/A
Competing interests	26	Declare any competing interests of review authors.	N/A

Section and Topic	ltem #	Checklist item	Location where item is reported
Availability of data, code and other materials	27	Report which of the following are publicly available and where they can be found: analytic code	P100

# Appendix C: Example Search Strategy in OVID Medline

#	Search Strategy
1	Child Development Disorders, Pervasive/
2	Asperger Syndrome/
3	Autism Spectrum Disorder/
4	Autistic Disorder/
5	Developmental Disabilities/
6	Neurodevelopmental Disorders/
7	autis\$.tw.
8	asperger\$.tw.
9	pervasive development\$ disorder\$.tw.
10	(child\$ adj3 pervasiv\$).tw.
11	(PDD adj3 (specified or unspecified)).tw.
12	PDD-NOS.tw.
13	(PDD or PDDs or PDD-NOS or ASD or ASDs).tw,kf.
14	1 or 2 or 3 or 4 or 5 or 6 or 7 or 8 or 9 or 10 or 11 or 12 or 13
15	Crime Victims/
16	Child Abuse, Sexual/
17	Violence/
18	Aggression/
19	Hostility/
20	Rape/
21	Victim*.tw.
22	Abus*.tw.
23	Maltreat*.tw.

	leglect*.tw.
26 T	
20	rauma*.tw.
<b>27</b> C	rime victim*.tw.
<b>28</b> A	dverse.tw.
<b>29</b> A	ggress*.tw.
<b>30</b> C	rim*.tw.
<b>31</b> Ex	xploit*.tw.
<b>32</b> H	lostil*.tw.
<b>33</b> A	ssault*.tw.
<b>34</b> St	talk*.tw.
<b>35</b> H	larrass*.tw.
<b>36</b> T	hreat*.tw.
<b>37</b> C	oerc*.tw.
<b>38</b> Ir	ntimidat*.tw.
<b>39</b> B	ull*.tw.
<b>40</b> C	yber?bull*.tw.
<b>41</b> Fo	orc*.tw.
<b>42</b> N	/lanipulat*.tw.
<b>43</b> G	Gaslight*.tw.
44 "	Hate Speech".mp.
<b>45</b> c	5 or 16 or 17 or 18 or 19 or 20 or 21 or 22 or 23 or 24 or 25 or 26 or 27 or 28 or 29 or 30 or 31 or 32 or 33 or 34 or 35 or 36 or 37 or 38 or 39 or 40 or 41 or 42 or 43 or 44
<b>46</b> q	ualitative research/
<b>47</b> N	Iursing Methodology Research/
48 "9	Surveys and Questionnaires"/

49	exp Attitude/
50	Focus Groups/
51	interview/
52	discourse analysis.mp.
53	content analysis.mp.
54	Ethnology/
55	personal narrative/
56	ethnographic research.mp.
57	ethnological research.mp.
58	ethnonursing research.mp.
59	constant comparative method.mp.
60	qualitative validity.mp.
61	purposive sample.mp.
62	observational method*.mp.
63	field stud*.mp.
64	theoretical sampl*.mp.
65	phenomenology.mp.
66	phenomenological research.mp.
67	life experience.mp.
68	cluster sampl*.mp.
69	ethnonursing.af.
70	ethnograph*.mp.
71	phenomenol*.af.
72	grounded theory.mp.
73	(grounded adj (theor\$ or study or studies or research or analys?s)).af.
74	life stor*.mp.

75	(emic or etic or hermeneutic* or heuristic* or semiotic*).af. or (data adj1 saturat*).tw. or participant observ*.tw.
76	(social construct* or postmodern* or post-structural* or post structural* or poststructural* or post modern* or post-modern* or feminis* or interpret*).mp.
77	(action research or cooperative inquir* or co operative inquir* or co-operative inquir*).mp.
78	(humanistic or existential or experiential or paradigm*).mp.
79	(field adj (study or studies or research)).tw.
80	human science.tw.
81	biographical method.tw.
82	qualitative validity.af.
83	purposive sample.af.
84	theoretical sampl*.af.
85	((purpos* adj4 sampl*) or (focus adj group*)).af.
86	(account or accounts or unstructured or open-ended or open ended or text* or narrative*).mp.
87	(life world or conversation analys?s or personal experience* or theoretical saturation).mp.
88	lived experience.tw.
89	life experience*.mp.
90	cluster sampl*.mp.
91	(theme* or thematic).mp.
92	categor*.mp.
93	observational method*.af.
94	field stud*.mp.
95	focus group*.af.
96	questionnaire*.mp.

97	content analysis.af.
98	thematic analysis.af.
99	constant comparative.af.
100	discourse analys?s.af.
101	((discourse* or discurs*) adj3 analys?s).tw.
102	(constant adj (comparative or comparison)).af.
103	narrative analys?s.af.
104	heidegger*.tw.
105	colaizzi*.tw.
106	spiegelberg*.tw.
107	(van adj manen*).tw.
108	(van adj kaam*).tw.
109	(merleau adj ponty*).tw.
110	husserl*.tw.
111	giorgi*.tw.
112	foucault*.tw.
113	(corbin* adj2 strauss*).tw.
114	(glaser* adj2 strauss*).tw.
115	(strauss* adj2 corbin*).tw.
116	(glaser* adj2 strauss*).tw.
117	glaser*.tw.
118	qualitative.af.
119	findings.af.
120	interview*.af.
121	experience*.af.

122	46 or 47 or 48 or 49 or 50 or 51 or 52 or 53 or 54 or 55 or 56 or 57 or 58 or 59 or 60 or 61 or 62 or 63 or 64 or 65 or 66 or 67 or 68 or 69 or 70 or 71 or 72 or 73 or 74 or 75 or 76 or 77 or 78 or 79 or 80 or 81 or 82 or 83 or 84 or 85 or 86 or 87 or 88 or 89 or 90 or 91 or 92 or 93 or 94 or 95 or 96 or 97 or 98 or 99 or 100 or 101 or 102 or 103 or 104 or 105 or 106 or 107 or 108 or 109 or 110 or 111 or 112 or 113 or 114 or 115 or 116 or 117 or 118 or 119 or 120 or 121
123	14 and 45 and 122

## Note for abbreviations in search terms:

\* = acts as a truncation symbol, allowing you to find multiple variations of a word.

\$ = also a truncation wildcard, used to find variations of a word within a search. It allows you to retrieve multiple terms that share the same base word.

? = acts as a wildcard, specifically representing any single character. This means that when you use a question mark in your search term, the database will search for all possible variations of the word that differ by only one character.

Adj2 = a proximity operator that tells the database to search for two terms that are within two words of each other, in any order. It's part of a family of adjacency operators (adj1, adj2, adj3, etc.) that specify the maximum distance between terms.

.tw = title, abstract.

.kf = Keyword Heading words.

.mp = multipurpose and searches for keywords in a variety of fields including title, abstract, keyword heading word and unique identifier.

.af = used as a field tag to search for terms in all indexed fields, including title, abstract, and MeSH terms.

# Search terms for other databases can be found at: https//osf.io/vmf3y

# Appendix D: Adapted CASP Qualitative Research Checklist (Long et al., 2020)

1. Was th resear	ere a clear statement of the aims of the ch?	Yes No	Can't Tell
CONSIDE	?:		
• why	was the goal of the research? was it thought important? levance		
2. Is a qu	alitative methodology appropriate?	Yes No	Can't Tell
parti	?: research seeks to interpret or illuminate the cipants alitative research the right methodology for		
	e research design appropriate to address ns of the research?	Yes No	Can't Tell
CONSIDE	?:		
	researcher has justified the research design od to use)	(e.g., have they discu	ussed how they decided which
ontologica theoretica	study's theoretical underpinnings (e.g. I and epistemological assumptions; guiding I framework(s)) clear, consistent and Ily coherent?	Yes No	Can't Tell

## CONSIDER:

- To what extent is the paradigm that guides the research project congruent with the methods and methodology, and the way these have been described?
- To what extent is there evidence of problematic assumptions about the chosen method of data analysis? e.g. assuming techniques or concepts from other method (e.g. use of data saturation, originating in grounded theory) apply to chosen method (e.g. Braun and Clarke's reflexive thematic analysis39,40) without discussion or justification.
- To what extent is there evidence of conceptual clashes or confusion in the paper? e.g. claiming a constructionist approach but then treating participants' accounts as a transparent reporting of their experience and behaviour.

5. Was the recruitment strategy appropriate to the aims of the research?	Yes No Can't Tell

CONSIDER:

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

6. Was the data collected in a way that addressed the research issue?	Yes No Can't Tell
CONSIDER:	
• If the setting for the data collection was justifi	ied
• If it is clear how data were collected (e.g. focu	s group, semi-structured interview etc.)
• If the researcher has justified the methods cho	osen
• If the researcher has made the methods explic how interviews are conducted, or did they use	cit (e.g. for interview method, is there an indication of a topic guide)
• If methods were modified during the study. If	so, has the researcher explained how and why
• If the form of data is clear (e.g. tape recording	gs, video material, notes etc.)
• If the researcher has discussed saturation of a	lata
7. Has the relationship between researcher and participants been adequately considered?	Yes No Can't Tell

CONSIDER:
-----------

• If the researcher critically examined their own role, potential bias and influence during (a) formulation of the research questions (b) data collection, including sample recruitment and choice of location

•	How the researcher responded to events during the study and whether they considered the implications of
	any changes in the research design

8. Have ethical issues been taken into consideration?      YesNoCan't Tell         CONSIDER:		
CONSIDER:         • If there are sufficient details of how the research was explained to participants for the reader to assess whether ethical standards were maintained         • If the researcher has discussed issues raised by the study (e.g. issues around informed consent or confidentiality or how they have handled the effects of the study on the participants during and after the study)         • If approval has been sought from the ethics committee         9. Was the data analysis sufficiently rigorous?         Yes   No   Can't Tell         CONSIDER:         • If there is an in-depth description of the analysis process         • If there is an in-depth description of the analysis process         • If there the researcher explains how the data presented were selected from the original sample to demonstrate the analysis process         • If sufficient data are presented to support the findings         • To what extent contradictory data are taken into account         • Whether the researcher critically examined their own role, potential bias and influence during analysis and selection of data for presentation         10. Is there a clear statement of findings?		∐Yes ∐ No ∐ Can't Tell
<ul> <li>If there are sufficient details of how the research was explained to participants for the reader to assess whether ethical standards were maintained</li> <li>If the researcher has discussed issues raised by the study (e.g. issues around informed consent or confidentiality or how they have handled the effects of the study on the participants during and after the study)</li> <li>If approval has been sought from the ethics committee</li> <li>9. Was the data analysis sufficiently rigorous?</li> <li>Yes No Can't Tell</li> <li>CONSIDER:</li> <li>If there is an in-depth description of the analysis process</li> <li>If there is earcher explains how the data presented were selected from the original sample to demonstrate the analysis process</li> <li>If sufficient data are presented to support the findings</li> <li>To what extent contradictory data are taken into account</li> <li>Whether the researcher critically examined their own role, potential bias and influence during analysis and selection of data for presentation</li> </ul>	consideration?	
<ul> <li>If there are sufficient details of how the research was explained to participants for the reader to assess whether ethical standards were maintained</li> <li>If the researcher has discussed issues raised by the study (e.g. issues around informed consent or confidentiality or how they have handled the effects of the study on the participants during and after the study)</li> <li>If approval has been sought from the ethics committee</li> <li>9. Was the data analysis sufficiently rigorous?</li> <li>Yes No Can't Tell</li> <li>CONSIDER:</li> <li>If there is an in-depth description of the analysis process</li> <li>If there is earcher explains how the data presented were selected from the original sample to demonstrate the analysis process</li> <li>If sufficient data are presented to support the findings</li> <li>To what extent contradictory data are taken into account</li> <li>Whether the researcher critically examined their own role, potential bias and influence during analysis and selection of data for presentation</li> </ul>		
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<ul> <li>If there are sufficient details of how the research was explained to participants for the reader to assess whether ethical standards were maintained</li> <li>If the researcher has discussed issues raised by the study (e.g. issues around informed consent or confidentiality or how they have handled the effects of the study on the participants during and after the study)</li> <li>If approval has been sought from the ethics committee</li> <li>9. Was the data analysis sufficiently rigorous?</li> <li>Yes No Can't Tell</li> <li>CONSIDER:</li> <li>If there is an in-depth description of the analysis process</li> <li>If there is earcher explains how the data presented were selected from the original sample to demonstrate the analysis process</li> <li>If sufficient data are presented to support the findings</li> <li>To what extent contradictory data are taken into account</li> <li>Whether the researcher critically examined their own role, potential bias and influence during analysis and selection of data for presentation</li> </ul>		
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- If the findings are explicit
- If there is adequate discussion of the evidence both for and against the researcher's arguments
- If the researcher has discussed the credibility of their findings (e.g. triangulation, respondent validation, more than one analyst)
- If the findings are discussed in relation to the original research question

11. How valuable is the research?	Yes No Can't Tell
CONSIDER:	
<ul> <li>If the researcher discusses the contribution the sture (e.g., do they consider the findings in relation to culture</li> </ul>	dy makes to existing knowledge or understanding urrent practice or policy, or relevant research-based

- If they identify new areas where research is necessary
- If the researchers have discussed whether or how the findings can be transferred to other populations or considered other ways the research may be used

## Appendix E: Meta-Ethnography Reflexivity Log

### **Personal and Professional Context**

Awareness of my own identity as a neurotypical white male with limited clinical and no personal experience of working with autistic people. I have also worked in many settings where autism is still viewed largely through a medicalised and deficit focused lens. I am not a member of a minority group and have not experienced significant victimisation experiences in my lifetime.

#### **Initial Assumptions and Beliefs**

Given my educational and clinical experience in particular settings prior to embarking on this project I would have been more likely to relate the increased risk of victimisation experiences among autistic people to hypothesised deficits and difficulties in areas such as social communication and cognition.

#### **Familiarisation with Literature**

The narratives in many studies were emotive and harrowing. I found myself gravitating towards concepts such as neurodiversity and minority stress. I was moved by the impact of stigma on people's self-concept, and this theme, along with the normalisation and expectation of victimisation among autistic people really stood out.

### **Data Analysis Reflections**

The interaction between the normalisation and expectation of victimisation and stigma stood out for me. This along with the realisation that people generally felt trapped between hiding their identity in order to cope or withdrawing was stark. I felt challenged by interpreting the data from a neurotypical perspective and balancing a desire to foreground autistic people's experiences and perceptions of victimisation, e.g. attribution of individual risk without my reporting style being perceived to feed into the deficit focused or innate vulnerability narrative of autism on this topic.

Although masking and camouflaging were mentioned in only one of the included studies, I was particularly drawn to this coping mechanism due to its prominence in the wider autism literature. I was aware that its limited appearance in the included studies might reflect a gap in the specific research focus rather than its relevance, and I remained attentive to its potential role in how autistic individuals navigate and respond to experiences of victimisation.

#### **Broader Contextual Factors**

Supervision was very important in ensuring my portrayal of autistic people and researchers accounts was respectful. Trying to make sense and interpret experiences when there was intersectionality of minority identities was also a challenge.

# **Evolving Insights**

I experienced a significant perspective change related to the risk of victimisation of autistic people from my own attributions of individual risk to consider the influence that systemic attitudes towards autism and power imbalances play on this issue. I became aware of the need for systemic change and collaborative working with autistic people to reduce barriers which contribute to these experiences, and impact on access to support services for people who have been victimised.

#### Appendix F: Example of Synthesis Process (Translations & Synthesising Translations)

#### Step 5 of Sattar et al (2021) Translating Studies into one another (Excerpt)

#### Paper 3: Forster & Pearson (2020)

Similarly, to papers 1 and 2, paper 3 found bullying to be commonplace, particularly during adolescence and at school. It also added to these papers by highlighting that the autistic people in this study learned how to socialise and try to fit in with age. Like paper 1 and 2, it also discussed attempts to fit in and camouflaging/masking behaviour. It also provided further insight into the frequent self-monitoring and vigilance to other's reactions that their sample experienced during social interactions. The negative impact of masking strategies on mental health was also discussed.

Like paper 1 and 2, misreading social signals was seen as a vulnerability factor to victimisation, along with being trusting and gregarious. Paper 3 also highlighted awareness of a perception that autistic people will not pick up on manipulation and bullying. Added further insight from earlier papers by discussing how more subtle forms of victimisation such as mate crime is harder to recognise – bullying quite overt, whereas with mate crime someone is pretending to be your friend in order to exploit or take advantage of you.

Paper 3 also added to the earlier papers in that it highlighted whilst a diagnosis of autism could be helpful in helping someone to make sense of their experiences, they were reluctant to inform others of this due concerns about how it would be perceived and acted on by others – external attitudes impacting on self-acceptance and recognition of support needs. As in earlier papers, there was an increased risk of compliance from people not wanting to say no or be perceived as rude. This paper also added to earlier (1 &2) by emphasising that social skills and compliance training interventions – could impact the ability to trust your own judgement or express concern when faced with socially inappropriate behaviour from others. Indeed, they provided a further level of interpretation by suggesting that this issue is consistent with concerns raised by the double empathy problem (Milton, 2012), where there is a risk that the focus is on training autistic people to conform to neurotypical expectations/demands, rather than creating a bidirectional understanding. There was also a greater sense of shame and blame at being exploited by perceived friends than in paper 1 and 2, but some did recognise that blame should lie with the perpetrator. This paper also added to earlier papers by discussing the relationship between feeling shame, negative self-perceptions and not wanting to appear outwardly vulnerable. The authors suggested that this creates a vicious cycle where outward

perceptions of vulnerability lead to dehumanisation, which in turn leads to further shame about disability. Urgent need to reduce stigma. As in earlier papers, social support and having people to discuss concerns with, especially if unsure of other's intentions very important.

Descriptor/Category	1st Order Data (Participant Quotes/Primary Data from Studies)	2nd Order Themes (Developed by Primary Authors)	Third Order Themes (Researcher Interpretations)
	'I take things liter- ally and miss so much of some people's manipulative be- haviour, I'm oblivious" (Pearson et al., 2022; P.24, woman, 54). 'Someone with a more trusting nature	Perceptions of Victimisation (Pearson et al., 2022) Socialisingit's more complicated than that (Forster	
	would be the victim of it' (Forster & Pearson, 2020; P1) it's just that we are more susceptible to	& Pearson, 2020) Taking Advantage of You (Forster &	
Individual Risk Factors	behaviours that other people can do towards us, we are not able to defend ourselves because we just don't have the skill set' (Gibbs & Pellicano, 2023; AD21).	Pearson, 2020) Every one of my autistic friends has been abused in some way, shape or form (Gibbs & Pellicano, 2023)	Theme (Sub-Theme) Internalisation of Stigma (Attribution of Indivdual Risk)
	I trusted people to not do horrible things 'cause I would never imagine that they would do those thing. (Douglas & Sedgewick, 2024; Participant 4, autistic woman)	Maybe we just seem like easy targets (Gibbs & Pellicano, 2023)	
	woman) "People with ASD don't always pick up social cues. Certain body language could	Autism Used Against You (Douglas & Sedgewick, 2024)	
	be missed" (Fardella et al., 2018; Participant 18).	Individual Needs (Fardella et al., 2018) Reasons for bullying (Fisher & Taylor, 2016)	

## Excerpt from translations table

# Appendix G: Reflexive Thematic Analysis Reporting Guidelines (RTARG)

Advice for aspects of the research report/approach to reporting	Guiding Notes & Further Explanations	Practices, concepts and terminology to avoid	Reported on Page(s)
	Background & Rat	ionale	1
Provide a robust context and rationale for the proposed research in the Introduction.	Can discuss existing research, theory, and the wider context; the researcher is understood as entering a conversation with existing scholarship.	Critiquing the methodological limitations of existing research from a (post)positivist/ quantitative standpoint; orienting a literature review to finding a "gap" that the research fills.	P54-56
Clearly articulate a research question –one that is methodologically coherent.	Can discuss refining an initially broader research question to a more specific one for the paper.	Formulating research questions as hypotheses or expectations about what might be "found".	P56
	"Owning your persp	ectives"	
Include information on guiding theoretical assumptions and other (e.g., explanatory theory informing the use of TA).	Guiding (e.g., paradigmatic, ontological and epistemological) and other theory should be coherent with RTA.	(Post) positivism and (simple) realism.	P56
Report in a way that is consistent with stated theoretical assumptions throughout.	Theoretical coherence is evidenced through the use of language and concepts (e.g., around theme development, research subjectivity, data interpretation), the treatment of data, and use of quality practices consistent with RTA.	Inadvertently "mashing-up" of RTA and (post)positivism/ realism (e.g., assuming data interpretation can be accurate and reliable) – without a clear rationale.	ALL
Evidence methodological coherence/integrity in both the research and the report.	Theoretical assumptions, research questions, methods/practices of data generation, RTA, and specific orientation to RTA, purpose	Ontological and epistemological confusion (e.g., claiming constructionism but focusing on lived experience and	ALL

	of research etc. all "fit together", conceptually.	treating language as a transparent window onto this).	
Show evidence of reflexive practice.	Can discuss researcher professional or personal positioning and experience in relation to the topic, and/or participant group, and/or their role in shaping the research; use of reflexive journaling.	Evoking researcher bias (positivist), or even researcher influence, in a way that evokes it as possible rather than inevitable.	P60 & 116
Write in a methodologically coherent style.	A first-person writing style suits RTA, as it "writes in" the researcher and contributes to situated and reflexive reporting.	A third person writing style – writing the researcher out of the research.	ALL
	The Methodolo		
	Participants/data	items	
Describe selection of participants /data items.	Should include criteria for selection and/or recruitment strategies and settings.	Terms "sample/sampling", which connote "sampling" from a population (for the purpose of statistical generalisation).	P57-58
Describe number of participants/data items; provide a rationale or explanation around dataset or participant group size/composition.	Non-positivist qualitative concepts, such as "information power" or sufficiency offer conceptually appropriate justifications for "dataset" or "participant group" size and composition.	Justification based on saturation (simple realist), or statistical models (positivist); reporting rates of non- participation (an indicator of the representativeness of the "sample" in quantitative research).	P57-58
Discuss characteristics of participants/data items.	Balance the need to "situate the participant group" with participant anonymity (e.g., aggregate or report minimal demographics where appropriate).	Tables with each participant's demographic information listed line-by- line.	P57-58
Detail ethical approval and ethical code/principles followed, participant	Ethical discussion usually includes institutional ethical approval (if needed), but may include wider principles;	Compromising participant anonymity by the details provided.	P58-61 & P111

informed consent, etc.	providing research materials		
	(participant information,		
	consent form, etc.) in		
	supplementary materials		
	may be useful to support		
	reflexive openness.		
	Dataset Generat	tion	
Provide some rationale	Discuss why the method(s) of	Triangulation as a rationale	P59-60
for method(s) for data	data generation/data source	for different data sources	F 33-00
generation/data item	was a good fit with the	(realist).	
sources chosen.	-	(realist).	
sources chosen.	research question, participant		
	group, guiding theory, etc. If		
	multiple data sources are		
	used, any rationale for		
	combination should be		
	conceptually appropriate		
	(e.g., crystallisation).		
Describe development	Include tool(s) in	Using an existing tool with	P58 & 111
and/or characteristics	supplementary materials	the aim of replicating	
of data generation	when possible; discuss	existing "findings", or	
tool(s).	piloting if used, and any	developing and describing a	
	changes following piloting, or	tool in a way that is intended	
	during data generation.	to facilitate future	
		replication (positivist).	
Include details such as	Relevant information		P58 & 111
	includes: the mode of a data	Standardisation as a gold	P38 & 111
modality and/or		standard (realist); justifying an aimed for standardisation	
setting of data	generation tool (e.g., video		
generation, time	call focus groups; chat-based	in data generation tools as a	
frame, and other	interviews); the context of	means to facilitate the	
pertinent procedural	data generation (location;	"reliability" or "accuracy" of	
information.	timeframe) – where this	the research; treating a lack	
	doesn't compromise	of standardisation in data	
	participant anonymity; and	generation method,	
	mode of recording interactive	modality or setting as a	
	data generation.	problem, a potential source of "bias".	
Describe who	Can include what, if anything,	Seeking standardisation	P60
conducted any	the researcher disclosed	(e.g., through the training of	
interactive data	about their personal or	researchers) in interactive	
generation (which	professional positioning or	data collection; treating non-	
author or research	motivation; what skills and	standardisation as a threat	
role), and how.	experience they brought;	to "reliability" or "accuracy".	
	note researcher's relationship		
	with participants prior to,		

	during and after the research.		
Describe the size/scope of dataset and dataset items.	Such as the range and average length for interviews/focus groups; range and average word length for textual data items.	Equating data quantity with data quality.	P58-59
Describe, and if relevant explain, any preparation of data for analysis.	Such as method of transcription of audio/video data (a transcription key can go in supplementary materials); changes and "corrections" – such as typographical errors in written data were corrected; system for removing any identifying information; use of pseudonyms and/or data codes.	Describing transcription as "verbatim" or "orthographic" with no further details; using edited or "cleaned up" data without acknowledgement of this; participant validation of the "accuracy" of transcripts (realist).	P58-59
	Data Analysis	5	I
Provide some rationale for use of RTA, and, where relevant, for combining RTA with other approaches and procedures.	Any combining of RTA with other methodologies or procedures should be warranted, rather than being based on misunderstanding of RTA, and conceptually coherent (unless clearly justified).	Citing generic characteristics of RTA (e.g., accessible, flexible) without explaining how they were relevant to the study; using a codebook without acknowledging this is not part of RTA and justifying its use.	P59-60
Describe specific orientation to RTA.	Locate RTA on dimensions of inductive<> deductive and semantic<>latent.	A generic discussion of TA (or even RTA), not specifically situated in relation to the study or approach.	P59-60
Discuss how the researcher(s) engaged with the analytic process.	Provide a specific and situated account of the analysis process; use supplementary materials to provide a fuller account of the analytic process.	Offering a generic description of the six phases of RTA in lieu of an account of analytic process.	P59-60 & 116
Where more than one person is involved, describe who analysed the data (author or	Role(s) or involvement throughout the process should be discussed; where coding was collaborative, what this involved and how	Use of inter-coder agreement measures, consensus coding approach (positivist).	N/A

research role).	differences in coding and theme development were tackled, should be included.		
Use language to describe the process and products of RTA that is coherent with the values and assumptions of RTA.	Language should convey the active role of the researcher(s) in "generating" "crafting", "constructing", "creating", "producing" or "developing" themes; language around themes should evokes them as products of a researcher-data process.	Passive language of discovery, such as "emerging", "found", "identified" "discovered" – these evoke themes as "diamonds scattered in the sand" (p. 740)10; unexplained use of language and concepts from other approaches, such as emergent or superordinate themes (IPA), or line-by-line and/or open coding and constant comparison (grounded theory).	P59-60
	The Analysis		
	Reporting the data of	analysis	
Provide an overview of themes or thematic structure.	Overviews can include a list, map or table of themes to preview the analysis.	An unclear thematic structure, including unexplained headings in the analysis.	P61
Ensure theme conceptualisation is appropriate to RTA, and any divergences are justified and explained.	In RTA, themes report shared meaning, united around a central organising concept that differs for each theme.	Topic summaries; data generation questions reported as "themes".	P61-70
Name themes appropriately.	Use theme names that capture the "essence" or "story" of each themes; brief data quotations can be used.	(One-word) theme names that only identify a topic, and offer no story (evoking topic summaries).	P61-70
Report themes in sufficient depth and detail.	As RTA is an interpretative method, themes should be multifaceted, and contain both data and analytic narrative; if useful, additional data extracts may be include in supplementary materials.	Thin, one dimensional themes effectively conflating codes and themes; large number of themes relative to the length of the manuscript.	P61-70 & 116
Use subtheme	Themes are the main analytic	Fragmenting the analysis	P61-70

judiciously.	purpose, and should be multifaceted; only use subthemes where doing so highlights an important facet or aspect of the central concept of a theme.	through overuse of subthemes, and an overly elaborated/"bitty" thematic structure.			
Ensure the analytic narrative explains the meaning and significance of the data.	For RTA, each theme needs an analytic narrative that outlines its meaning and importance in relation to the topic, research question and dataset; the reader needs to be told about why/how data excerpts matter and "evidence" the theme; the Analysis section also needs to convey the overall story of the analysis	Frequency counts as a justification for themes presented; simple paraphrasing of data as "analytic narrative"; treating data meaning as self- evident (data are assumed to speak for themselves) "arguing" with the data (treating the data as something to [dis]agree with, rather than to interpret and make sense of).	P61-70		
Provide an appropriate balance of analytic narrative and data extracts – both data extracts and analytic narrative matter.	The rich descriptive and/or interpretative story of the analysis needs to be woven around sufficient analytic extracts from across the dataset.	Presenting either a long string of data extracts with barely any analytic narrative, or only the researcher's narrative summary of the theme, without any data extracts to support it.	P61-70		
Demonstrate coherence between analytic narrative and illustrative/evidentiary data extracts.	Data extracts should convincingly and compellingly evidence the analytic claims.	Mismatches between data extracts and analytic claims; not countering obvious alternative readings of the data	P61-70		
Integrate existing research and theory into the analytic narrative.	In RTA, an interpretative analytic narrative is enriched by incorporating relevant existing research and theory into the reporting of themes, reflecting notions of contextualised meaning, and contributing to an ongoing "conversation" about a topic.	The positivist tradition of separating a description of analytic "Results" and their interpretation with reference to scholarship and theory in a "Discussion" section.	P61-70		
The Final Section – A General Discussion or "Conclusions"					
Quality, evaluation and conclusions					

Draw analytic conclusions across themes.	Orient to the "so what" of the overall analysis – the "point" of the story told; this might include discussion of implications for practice and "actionable" outcomes.	Repetitive theme-by-theme integration of the analysis with existing literature; no overall conclusions drawn; no overall analytic story.	P70
Discuss implications or directions for future research.	Any suggestions for future research should stem from the analysis and be evidence- based (e.g., provide grounds for other groups potentially having different experiences or views) rather than generic.	Generic recommendations for other research, such as with a different "population".	P70-72
Use and report quality practices coherent with RTA.	Ensure evaluation of research quality deploys conceptually coherent notions, such as: member reflections; crystallisation; others serving as a critical friend/sounding board to enhance insight; reflexive journaling.	Incoherent quality measures such as: member checking/participant validation; triangulation (realist); the use of theme agreement/consensus among researchers or corroboration of themes by another researcher (positivist).	P72
Evaluate the research from a Big Q standpoint.	Such evaluation might including considering how the specifics of the study may have shaped the research produced (for example, the characteristics and context of the participant group/dataset; the methods and modalities for generating the data); situadedness should not be treated as a limitation.	Evaluations and descriptions of limitations that orient to quantitative or positivist norms, such as reference to lack of generalisability – positioned as a limitation, and equated only with statistical generalisability – or a "small" (by implication non-ideal) and "under- representative" sample.	P72
Include reflections on research process and practices, including researcher reflexivity.	Some consideration of the researcher(s)'s role in shaping the research and the knowledge generated is an important quality marker.	Reference to researcher bias/influence (positivist).	P72

Appendix H: Approved Major Research Project (MRP) Proposal & Participant/Study Materials

Approved MRP Proposal: <u>https://osf.io/afjs3</u> Participant Demographic Questionnaire: <u>https://osf.io/2697w</u> Interview Topic Guide - <u>https://osf.io/qds9m</u> Study Information Leaflet - <u>https://osf.io/6qcnz</u> Participant Information Sheet - <u>https://osf.io/vcs5h</u> Participant Consent Form - <u>https://osf.io/r3xma</u> Privacy Notice - <u>https://osf.io/4qtm3</u> Follow up Telephone Check in Call - <u>https://osf.io/pqmf4</u>
# Appendix I: Coding Excerpt & Theme Development Example

Transcript	Code
Interviewer: You might articulate it better than me umm	
Participant: Yeah so how I understand it is emmm because they're neuro-typical, they're like observant of my communication and like we're coming to a different like, different consensus, I don't know.	Different perspectives on same conversation Mutual misunderstanding Double empathy problem?
Interviewer: Yeah	
Participant: coming to different points but yeah. I walk away from the conversation thinking one thing and they walk away thinking one thing and their observation is psychosis. Mine is different and then it comes back and it attributes to the psychosis itself.	Lack of mutual understanding again Imposition of neurotypical assumption Not collaborative? 'Expert' opinion, symptom of psychosis Imbalance of power
Interviewer: Ok.	
Participant: because it's like the communication is making me paranoidwhich is not a good place to be because then I'm constantly like, did they understand? You didn't understand me?	Demands of social interaction Stressful Differences in communication contributing to worry/paranoia
Interviewer: Ok.	
Participant: whereas like ehhh	
Interviewer: so that I suppose that, maybe, where, I	

don't even know if misunderstanding is the right word, let's just say the way you described it, of like a kind of difference in consensus or opinion,

Participant: Uh huh...

Interviewer:

maybe just in that it's different ways of communicating with each other. Emm.. for you then, I guess, you're saying that as well that can make you to start of kind of doubt what they, well they might start saying well that's paranoia.

Participant: Yes

Initial Code	Participant Quotes	Additional Code	Contribution to Theme Example
Autism Stigma	Because sometimes people might think of me different because of it might act or treat me a bit different thinking they need to be different to talk to me. I, yeah, cause I just like them treating me normally	Feeling othered by society Expectation of different treatment Internalised stigma and feeling have to be 'normal'	
Other's Perceptions Of Autism	Yeah. Just emmm so a neuro-typical person wouldn't emm fully understand or like just when it comes to interacting with the broad public, so like when at school or at work, the majority of people don't understand me or don't get along with me.	Double empathy Differences in communication Feeling like an outsider Not liked by others?	Nuances of an Autistic Identity
	Ehh I'd just say, cause I think a little bit different. things just like feel a little bit different (P4)		
	It's kinda, like to the side of being		1:

Self-Perception of Identity	normal, kinda similar thing, like there's no positives or negatives cause both, both being normal and being autistic have negatives	Autism as a difference rather than deficit	
		Neutral value to identity	
		Perspective taking of autism v neurotypical experience	

## **Appendix J: Reflexivity Log RTA Excerpts**

### **1. Personal and Professional Context**

Background: Trainee Clinical Psychologist who has experience of working with autistic children, young people and adults, but primarily in CAMHS and LD settings. No professional or personal experience of FEP. The majority of my knowledge of psychosis is theoretical, rather than a combination of theoretical knowledge and anecdotal clinical experience. This likely influenced the development of my topic guide, how I interacted during interviews and the interpretative lens through which I approached data analysis. This was predominantly from a psychosocial perspective and taking a strengths based and neurodiversity perspective to my interpretation of participant's accounts.

### 2. Initial Assumptions and Beliefs

From engagement with the literature, I perceived the relationship between autism and psychosis to be centred as an interaction between the person and their environment. I approached my analysis of accounts from this perspective.

### 3. Participant Engagement

Advanced contact on two occasions prior to interview and enabling participant choice with regards to interview location seemed to help people to feel more comfortable and be fully engaged in the interview. Able to build rapport and create a more informal and naturally flowing conversation by taking breaks to talk about hobbies and interests for example.

Being sensitive to the difficult nature of conversation and regularly checking in seemed to also facilitate rapport and engagement. Reflecting on interview experiences in supervision helped to consider any adaptations required, or areas that seemed to produce richer accounts. I felt moved by participant accounts and inspired by their resilience. I left interviews feeling determined to ensure my analysis foregrounded participant experiences and highlighted areas for innovation in support.

## 4. Analysis and Interpretation

Always trying to keep a balance between brining participant accounts to life and relating data to research questions and the wider literature. Careful not to project my own understanding at expense of lived experience and use of supervision to do this.

### **5. Broader Contextual Factors**

Making note of people's experiences of identifying with more than one stigmatised identity. From my own perspective it was important to acknowledge feelings of being an outsider to this and to consider how future research may able to take more account of this and elicit a more detailed understanding.

### 6. Evolving Insights

The importance of social connection and the influence of personal and social identity was a key them and my understanding of this process evolved through immersion in the date, reviewing relevant literature and supervisory discussion.

### **Appendix K: NHS REC Approval Letter**



Mr Paul Reynolds-Cowie



West of Scotland REC 3 West of Scotland Research Ethics Service Ground Floor Ward 11 Dykebar Hospital Grahamston Road Paisley PA2 7DE

 Date
 05 April 2024

 Direct line
 0141 314 0212

 E-mail
 WoSREC3@ggc.scot.nhs.uk

Dear Mr Reynolds-Cowie

Study title: REC reference: Protocol number: IRAS project ID: An Exploration of Experiences of First Episode Psychosis Amongst Autistic Adults. 24/WS/0025 N/A 330394

Thank you for your letter of 04 April 2024. I can confirm the REC has received the documents listed below and that these comply with the approval conditions detailed in our letter dated 03 April 2024

#### **Documents received**

The documents received were as follows:

Document	Version	Date
Non-validated questionnaire [Demographic Questionnaire]	1.3	04 April 2024
Participant information sheet (PIS) [Participant Information Sheet]	1.9	04 April 2024

#### Approved documents

The final list of approved documentation for the study is therefore as follows:

Document	Version	Date
Copies of materials calling attention of potential participants to the research [Study Information Leaflet]	1.2	24 January 2024
Evidence of Sponsor insurance or indemnity (non NHS Sponsors only) [Sponsor Insurance]		14 July 2023
GP/consultant information sheets or letters [GP Information Letter]	1.1	21 December 2023
Interview schedules or topic guides for participants [Interview Topic	1.9	23 January 2024

Document	Version	Date
Guide]		
IRAS Application Form [IRAS_Form_05022024]		05 February 2024
Non-validated questionnaire [Demographic Questionnaire]	1.3	04 April 2024
Other [Privacy Notice]	1.0	24 January 2024
Other [Follow up Call]	1.1	21 December 2023
Participant consent form [Participant Consent Form]	1.5	17 March 2024
Participant information sheet (PIS) [Participant Information Sheet]	1.9	04 April 2024
Research protocol or project proposal [Study Protocol]	1.4	18 March 2024
Response to Request for Further Information [Response to REC Provisional Opinion ]	1	20 March 2024
Summary CV for Chief Investigator (CI) [CI CV]		15 September 2023
Summary CV for student [Principal Investigator CV]		08 December 2023
Summary CV for supervisor (student research) [Academic Supervisor CV (Prof Gumley)]		12 June 2023

You should ensure that the sponsor has a copy of the final documentation for the study. It is the sponsor's responsibility to ensure that the documentation is made available to R&D offices at all participating sites.

### IRAS Project ID: 330394

Please quote this number on all correspondence

Yours sincerely

#### Ashley Nisbet REC Manager

E-mail: wosrec3@ggc.scot.nhs.uk

Copy to: Dr Louise Beattie Mrs Shirley Mitchell

Lead Nation Scotland: gram.nrspcc@nhs.scot

### Appendix L: NHS GGC R&I Approval Letter



Research & Innovation Dykebar Hospital, Ward 11 Grahamston Road Paisley, PA2 7DE Scotland, UK

Coordinator/administrator: Euan Rennie Telephone Number: E-Mail: <u>euan.rennie@ggc.scot.nhs.uk</u> Website: <u>https://www.nhsggc.org.uk/about-</u> us/professional-support-sites/research-innovation

15/04/2024

Dr Nikos Xanidis NHS Greater Glasgow & Clyde

#### NHS GG&C Board Approval

Dear Dr Nikos Xanidis

Study Title:	An Exploration of Experiences of First Episode Psychosis Amongst Autistic Adults.
Principal Investigator:	Dr Nikos Xanidis
GG&C HB site	NHS Greater Glasgow and Clyde
Sponsor	University of Glasgow
R&I reference:	UGN24MH016
REC reference:	24/WS/0025
Protocol no:	V1.3 24/01/2024
(including version and	
date)	

I am pleased to confirm that Greater Glasgow & Clyde Health Board is now able to grant Approval for the above study.

#### **Conditions of Approval**

- 1. For Clinical Trials as defined by the Medicines for Human Use Clinical Trial Regulations, 2004
  - a. During the life span of the study GGHB requires the following information relating to this site
    - i. Notification of any potential serious breaches.
      - ii. Notification of any regulatory inspections.

It is your responsibility to ensure that all staff involved in the study at this site have the appropriate GCP training according to the GGHB GCP policy (<u>www.nhsggc.org.uk/content/default.asp?page=s1411</u>), evidence of such training to be filed in the site file. Researchers must follow NHS GG&C local policies, including incident reporting.

- 2. For all studies the following information is required during their lifespan.
  - a. First study participant should be recruited within 30 days of approval date.
  - b. Recruitment Numbers on a monthly basis
  - c. Any change to local research team staff should be notified to R&I team
  - d. Any amendments Substantial or Non Substantial
  - e. Notification of Trial/study end including final recruitment figures
  - f. Final Report & Copies of Publications/Abstracts

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letter



g. You must work in accordance with the current NHS GG&C COVID19 guidelines and principles. Please add this approval to your study file as this letter may be subject to audit and monitoring.

Your personal information will be held on a secure national web-based NHS database. I wish you every success with this research study

Yours sincerely,

Euan Rennie Research Co-ordinator

CC: Shirley Mitchell (UoG)

## Appendix M: Further Illustrative Quotes for RTA Themes

### **Theme 1: Experiences and Impact of Psychosis**

I thought my family were trying to hurt me, so that's why I was trying to run out of the house....I was trying to be alone basically.....I was planning to run away from home basically and I didn't really get far.....em so I don't know, you just think everyone is trying to harm you and trying to get you, that's about it to be honest (Dylan)

so when I would go out, go outside, I would find that I would be really, really paranoid and just feeling over the edge. Sometimes I would find myself I'm being stalked or followed or people are looking at me, they are talking about me or laughing about me, mocking me (Aaron)

Things couldn't have gone worse I felt because then what had happened was I was also experiencing other sensations, such as hallucinations, hearing voices (Aaron)

### Theme 2: Adverse Experiences as Pathways to Psychosis

em....it was in January 2022, so I was in 6th year and it was my Christmas prelims for highers. I had to repeat my highers because I didn't get them in 5th year, that was during COVID in 2021. No sorry, during Christmas in 2021 I caught COVID and I was feeling unwell for about two weeks and I emailed the year head and I was like......I think there was a like a thing on the newsletter that said if you're unwell you could sit them later on when you're feeling better (Dylan)

## Theme 3: Nuances of an Autistic Identity

"yeah, the positives are......I mean I can just......be in my own world and not have any, just ......just......like.....sometimes just be fixed on things like outdoors and nature". (Cam)

Yeah I was em......I don't know like.....emmmm.....I'm trying to think, I mean as a kid I found it kinda difficult to talk and walk as well, I wasn't really gifted with these things and I had to learn. It was difficult for me and it took a while for me to acquire these skills, and it was a lot of effort for me as a kid, but I think I've had a normal life, it's not really segregated me too much (Dylan)

well I remember feeling even.....emmmm.....quite relieved that I've got something to......some....or a reason, I don't know, that I was not socialising, or, but eh, yeah I was in like third year of secondary school (Cam)

It was, it didn't really change how I felt too much, since I already had feelings of it. It was nice to put a name to it. It just gave me an explanation about why I always felt a bit different (Jack).

You have better conversation. LAUGHS. Cause you are tearing things apart all the time. You have a thinky brain. You are more likely to just like come up with something new. Instead of like sitting in

the background of what ifs. And that is such a positive because like you are always expanding. The negatives is, anytime you expand, people are like no. Also the negatives are like if there's a bright light you might be a bit sad (Emily)

### Theme 4: The Importance of Interpersonal Support and Social Connection

yeah, it was weekly visits from a keyworker who'd visit me every week and would phone in, check in and give me texts, making sure I'm getting on ok, and making sure I was taking my medication, getting to sleep properly.....really getting into the nitty gritty of my routine and making sure I'm taking care of myself and getting better, especially for my family and stuff as well.....yeah just esteem and that concentrated support, it shows you that they care and want you to do well (Dylan).

"when I am working with the psychologist I'm also learning as I go along, more about autism as well, and like how I can use the information that I have been given about autism and link it back to my own personal experiences." (Aaron).

"Yeah so how I understand it is emmm... because they're neuro-typical, they're like observant of my communication and like we're coming to a different like, different consensus, I don't know, coming to different points but yeah. I walk away from the conversation thinking one thing and they walk away thinking one thing and their observation is psychosis. Mine is different and then it comes back and it attributes to the psychosis itself" (Emily).

"Well that's a big thing for me because throughout my whole ordeal it's my family that have always supported me especially my mum. Throughout my whole ordeal, throughout my experiences and she was there cooking for me, motivating me, encouraging me, and she has been, that one person I have to, had to rely on and now that I thank her, because if it wasn't for her I wouldn't be in a better place today" (Aaron).

"My mums been really helpful through the full thing. She helps me go to appointments and things like that" (Jack).