Homelessness amongst autistic people and people with ADHD: a systematic review of the prevalence rates and risk factors and a qualitative exploration of individual experiences

Submitted in partial fulfilment of the requirements for the degree of Doctorate in Clinical Psychology

School of Health and Wellbeing
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July 2023

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Acknowledgements

I am very grateful to the participants for offering their time and insights into this topic. The process of interviewing was very rewarding due to their enthusiasm to share their experience. I was especially impressed by their candour given the often-emotional nature of the topic being discussed and hope my interpretation reflects their journeys. I feel a great deal of gratitude towards my Academic Supervisor whose consistent support from early on in the project has helped keep it on track. Her expertise and passion for this topic has motivated me throughout and I have appreciated her patience in guiding me through the unfamiliar grounds of this project. The progress of this project is also due to the support of my Field Supervisor whose expertise on equity in healthcare and advice on the practicalities of research in this area helped guide this project. Advice from both supervisors on the recruitment process was greatly appreciated and their constructive feedback on proposals, outlines and drafts hugely helpful. Their responsive and organised approach to supervision is one I hope to continue to learn from. I am also grateful to Paul Cannon, College Librarian, for his valuable feedback and advice on the systematic review process. Additional thanks to my project advisor for his feedback on the project proposal and advice throughout the project.

A number of third sector organisations and council service staff were hugely helpful in the recruitment process. Council housing services within the Scottish Highlands and Edinburgh were generous with their time in helping to advertise the project as were the Scottish Women's Autism Network, Autism Rights Group Highland and One Stop Shop. Recruitment would not have been possible if not for the staff in these services taking the time to meet with me and advertise this project, I'm especially thankful considering the resource pressures these services are facing. Thanks to the Highland Trainees and Assistants who offered encouragement and validation through the process and also to my Clinical Supervisor, Dr Penelope Noel, whose genuine interest in my journey along with her calmness and wisdom on self-care carried me through training. Lastly, I want to thank my family, my partner Dan, and friends for the emotional support and understanding they provided throughout this project. Mum, Mairead and Maisie's visits were very welcome breaks on long write-up days.

Chapter1: ADHD & autism in the homeless population: a systematic review of prevalence and risk factors.

Prepared in accordance with the author requirements for the Journal of Autism & Developmental Disorders; Author submission guidelines:

Abstract

Purpose The aims of this systematic review were to evaluate the prevalence of Attention Deficit Hyperactivity Disorder (ADHD) and autism in homeless populations and identify risk factors associated with homelessness in these groups.

Methods A systematic search was conducted on Medline, CINAHL, PsycINFO and Embase databases on 24th June 2022, for English-language, peer-reviewed, original research with samples including autistic participants and/or participants with ADHD who experienced homelessness. Studies focussing on other neurodevelopmental conditions without autistic participants or participants with ADHD were excluded. No funding was granted for this review, which was registered on PROSPERO (CRD4202124721).

Results Twenty-three studies were included. Results were reported in a narrative synthesis, with risk of bias measured using the QualSyst tool. Prevalence rates of ADHD in homeless populations, measured in 14 studies, varied between 0-65%. Equivalent rates for autism, measured in two studies, varied between 12-19%. Rates of homelessness amongst ADHD samples, measured in two studies, varied between 8-24%. Risk factors were mainly quantified in ADHD studies, including elevated substance use, school dropout, and coexisting anxiety and personality disorders and depression. Limitations of the evidence related to small samples and lack of autism research.

Conclusion Heightened risk of homelessness was indicated by most ADHD and autism prevalence estimates being higher than general population prevalence. The need for autism/ADHD training in homelessness services and more autism research were discussed.

Keywords Attention Deficit Disorder with Hyperactivity, Autism Spectrum Disorder, Homeless Persons, Homelessness, Systematic Review.

Introduction

Autism is a neurodevelopmental condition affecting communication and interaction with others alongside the presence of restricted interests and repetitive behaviours (APA, 2013). ADHD is defined by the persistent presence of inattention and/or hyperactivity and impulsivity which interferes with functioning (APA, 2013). General population prevalence has been estimated at 2% for children and 1% for adults in UK studies (Roman-Urrestarazu et al, 2021; McManus et al, 2016). Global prevalence of ADHD ranges between 5-8% for children (Salari et al, 2023). Adult prevalence is lower at 3-5%, thought to be a result of this often being unrecognised in later life (Vos & Hartman, 2022). ADHD and autism have high rates of co-occurrence at around 39% for children and 22% in adults (Rong et al, 2021).

Quality of life indicators have been reported to be lower for autistic[1] than non-autistic people, including lower social functioning, number of friends, good physical health and fewer intimate relationships (van Heijst & Guerts, 2015). Similarly, people with ADHD have been found to experience increased anxiety and depression and score lower on the World Health Organization Quality of Life measure compared to people without ADHD (Agarwal et al, 2012). Additionally, both groups have significantly increased risk of mortality (Catalá-López et al, 2022). ADHD symptoms amongst autistic adults have also been associated with lower quality of life and less independence (Yerys et al, 2022)

Definitions of homelessness vary between countries. In the UK, people are legally homeless if they do not have a secure place to stay or are residing where they are not reasonably able to stay (Crisis UK, 2023). It was estimated that 53,400 adults in Scotland were experiencing homelessness in 2019 (Bramley et al, 2019).

Risk factors associated with homelessness

A meta-analysis of 116 studies calculated odds ratios (ORs) for risk factors for homelessness, namely experiencing physical abuse (OR=2.9), care experience (OR=3.7),

[1] Identity-first language has been used in this review in reference to autism (i.e. ‘autistic’, not ‘person with autism’). Views differ on person vs. identity-first language, although most autistic adults in one UK survey preferred ‘autistic’, as does the National Autistic Society and some academic journals (Kenny et al, 2016; National Autistic Society, 2023; Journal of Autism & Developmental Disorders, 2023).

history of incarceration (OR=3.6), suicide attempts (OR=3.6) and psychiatric conditions (OR=2.9). Being female (OR=1.7) and having a partner (OR=1.7) increased odds of exiting homelessness, while psychotic disorders (OR=0.4) and substance use (OR=0.7) were associated with decreased odds of exiting homelessness (Nilsson, Nordentoft & Hjorthøj, 2019).

Homelessness & neurodevelopmental conditions

Research into neurodevelopmental conditions and homelessness appears mostly limited to populations with intellectual disability (Brown & McCann, 2019). Some research has indicated an over-representation of ADHD and autism in homeless populations (Stone, Dowling & Cameron, 2019). However, much of the research has not analysed ADHD and autism separate from other conditions, making it difficult to assess the scale of this over-representation. The aim of this systematic review is, hence, to extract data on homelessness specifically relating to ADHD and autism. Both conditions are included in this review as they often coexist together, thus are often studied together (Catalá-López, Hutton, Page et al, 2022). This review will seek to answer the following research questions;

1. What is the prevalence of ADHD and autism in the homeless populations?
2. What are the risk factors associated with homelessness for autistic people and people with ADHD?

Methods

Search strategy

The Preferred Reporting Items for Systematic Reviews and Meta-Analysis (PRISMA) guidelines were used for this review (Page et al, 2021). Reporting checklists are included in Appendices 1.1 & 1.2 (pages 70-74). A systematic search without time limits was conducted on Medline, CINAHL, PsycINFO and Embase databases on 24th June 2022. The review was prospectively registered with PROSPERO (registration no. CRD4202124721). Search terms included “Autism” OR “ASD” OR “ASC” OR “Asperger*” OR “Kanner” OR “Pervasive Developmental*” OR “((delay* or disorder* or impair* or disab*) adj3 (development*))” OR “ADHD” OR “Attention Deficit Hyperactivity Disorder” OR AND “Bed & Breakfast” OR “couch-surfing” OR “fixed

abode" OR "homeless" OR " hostel" OR "housing". A line-by-line search strategy is included in Appendix 1.3 (page 75). These were chosen through review of previous literature and consulting with project supervisors and a university librarian. Reference lists of relevant reviews and included studies were screened to identify additional studies.

Eligibility criteria & study selection

Title and abstracts of results were screened before full articles were then screened by the first reviewer (AG). A second reviewer (ER) independently screened 10% of titles and abstracts and 10% of full text studies. Disagreements were settled through discussion based around inclusion/exclusion criteria.

Study inclusion criteria were:

- Studies with autistic participants and/or participants with ADHD

AND

- Participants who have experienced homelessness. Homelessness was defined broadly, including those residing in hostels, temporary accommodation or experiencing street-homelessness currently or at any point in their lives
- Where homelessness was investigated in samples not exclusively including autistic people/people with ADHD and did not report results separately for autism/ADHD, the sample had to include at least 30% of autistic/ADHD participants (e.g. samples of 'developmental disorders', including autism and ADHD). This criterion was updated to the original review protocol due to the number of studies noting 'developmental disorders' without specifying specific disorders.
- All ages, ethnicities, and genders
- Original research, qualitative and quantitative studies; including but not limited to cross-sectional, cohort and qualitative case series.
- Peer-reviewed
- English language

Study exclusion criteria were;

- Non-human studies
- Grey literature

- Literature focussing on other nuerodevelopmental conditions without autism/ADHD (e.g. intellectual disability, dyslexia).

Data extraction

The main outcome of this review was prevalence of ADHD and autism amongst homeless populations. Secondary outcomes were risk factors associated with homelessness for autistic participants and participants with ADHD. All relevant data were extracted by the first reviewer (AG), using a structured database and included authors, publication year, country the research was based in, study design, sample size, gender, ethnicity and age of participants, measures used to screen for ADHD/autism, number of existing diagnoses of autism/ADHD in the sample, recruitment sources, main findings regarding prevalence of ADHD/autism in samples (converted to percentages for synthesis), risk factors, and length of time participants experienced homelessness, if available. Risk factors sought included, but were not limited to, increased levels of coexisting conditions and adverse life events. No assumptions were made regarding missing data.

Critical appraisal

The quality of the included studies was assessed using the QualSyst tool (Kmet, Lee, & Cook, 2004), which can be used for appraising quantitative and qualitative research studies. Items are scored according to the extent each criterion is met ("yes"=2, "partial"=1, "no"=0). Items not applicable to a study are scored "n/a" and excluded from the summary score, calculated for each study by summing the total score obtained across relevant items and dividing by the total possible score, before converting to a percentage with 0% being the lowest possible quality score and 100% being the highest. The first reviewer (AG) critically appraised included studies and second reviewer (ER) duplicated appraisal on a randomly selected 39% (*n*=9) of included studies. Results were independently recorded on an Excel spreadsheet, with reviewers blinded to each other's decisions until comparisons were made. Any discrepancies were resolved through discussion.

Inter-rater reliability

Inter-rater reliability was assessed at several stages: title and abstract eligibility, full-text screen reviewing and critical appraisal. As two reviewers were involved, Cohen's Kappa coefficients were calculated using an online calculator to assess inter-rater agreement at the title and abstract and full-text screening stages. There was fair agreement between the raters at the title and abstract screening stage (κ=.351), with this discrepancy likely a result of the second reviewer erring on the side of over-inclusion due to the volume of records to screen at this stage (*n*=180). Perfect agreement was reached at the full-screening review stage (κ=1.0). 39% of critical appraisal scores were checked by the second reviewer, with consensus reached following discussion. Inter-rater checks on data extraction were done for 10% of studies (*n*=2) with 100% agreement.

Results

Study search summary

The search returned 2382 results. After removal of duplicate results (*n*=388) and results removed for other reasons (*n*=204), 1790 results remained. Following title/abstract screening, 1739 studies were excluded. Full texts of the remaining 51 studies were screened, leaving 16 studies for initial inclusion. Full-text screening of included studies identified three additional studies for inclusion. Following inter-rater discussion, four studies which were initially excluded by the first reviewer were added to the review. Overall, 23 studies were included (Figure 1.1).

Results Synthesis

Due to diversity in the statistical analysis (e.g. path analysis, logistical regression, descriptive, correlational), methodological design (e.g. longitudinal, cross-sectional) and participant groups (veterans, prisoners, adults, children) of included studies, it was not possible to conduct a meta-analysis. The few studies with similar statistical analysis, design and participant groups used different screening measures for autism/ADHD or assessed different risk factors. Thus, a narrative synthesis was used to report results; a textual approach aimed to provide a descriptive summary of outcomes related to the research questions and describe relationships between outcomes across studies. Studies were grouped separately for synthesis by population (autism and ADHD) and design (qualitative and quantitative).

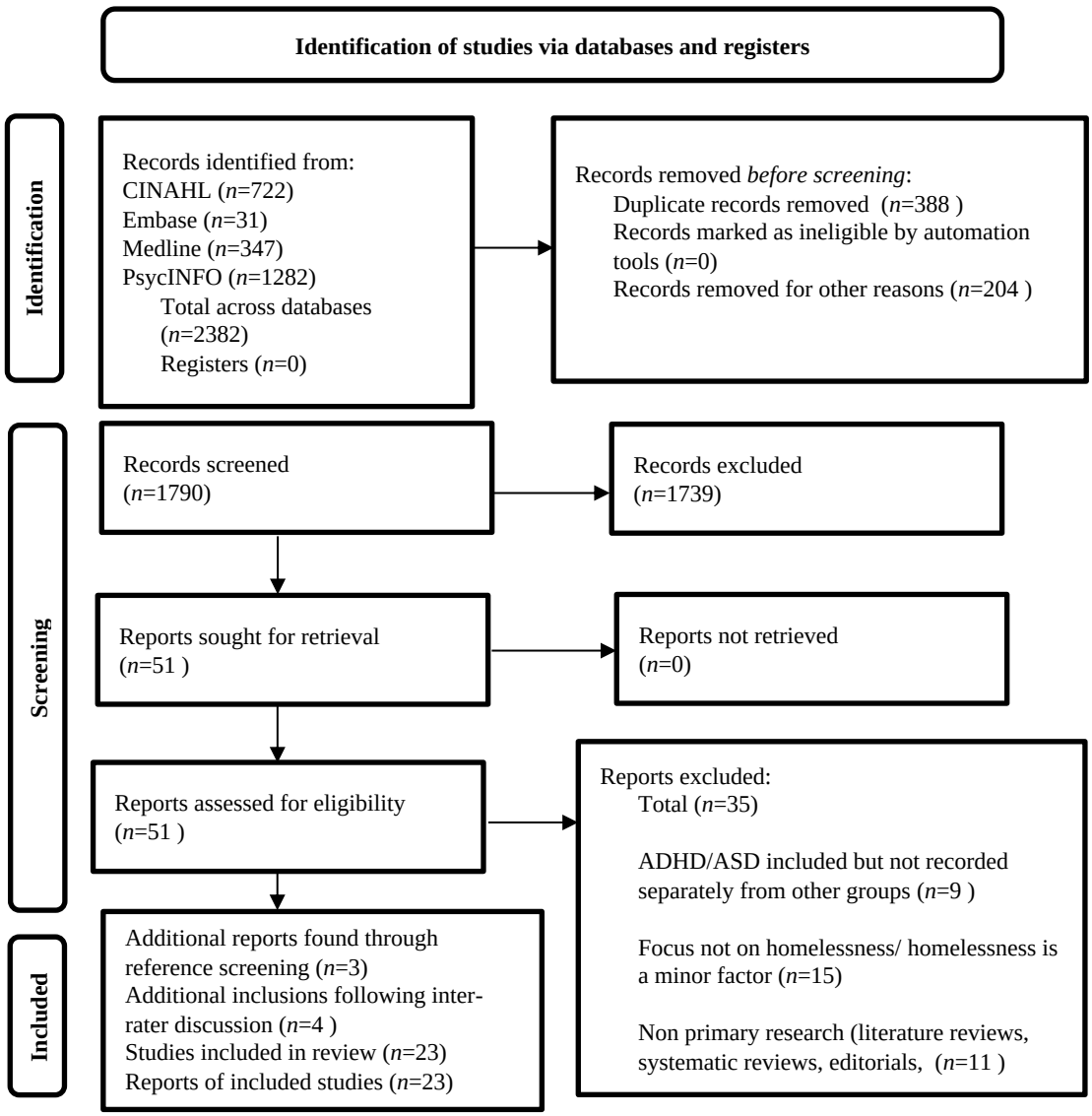

Figure 2.1: PRISMA Flow diagram of search results

Study characteristics

Seventeen studies included samples with ADHD, four included samples with autism, two studies included both autism and ADHD. Sixteen studies were cross-sectional with three being cohort studies, one quantitative case series, two qualitative case series, and one was an RCT (Randomised Control Trial). Eleven studies focussed on adults, eight on youth, one on both adults and youth, two on families and one study did not provide sufficient details on age. Most of the studies were conducted in the USA (14), followed by the UK (4), with one study each in Canada, Denmark, Sweden, Spain and Japan. As for measures

used, seven studies used self or parental report for ADHD or autism, six used scales typically used as part of the diagnostic process such as the Wender Utah Rating Scale (WURS) (Ward, Wender & Reimherr, 1993), four used screening tools such as the ADHD Self-Report Scale (ASRS) (Adler et al, 2006), four used record reviews either citing diagnoses or citing information suggesting diagnosis. Two used diagnostic interviews based on DSM III, IV, and 5 criteria.

Excluded Studies

Some studies appearing to meet inclusion criteria were excluded after full-text screening. This was due to studies focussing on 'developmental disorders', which did not report results for ADHD separately (Wolfe, Toro & McCaskill, 1999) or studies in which homelessness was a minor factor (i.e. participants were not recruited on the basis of experiencing homelessness or homelessness was not a primary or secondary outcome) (Billstedt, Gillberg & Gillberg, 2011).

Table 1.1: Study characteristics

STUDY & COUNTRY	STUDY TYPE	GROUP	SAMPLE SIZE & GENDER	AGE	ETHNICITY	HOMELESS DEFINITION USED	RECRUITMENT SOURCE	TOTAL TIME HOMELESS	STRENGTHS	LIMITATIONS	CRITICAL APPRAISAL SCORE
ADHD STUDIES- QUANTITATIVE											
LOMAS & GARTSIDE (1997), USA	Cross-sectional	Veterans experiencing homelessness	81(97% male, 3% female)	41 (mean)	60% White, 40% Black	Domiciliary residence	Domiciliary for veterans experiencing homelessness	Not reported. Residents' average stay; 180 days	Outcome measures well defined . Use of developmental interviews where possible. Use of multiple validated screening tools	Insufficient data to assess prevalence; no statistical analysis reported for significance or variance. Results not fully reported for all ADHD measures	68%
UNGER ET AL (1997), USA	Cross-sectional	Youth experiencing homelessness	432 (65% male, 35% female)	Range: 12-23. 78% between 16-21	51% White, 21% Black, 15% Latino, 13% Other	'Primary residence in supervised shelter, an institution that provides a temporary residence, or a public or private place not ordinarily used as regular sleeping accommodation.'	Shelters, drop-in centres, street-based sampling.	30% <90 days 26% 91-365 days 23% 1-3 years 21% >3 years	Outcome measures well defined. Accessed 'hidden' homeless by street-sampling. Large sample. Analysis well described. Variance reported for main outcomes. Possible confounds controlled for through logistic regression. Internal consistency of ADHD measure reported (Cronbach's alpha =.83)	Only using a 4-item screening tool. Very brief self-reports. Possible sampling bias	100%
CAUCE ET AL (2000), USA	Cross-sectional	Youth experiencing homelessness	364 (58% male, 41% female, remainder unreported)	16 (mean)	63% White, 14% Black, 6% Native American, 5% Latino 3% Asian/Pacific Islanders, 9% Mixed/Other	Those with no viable stable residence who were not in state custody	Street-based sampling	Not reported	Large sample. Formal assessment of risk factors. Inclusion of street homeless. Validated measures	No comparison rates of results for housed population. DISC-R was 'lay-administered'	75%
VAN WORMER (2003), USA	Cross-sectional	Youth experiencing homelessness	132 (60% female, remainder unreported)	Range: 14-21	64% White, 22% Native American, 9% Black, 4% Hispanic, 1% Asian American/Other	'The condition of being without a home'	Transitional housing program	Not reported	Inclusion of younger participants. Exploration of causes of homelessness	Small subsample. Vague objective	60%
SLEATH ET AL (2006), USA	Cross-sectional	Homeless mothers with psychiatric disorders/ SUD/children in homeless families	164 (100% female)	Only reported for homeless mothers; 32 years (mean)	Only reported for homeless mothers; 83% Black, remainder unreported	Not defined	Homeless shelters	Not reported	Use of validated measures	Confound of SUD/psychiatric conditions in mothers not accounted for	68%
GRANT ET AL (2007), USA	Cross-sectional	Children in homeless families	520 (49% male, remainder unreported)	5 (mean)	56% Black, 42% Latino, 2% other /unknown	'Residence in a supervised shelter/transitional housing situation/public place not designed as sleeping accommodation. Individuals or families who have children who do not have a fixed residence.'	Paediatric patients	Not reported	Large sample	Prevalence rates for ADHD in housed children not reported for comparison	85%
MERSCHAM ET AL (2009), USA	Cross-sectional	Youth experiencing homelessness	182 (58% male, 42% female)	20 (mean)	54% White, 20% Black, 14% Hispanic; 4% Asian, 4% Mixed, 3% Native American, 1% Pacific Islander	Not defined	Homeless shelter for youth	Not reported	Large sample	Study instrument had no reliability or validity data. Limited generalisation to other settings (e.g. street-homelessness). No statistical analysis of main outcome	77%
HENNESSEY ET AL (2010), USA	Cross-sectional	Prisoners	192 (100% female)	33 (mean)	70% White, remainder unreported	Not defined	Prisons	Not reported	Large sample. Significant results for main outcomes. Variance reported	Homelessness not defined. Some inconsistent reporting of measures	91%

Table 1.1: Study characteristics (continued)

STUDY & COUNTRY	STUDY TYPE	GROUP	SAMPLE SIZE & GENDER	AGE	ETHNICITY	HOMELESS DEFINITION USED	RECRUITMENT SOURCE	TOTAL TIME HOMELESS	STRENGTHS	LIMITATIONS	CRITICAL APPRAISAL SCORE
HESSE & THIESEN (2013), DENMARK	Cross-sectional	Adults experiencing homelessness	72 (18% female, remainder unreported)	44 (mean)	59% Danish, 20% Other European, 14% Inuit (Greenland), 8% Other (America /Africa/ Asia)	Temporary housing/shelters	Homeless outreach clinic	Not reported	Novel contribution: assessment of ADHD screening tool use in homeless population	Raters not blinded when it was possible. Raters' knowledge/experience of ADHD may have confounded screening results	85%
SALAVERA ET AL (2014), SPAIN	Cross-sectional	People experiencing homelessness	196 (gender not reported)	65% under 40 years	Not reported	Not defined	Residents of 'insertion' centre	Not reported	Validated outcome measures well defined. Formal & informal identification of risk factors; enquired about causes of homelessness	Demographics only reported as frequencies. ADHD not analysed separately. No control group. Small sample	68%
BIHLAR MULD ET AL (2015), SWEDEN	Cohort study	Adults with ADHD & SUD	60 (100% male)	26 (mean)	Not reported	Not defined	Substance use inpatient treatment centre	Not reported	Outcome measures well defined. Comparison group. Consensus agreement on ADHD diagnosis by 2-3 Clinical Psychologists. Possible confounds controlled for through logistic regression. Follow-up.	Very small subsamples to draw conclusions from (n=3 vs. 2)	79%
NISHIO ET AL (2015), JAPAN	Quantitative case series	Adults experiencing homelessness	18 (100% male)	57 (mean)	100% Japanese	'A person who takes up residence in a city park, riverbank, roadside, station building, or other place to live without a reason. 'Absolute homeless' are those who sleep outdoors, such as in a park or subway station, as opposed to 'relative homeless', who are in precarious circumstances, such as a shelter for the homeless.'	Meal kitchen, social welfare centre.	7 years (mean)	Use of more than screening measures in prevalence study	Very small sample size limiting conclusion for prevalence study	65%
GARCÍA MURILLO ET AL (2016), USA	Cohort study	Children & adults with ADHD	135 (100% male)	41 (mean)	100% White	Absence of a permanent residence or fixed address for longer than one week	Participants referred by schools to medical clinic	Mean = 15.5 months, median = 6 months	Large sample. Significant results for main outcomes. Variance reported. Longitudinal. Examined specifics of homelessness; duration, times homeless, type; e.g. street/shelter. Blinding of interviewers at follow-up. Assessment of risk factors. Comparison group	Hard to draw conclusions on risk factors as comparison group had much smaller homelessness rate. 'Probable/definite' diagnoses reported together. No females or ethnic diversity. Exposure variables non reproducible/unclear how they measured them. Validity of conclusion limited; reported in related study that only 22% of these 'ADHD' probands met DSM-IV ADHD diagnosis	91%
NARENDORF ET AL (2017), USA	Cross-sectional	Youth experiencing homelessness	416 (57% male, 43% female)	Range: 13-24	54% Black, 14% White, 11% Hispanic, 15% Mixed, 6% Other.	'Previous night stay in shelter/on the streets or staying with friends/ family/acquaintances they couldn't stay at for more than the next 30 days.'	Shelters, transitional housing, food banks, street canvassing & snowball sampling.	Not reported	Formal quantitative identification of associated risks. Varied sampling; 95 episodes of screening at 47 locations	Confound: ADHD was comorbid with bipolar disorder & depression for most participants	100%
PIERCE ET AL (2018), USA	Cohort study	Youth with previous experience of homelessness	174 (42% male, 58% female)	56% under 19 years	20% White, 80% Black	Street homelessness, emergency shelter status	Transitional housing program	Not reported	All main outcomes had significant results. Intervention with specific outcomes focus	Diagnoses methods uncited	77%
FERGUSON (2018), USA	Randomised Control Trial	Youth with mental illness experiencing homelessness	72 (83% male, 17% female)	22 (mean)	38% Black, 17% Hispanic, 10% White, 2% Asian, 33% Mixed	Street homelessness, residence in a shelter or institution	Drop-in centre for youth experiencing homelessness	Not reported	Rare use of RCT in homelessness research. Identification of protective factors	No formal diagnosis of ADHD	79%
LABELLE ET AL (2020), CANADA	Cross-sectional	Youth experiencing homelessness	76 (57% female, 43%male)	Range: 12-19	Not reported	'Living without their parents/legal guardians and who do not have the means or the capacity to reside in a stable, secure and permanent place'	Temporary shelters	Participants 'in the 1st segment of homeless continuum' i.e. not long left their family home	Significant results. Possible confounds controlled for through logistic regression..	No robust diagnostic procedure. Small sample, selection bias, conclusions regarding some ADHD related risks don't seem to be explained/supported by their data	85%

Table 1.1: Study characteristics (continued)

STUDY & COUNTRY	STUDY TYPE	GROUP	SAMPLE SIZE & GENDER	AGE	ETHNICITY	HOMELESS DEFINITION USED	RECRUITMENT SOURCE	TOTAL TIME HOMELESS	STRENGTHS	LIMITATIONS	CRITICAL APPRAISAL SCORE
AUTISM STUDIES - QUANTITATIVE STUDIES											
KARGAS ET AL (2019), UK	Cross-sectional	Adults experiencing homelessness	65 (95% male, 5% female)	Ranges: 18-25, *n*=13 26–30, *n*=9; 31–60 *n*=43	Not reported	'Rough sleeping, residing where they do not have rights to stay (statutory homelessness) or sofa-surfing'	Temporary housing/support charity & day centre for homeless/ experiencing poverty	Not reported	Quantified correlation between autistic features and barriers to homelessness services. One significant result	Some confounds not considered (e.g. trauma). Conclusions report 'clinical' levels of ASD were over-represented despite measure only being screening tool. Comparison group size difference was large.	65%
CHURCHARD ET AL (2019), UK	Cross-sectional	Adults experiencing homelessness	106 (86% male, 14% female)	49 (mean)	88% White British, remainder unreported.	'Rough sleeping, residing in a place designed for habitation, but who do not have any legal title to their accommodation or access to any private spaces for social relations'	Homeless outreach team	12 years (mean)	Diagnostic screening based on DSM criteria. Blinding of raters, excluded confounds (refugees etc.). Validation of autism screening tool for homeless population	Unclear if whole sample was experiencing homelessness, possibly experienced homelessness in the past but not reported. Informant reports, not self-reports/diagnosis	100%
AUTISM STUDIES - QUALITATIVE STUDIES											
STONE (2019), UK	Qualitative case series	Previously homeless autistic adults	2 (100% male)	Not reported	Not reported	Not defined	'Residence designed to rehabilitate homeless people'	Less than 1 year	Inclusion of exploration of barriers to help when experiencing homelessness	No methods, theoretical approach or demographics reported	20%
GARRATT & FLAHERTY (2021), UK	Qualitative case series	Adults experiencing homelessness	39 (gender only reported for autistic participants ,*n=5*, 40% male, 60% female)	Only reported for 5 autistic participants ; over 30 years	Not reported	'Sofa-surfing, sleeping in tents, homeless and commercial hostels, and street homelessness. Participants were eligible if they self-identified as currently homeless or had been homeless in the past three years.'	Drawn from broader study. Purposive sampling through third sector organisations, advice centres, housing departments, local classifieds website. Snowball sampling	Not reported	Inclusion of exploration of triggers for homelessness and barriers to help when homeless. Inclusion of diverse homelessness experiences (sofa-surfing, housing association accommodation). Lifespan focus, not just focussing on one or most recent period of homelessness. Sets outs policy implications directly related to themes from their data.	3/5 participants displaying 'autistic traits' analysed as autistic. While one was awaiting diagnosis, it is unclear if the remaining two self-identified. No reflexivity of account evident	75%
ADHD & AUTISM STUDIES - QUANTITATIVE											
MORTON II & CUNNINGHAM-WILLIAMS (2009), USA*	Cross-sectional	Adults with developmental disabilities experiencing homelessness	62 (74% male, 26% female)	36 (mean)	Black 93.5%, White 6.5%	'Temporarily doubled up with others or residing in a halfway house; emergency shelter; or on the streets'	Snowball sampling. Soup kitchen. Street-sampling	1 year (mean)	Street sampling	Unrepresentative sample through exclusion of those who did not attend 'special education'. No comparison group of non-developmental disorder sample, which may have better addressed research questions	73%
MORTON II, CUNNINGHAM-WILLIAMS & GARDINER (2010), USA*	Cross-sectional	Adults with developmental disabilities experiencing homelessness	62 (74% male, 26% female)	36 (mean)	Black 93.5%, White 6.5%	'Temporarily doubled up with others or residing in a halfway house; emergency shelter; or on the streets'	Snowball sampling. Soup kitchen. Street-sampling	1 year (mean)	Focus on strengths in homeless research	Used dichotomous outcomes to quantify independent and dependant variables, which may have over-simplified their impact; e.g. categorising into employed/unemployed. Snowball sampling reduced generalisability of results	75%

Note: Abbreviations: DISC-R = Diagnostic Interview Schedule for Children-Revised. DSM = Diagnostic and Statistical Manual of Mental Disorders. SUD = Substance Use Disorder.

*Both studies used same sample for different study phases

Table 1.2: Prevalence Results

STUDY	CLINICAL DIAGNOSIS PRIOR TO STUDY	SCREENING MEASURES	PREVALENCE RESULTS
		ADHD STUDIES	
LOMAS & GARTSIDE (1997)	No	WURS-61, DSM-III criteria, Hallowell & Rattay's criteria for adult ADHD, 1st degree relative developmental interview where possible	62% ADHD prevalence
UNGER ET AL (1997)	Not reported	4-item scale contained within Adolescent Diagnostic Interview	11% scored above threshold on ADHD screening tool
CAUCE ET AL. (2000)	No	DISC-R	32% 'qualified for a diagnosis' of Attention Deficit Disorder
VAN WORMER (2003)	Yes	Self-report of clinical diagnosis	9% self-reported ADHD
SLEATH ET AL (2006)	Not reported	Parental report	12% reported having a child with ADHD
GRANT ET AL (2007)	Yes	Health records review for diagnoses. Paediatric files noted that diagnoses were made by a Clinical Psychologist using DSM & ICD criteria	Out of a subsample of 315, 15% of 3–4-year-olds had ADHD, as did 25% of 5-11 year olds & 18% of 12-19 years olds. Overall, 20% of 3-19 year olds in subsample had ADHD/12% of whole sample
MERSCHAM ET AL (2009)	Not reported	Clinical record review for diagnoses based on DSM-IV symptom checklist. Collateral information from involved professionals. Information from mental health evaluation questionnaire developed by Mental Health Center for Denver	4% had ADHD as primary diagnosis
HENNESSEY ET AL (2010)	Partial; 47% of participants meeting ADHD criteria reported existing diagnosis	WURS-61	46% met WURS criteria for ADHD, who had increased odds of experiencing homelessness (OR=2.09, 95% CI=1.02–4.30)*
HESSE & THIESEN (2013)	No. 6% referred with possible ADHD	ASRS-6	No prevalence reported; focus of study was on inter-rater agreement of screening tool ('adequate' concordance; 0.56, 95 CI=0.4-0.72)
SALAVERA ET AL (2014)	Not reported	Clinical Psychologist assessed using ASRS-2 & WURS-25	14% 'could be diagnosed with ADHD in childhood', 8% 'could meet current diagnosis of ADHD'
BIHLAR MULD ET AL (2015)	Partial; 22% had prior clinical diagnosis	DSM-IV diagnostic assessment or previous diagnosis	8% homeless at follow-up*
NISHIO ET AL (2015)	No	ASRS-6 & structured diagnostic interview, developed by authors according to the Conners' Adult ADHD Diagnostic Interview for the DSM- IV	17% screened positive for ADHD on ASRS-6 but 0% met criteria following structured interview
GARCÍA MURILLO ET AL (2016)	Partial: 'Hyperkinetic reaction of childhood' diagnosis.	DSM II criteria for 'Hyperkinetic reaction of childhood' at intake. Authors stated this aligned with later DSM diagnosis for ADHD	Participants with 'childhood ADHD' significantly more likely to experience homelessness than controls without ADHD; 24 vs. 4% (p<.001). 'Childhood ADHD' significantly increased odds of homelessness independent of conduct disorder, incarceration, illicit substance use and school dropout (OR=3.6, 95% CI=1.32–9.76, p=.01)*
NARENDORF ET AL (2017)	Yes.	Self-report of formal diagnosis	44% self-reported ADHD diagnosis. 8% had ADHD without comorbidity
PIERCE ET AL (2018)	Yes	Administrative records citing 'diagnosed with ADHD'	19% of sample had ADHD
FERGUSON (2018)	Not reported	Adult Self Report scale. DSM-Oriented Scale for ADHD problems	26% met ADHD criteria
LABELLE ET AL (2020)	No	DISC-IV	65% with ADHD
		AUTISM STUDIES	
KARGAS ET AL (2019	Not reported	AQ-10	19% scored above AQ-10 threshold
CHURCHARD ET AL (2019)	Partial; 1 participant had prior diagnosis	Authors deigned a measure (DATHI), using in-depth, semi-structured interview with keyworkers, based on DSM-5 diagnostic criteria.	12% (95% CI=7-20.4) screened positive for ASD & further 9% (95% CI=4.5-15.3) screened 'marginal'
		ADHD & AUTISM STUDIES	
MORTON II & CUNNINGHAM-WILLIAMS (2009) & MORTON II, CUNNINGHAM-WILLIAMS & GARDINER (2010)**	Not reported	Self-report	2% autistic, 3% ADHD

Note: Abbreviations: AQ = Autism Quotient. CI= Confidence Interval. DATHI = DSM 5 Autistic Traits in the Homeless Interview. DISC-IV = Diagnostic Interview Schedule for Children ICD = International Classification of Diseases.

*Homelessness rate in ADHD sample, rest are ADHD/ASD rates amongst samples of people experiencing homelessness

**Both studies used same sample for different study phases

Table 1.3: Risk Factors

STUDY	RISK FACTORS ASSOCIATED WITH ADHD/AUTISM	RISK FACTORS FOR WHOLE SAMPLE (NOT ANALYSED SEPERATELY FOR ADHD/AUTISM)
	ADHD STUDIES-QUANTITATIVE	
LOMAS & GARTSIDE (1997)	88% of participants with ADHD had comorbidity vs. 52% of participants without ADHD; 3x likelihood of antisocial personality disorder, 18x likelihood of anxiety disorders. 44% major depression prevalence. 0% had prior ADHD diagnosis or had ADHD mentioned as possibility in records.	Veteran status (inclusion criteria), substance use (32% prevalence), comorbid mental health (45% on anti-depressants)
UNGER ET AL (1997)	85% of those with probable ADHD had comorbidity (e.g. depression). Increased risk of substance use without alcohol (OR=1.56, 95% CI=0.74-3.29)	Over half of sample experienced depression, suicidal ideation, and/or met the DSM-II criteria for drug or alcohol disorder
CAUCE ET AL (2000)	None reported	7% LGBT, 33% care experienced. 51% experienced physical abuse before leaving home. Sexual abuse ranging from 23-60%. 52-55% reported a parent with problem substance use or problem with the law (84%)
VAN WORMER (2003)	None reported	Reasons for homelessness reported in subsample of participants; family conflict (n=7), economic problems (n=6) & residential instability (n=6)
SLEATH ET AL (2006)	None reported	46% reported barriers to taking medication
GRANT ET AL (2007)	None reported	Obesity (31% prevalence), asthma (35% prevalence), iron deficiency (19% % prevalence)
MERSCHAM ET AL (2009)	Participants with ADHD were significantly more likely use caffeine (p=.014)	Illicit substance use (84% prevalence). 82% of sample reported at least one major trauma
HENNESSEY ET AL (2010)	None reported	None analysed separately for participants experiencing homelessness
HESSE & THIESEN (2013)	Higher ASRS-6 scores significantly associated with illicit drug use (p<.01)	None reported
SALAVERA ET AL (2014)	ADHD significantly positively correlated with scores on personality disorder measure (p<.05)	High school dropout (37%). Reasons for homelessness; divorce (16%), family issues (29%), work problems (11%), problem substance use (32%), psychological problems (12%)
BIHLAR MULD ET AL (2015)	None reported	None reported
NISHIO ET AL (2015)	None reported	Mental illness (61% prevalence) Intellectual disability (39% prevalence)
GARCÍA MURILLO ET AL (2016)	Conduct disorder, substance use without alcohol, antisocial personality, school dropout, & smoking all significantly higher in participants with ADHD experiencing homelessness than participants without ADHD experiencing homelessness (p<.01). School dropout significantly associated with increased odds of homelessness in ADHD probands (OR 3.04, 95% CI=1.26–7.37, p=.01). Substance use without alcohol associated with increased odds of homelessness in ADHD probands (OR=2.45, 95% CI=1–5.97, p=.05). ADHD increased odds of homelessness independent of conduct disorder, incarceration, illicit substance use and school dropout (OR=3.6, 95% CI=1.32–9.76, p=.01)	School dropout (OR=3.64, 95% CI=1.5-8.84, p<.01)
NARENDORF ET AL (2017)	Depression, bipolar disorder & cannabis use significantly associated with ADHD youth experiencing homelessness (p<0.001). Cannabis use & ADHD was the only diagnosis & substance use relationship not mediated by mental health factors	Significant correlations between bipolar disorder & depression (p<0.001), unmet need for mental health treatment (p<0.001) & marijuana use (p<.05). Likewise between depression & unmet need for mental health treatment (p<0.001), being LGBT (p<.01) & recent alcohol use (p<.01)
PIERCE ET AL (2018)	Youth with ADHD significantly less likely to achieve educational gains or gain >20hours employment after intervention than those without ADHD (p<.05)	Victim of physical abuse (61% prevalence) or neglect (66% prevalence). Mood disorders (51% prevalence) and LGBT over-represented (17%)
FERGUSON (2018)	None reported	Mental illness diagnosis, employment support needs (inclusion criteria for study)
LABELLE ET AL (2020)	90% of participants with ADHD reported suicidal behaviour. ADHD significant predictor of suicidal behaviour (OR=11.84, 95% CI=2.35–59.60)	Friend's suicide in previous year (OR=28.79, 95% CI=1.48–59.23), death in family (OR=8.52, 95% CI=1.67–43.45), breakup (OR=7.9, 95% CI=1.69–36.89) and lack of social support (OR=5.86, 95% CI=2.02-17) increased suicidality risk
	AUTISM STUDIES-QUANTITATIVE	
KARGAS ET AL (2019)	AQ-10 scores significantly positively correlated with barriers to homelessness services (e.g. big groups in shared accommodation) (r(52)=.27, p=.026)	None reported
CHURCHARD ET AL (2019)	Participants scoring above threshold on screening tool less likely to have friends (OR=0.26, 95% CI=0.1-0.72, p=0.01), contact with family (OR=0.21, 95% CI=0.06-0.68, p=0.01), and have increased risk of isolation (OR=4.62, 95% CI=1.61-13.29, p=.005)	Substance use (OR=2.92, 95% CI=1.07-7.98, p=.037)
	AUTISM STUDIES-QUALITATIVE	
STONE (2019)	System barriers, exclusion. Narrative of resilience, susceptibility to socioeconomic disadvantage, and disabling barriers to services.	N/A
GARRATT & FLAHERTY (2021)	Mental health comorbidities reported by 4/5 autistic participants. Themes emerging: Financial precarity, challenges living with others, autism as an additional risk for homelessness, reduced family and friendship networks, unmet needs in homeless hostels, limited access to social housing, barriers to navigating support services, risk of exploitation and mate-crime	N/A
	ADHD & AUTISM STUDIES- QUANTITATIVE	
MORTON II & CUNNINGHAM-WILLIAMS (2009) & MORTON II, CUNNINGHAM-WILLIAMS & GARDINER (2010)**	None reported	66% had less than a high school education. Only 18% in employment. 78% with intellectual disability.

Note: Abbreviations: LGBT=Lesbian, Gay, Bisexual, Transgender **Both studies used same sample for different study phases

Prevalence

ADHD & homelessness

Fourteen studies reported prevalence of ADHD in samples of people experiencing homelessness. As shown in Table 1.2, prevalence ranged widely. In larger samples (n>350), prevalence ranged from 11-44%. Studies with prevalence rates above 60% had small samples (n<100) (Labelle et al, 2020; Lomas & Gartside, 1997). Larger sample studies with the most robust measures of diagnostic clinical interviews (using DSM criteria or validated assessment instruments) had prevalence rates of 14-32%. Studies using self-reporting found prevalence rates between 9-44% (van Wormer 2003; Narendorf et al, 2017). Rates of homelessness in ADHD samples varied from 8-24%. (Bihlar Muld et al, 2015; García Murillo et al, 2016). Probable ADHD increased odds of homelessness amongst prisoners in one study (OR=2.09) and increased odds of homelessness independent of conduct disorder, incarceration, illicit substance use and school dropout in another (OR=3.6) (Hennessey et al, 2010; García Murillo et al, 2016).

Autism & homelessness

Three studies reported prevalence of autism in samples of people experiencing homelessness (Kargas et al, 2019; Churchard et al, 2019; Morton II & Cunningham-Williams, 2009). As shown in Table 1.2, these studies were more recent than most included ADHD studies. Kargas et al found 19% of their sample scored above clinical threshold on the AQ-10, a commonly used autism screening tool. 12% of Churchard et al's sample were considered to have autism based on the authors' autism interview schedule for the homeless population. The lower autism prevalence finding of 2% may have been impacted by inclusion criteria as this study only included participants who attended 'special education'.

Risk factors

Table 1.3 shows 13 studies quantified risk factors associated with homelessness in autism or ADHD. The remainder of included studies did not identify risk factors or did not analyse them separately for autism or ADHD.

ADHD related risk factors

Participants with ADHD experiencing homelessness had more DSM diagnoses of major depression, antisocial personality disorders, substance use, anxiety disorders and conduct disorder, than participants without ADHD experiencing homelessness (Lomas & Gartside, 1997; García Murillo et al, 2016). Self-reported formal diagnoses of depression and bipolar disorder were significantly correlated with ADHD youth experiencing homelessness (Narendorf et al, 2017). ADHD was also associated with increased odds of suicidal behaviour and substance use without alcohol (Labelle et al, 2020; García Murillo et al, 2016). Increased substance use risk was evident in other studies, with substance use in the previous month significantly correlated with self-reported ADHD or higher scores on an ADHD screening tool (Narendorf et al, 2017; Hesse & Thiesen, 2013). Seventy-four% of veterans with ADHD experiencing homelessness had also experienced problem substance use (Lomas & Gartside, 1997). School dropout was significantly associated with increased odds of homelessness in ADHD probands (OR=3.04) (García Murillo et al, 2016).

Autism related risk factors

Two studies quantified risk factors associated with homelessness amongst autistic participants. Autistic people experiencing homelessness were significantly more likely than non-autistic participants experiencing homelessness to be isolated from friends and family (Churchard et al, 2019). Higher scores on an autism screening tool were significantly correlated with facing barriers when using homelessness services (Kargas et al, 2019). Qualitative studies with autistic participants experiencing homelessness

reported low employment rates and being a victim of financial exploitation or sexual abuse (Garratt & Flaherty, 2021).

Critical appraisal results

Summarised in Table 1.1, quality assessment of the included studies by the QualSyst showed that studies quality scores ranged from 20-100%. Mean quality score was 77%. Most studies scored between 61-80% (*n*=13) with 8 studies scoring above 81%. Only two studies scored below 60%. The most common limitation amongst quantitative studies was a lack of variance reported for main outcomes (absent in 6 studies where this was possible) and not controlling for confounds (absent in 4 studies when this was possible). The most common limitations in qualitative studies were data collection and analysis procedures not being described and verification procedures not being implemented when possible (e.g. inter-rater reliability checks). The most common strength amongst studies were the objective being clearly described, study design appeared appropriate and participant characteristics being sufficiently described.

Discussion

Summary of the main findings

This systematic review sought to assess the prevalence of ADHD and autism in the homeless population and identify risk factors associated with homelessness for these groups. ADHD prevalence ranged from 0-65%. Some ADHD studies addressed the reverse, finding rates of homelessness amongst people with ADHD between 8-24%. Substance use, school dropout and coexisting mental health diagnoses were associated with homelessness in ADHD. Autism prevalence in homeless populations was reported between 12-19%. Amongst autistic participants, reduced social networks was common.

Assessing Autism & ADHD

NICE (National Institute for Health and Care Excellence) guidance states ADHD diagnosis should be made by healthcare professionals using DSM or ICD criteria, clinical

assessment, developmental and psychiatric history, where available, and observer reports (NICE, 2019). NICE guidance on autism suggests using the AQ-10 screening tool before a comprehensive assessment by professionals involving, where possible, informant interviews, direct observations and formal assessment tools (NICE, 2012).

Prevalence

Prevalence estimates can be limited by the generalisability of samples to the wider population they aim to represent. Random sampling, rare in included studies, can increase this but is difficult with small pools of available participants. Thus, more targeted, purposive sampling is a more feasible recruitment method. Prevalence estimates are also dependent on the methodology used, with different studies using different measures for estimating prevalence; from screening tools to thorough diagnostic interviews. In most studies, ADHD prevalence was higher than general population estimates of 5-8%. The finding of a 32% prevalence of ADHD may be the most reliable out of the large sample papers due to its use of the DISC-R, which has moderate levels of agreement with clinical diagnosis (Piacentini et al, 1993). Most studies with over 350 participants used screening tools or self-reports.

Rates of homelessness amongst people with ADHD were higher than equivalent rates of homelessness in the general population (5% lifetime occurrence) (Taylor et al, 2019). The 8% figure found by Bihlar Muld et al (2015) may be more reliable as it was based on clinical diagnosis procedures based on consensus amongst multiple Clinical Psychologists. 12-19% autism prevalence findings were higher than general population estimates of 1-2%. Literature on the prevalence of autism as well as literature on the prevalence of ADHD in homeless populations is limited but has been reported in Stone, Dowling & Cameron (2019), whose scoping review examined prevalence of neurodevelopmental disorders in homeless populations. The few ADHD and autism studies they cited were either included in this review, were not original research or did not analyse ADHD and autism separate from intellectual disability (McCarthy et al, 2016).

Risk factors

Studies which identified risk factors associated with homelessness specific to autism or ADHD identified elevated odds of of substance use, school dropout and coexisting mental health conditions. It is not known whether these risk factors were higher than they would normally be in housed autistic people or people with ADHD without direct comparisons. Elevated rates of mental health conditions are limited in their generalisation due to small samples or comparison of groups of different sizes. However, several odds ratios still approached or reached significance. Risk factors should be interpreted with an awareness that these mostly cross-sectional studies provide no insight into causation. Although not explicitly stated, most participants with ADHD were undiagnosed, indicating unrecognised ADHD as a potential risk factor for homelessness. Without a comparison group of participants diagnosed with ADHD, the significance of this is unknown. While not included in this review due to being published after the literature search, another study exploring autistic experiences of homelessness found similar themes of social exclusion, and additional themes of barriers to employment, early life adversity and reduced awareness of autism amongst services (Stone, Cameron & Dowling, 2022). Some similarities between risk factors reported in included studies and those reported for homelessness in general population samples include coexisting mental health conditions and substance use (Nilsson, Nordentoft & Hjorthøj, 2019). In their scoping review of cognitive impairment in homelessness, Stone, Dowling & Cameron (2019) also noted high levels of substance use and coexisting mental health conditions across samples.

Strengths and limitations of included studies

Generalisation of results was increased by sampling methods in some included studies with the inclusion of street-sampling, which allowed for analysis of 'hidden homelessness'. Some studies controlling for confounds through regression analysis or exclusion criteria facilitated a clearer picture of the impact of ADHD in homelessness. Quantifying odds ratios revealed the extent of some risks. Studies provided practical implications for services by producing and validating screening measures for autism and

ADHD specific to homeless populations. Blinding strengthened results in the evaluation of the autism screening measure. The use of clinical diagnostic procedures in some studies increased reliability of their prevalence findings.

Limitations of studies mainly related to assessment measures, with some lacking clarity in their source of information or reliance on screening tools. While screening tools are a useful first step in examining prevalence, they only indicate probable presence of conditions. Studies with more robust measures had relatively small samples below 100. Validity of some findings were limited by their methods of confirming ADHD; namely one study equating childhood diagnosis of Hyperkinetic Reaction of Childhood with the presence of ADHD (García Murillo et al, 2016). This claim was contradicted in their related finding in another study using the same participants, finding only 22% met current ADHD criteria (Klein et al, 2012). Higher prevalence results were confounded by samples fully consisting of veterans, who already have increased risk for homelessness (Tsai & Rosenheck, 2015).

Strengths and Limitations of the systematic review

This is the first systematic review to investigate the prevalence of ADHD and autism in homeless populations. Partial inter-ratings of search results, data extraction and critical appraisal increased reliability of results. Consultation with a university librarian helped ensure the search strategy was as inclusive as possible to answer the research questions. The date ranges of the literature search may have limited results, with at least one relevant study being published after this date range (Stone Cameron & Dowling, 2022).

Implication for research

There is a relative scarcity of autism research in the literature but recent research has started to explore this qualitatively (Stone, Cameron & Dowling, 2022). Further quantitative research on autism will help identify prevalence and identify training and awareness needs amongst homelessness services. Combining screening tools with more thorough measures represents a positive step in balancing resource availability with valid findings. Further research can build upon the lack of qualitative research involving people with ADHD experiencing homelessness.

Implications for policy and practice

Risk factors identified may inform neurodevelopmental services of those more at risk of homelessness. Use of the DATHI and ASRS-6 screening tools could help services identify those they support who may need further assessment or adapted support. In their future considerations, the Adult Neurodevelopmental Pathways Report set the aim of 'improving neurodevelopmental understanding and support for people in 'high risk' and vulnerable groups' (Rutherford et al, 2023). Given the findings of increased autism and ADHD in the vulnerable group of people experiencing homelessness, there is a clear implication for service funding of ADHD and autism training in the housing/homeless sector. NICE guidance for health and social care for people experiencing homelessness recommends that local services 'quantify and characterise the population experiencing homelessness', including their specific needs (NICE, 2022). Services screening for prevalence of these conditions in the population they support aligns with this recommendation.

Conclusions

Most prevalence estimates of ADHD in homeless populations were well above general population prevalence. It is difficult to reach an equivalent conclusion on autism prevalence due to the relatively few recent studies being based on screening tools. Further use of these screening tools in homeless research combined with thorough diagnostic measures will provide a more reliable scale of this issue.

Statements and Declarations

The author(s) have no competing interests to declare.

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Chapter 2: Major Research Project: A qualitative exploration into experiences of homelessness amongst autistic adults and adults with ADHD in Scotland

Prepared in accordance with the author requirements for the Journal of Autism & Developmental Disorders; Author submission guidelines:

Plain language summary

Title A qualitative exploration into experiences of homelessness amongst autistic adults and adults with ADHD in Scotland.

Background Research has suggested that autistic people and people with Attention Deficit Hyperactivity Disorder (ADHD) are more likely to experience homelessness

(Stone, Dowling & Cameron, 2019). There is currently a lack of research on homelessness in these groups.

Aims and Questions To explore autistic participants' and participants with ADHDs' experiences of homelessness as well as their experiences of receiving support from health, social care and homelessness services.

Methods Six adults with experience of homelessness who were also autistic, had ADHD or both (ADHD and autistic together) were recruited through advertising via social media and through organisations which provide homeless services in Scotland. Semi-structured interviews with participants were analysed through thematic analysis, which involves looking for important patterns of meaning (themes) in what participants have said.

Main findings and conclusions Analysis produced four themes; awareness and acceptance of autism and ADHD helping, autistic and ADHD traits acting as barriers or protective factors, that most participants felt they had a lack of support while experiencing homelessness, and the difficulty of paperwork and organisation needed to access support. Recommendations for services were discussed, including the need for more recognition of autism and ADHD amongst services, and adapting support to meet the needs of people who use their service.

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Abstract

Purpose Preliminary research has shown that people with certain neurodevelopmental disorders may have a heightened risk of experiencing homelessness. Attention Deficit Hyperactivity Disorder (ADHD) has been identified as being over-represented in

homeless populations and traits associated with autism have also been reported to be higher in these populations. This project investigated this group's experience of homelessness and their experiences of accessing/using homeless, health and social care services.

Research Questions 1) What are the participants' perceptions of their journeys in and out of homelessness? 2) How is accessing and using health and social care homelessness support services experienced by this group?

Methods The study used a qualitative approach. Six autistic participants and participants with ADHD who have experienced homelessness took part in semi-structured interviews relating to their experience of homelessness and the supports they received. Results were analysed through thematic analysis.

Results Analysis revealed four themes; (a) awareness and acceptance of autism and ADHD helping. (b) traits acting as barriers or protective factors, (c) going it alone, and (d) the impact of logistics

Conclusion Implications for services include the need for improved awareness of ADHD and autism, which can be supported by screening tools and training. The benefits of services accepting self diagnosis or pursuit of diagnoses in order to better understand people's needs is discussed, as are the benefits of strengths-based support.

Keywords Attention Deficit Disorder with Hyperactivity, Autism Spectrum Disorder, Homeless Persons, Homelessness.

Introduction

Autism is a neurodevelopmental condition affecting communication and interaction with others alongside the presence of restricted interests and repetitive behaviours (APA, 2013). ADHD is defined by persistent presence of inattention and/or hyperactivity and impulsivity which interferes with functioning (APA, 2013). Adult prevalence rates for autism and ADHD have been recorded at around 1% and 5% respectively (McManus et al, 2016; Polanczyk et al, 2007). High rates of co-occurrence of ADHD and autism has been found at around 22% in adults (Rong et al, 2021), although this figure is based on a meta-analysis in which the majority of studies used small, clinical or community samples. In the larger, population-based studies, this figure decreased. Additionally, there was a lack of longitudinal studies, which could help in ruling out confounding factors these cross-sectional studies have not accounted for, such as the impact of adverse childhood experiences or possible brain injury.

Homelessness in Scotland

Homelessness in the UK is defined as those residing in hostels, couch-surfing, supported homelessness accommodation, temporary accommodation and experiencing street-homelessness. Under the Housing Scotland Act (1987), Section 24, a person is considered homeless, even if they have accommodation, if it would not be reasonable for them to continue to stay in it (Scottish Government, 2022). This definition has been used in other homelessness research in Scotland (Waugh et al, 2018). In 2019, 53,400 adults in Scotland were estimated to be experiencing homelessness (Bramley et al, 2019). The Hard Edges Scotland report (Bramley et al, 2019) discussed the phenomenon that experiencing one Severe and Multiple Disadvantage (SMD) such as homelessness, greatly increases people's risk of experiencing other SMDs (i.e. substance dependency, poverty, mental ill health or violence). This report estimated that over the course of a year, roughly 5700 people in Scotland experience the triad of homelessness, substance dependency and offending. Equivalent lifetime estimates were that 876,000 people in Scotland had experienced all three of these disadvantages in their adult life, with homelessness being the most common. This report found poverty, trauma and care experienced people to be over-represented in homeless populations, suggesting a need

for trauma-informed practice (Bramley et al, 2019). The National Trauma Training Programme (NTTP), formed between NHS Education for Scotland and the Scottish Government, aims to build a trauma-informed workforce aware of and responsive to trauma and adversity (NES, 2017). A workforce survey of the NTTP in 2021 found 44% of over 3500 respondents working in public, private and third sector social care were confident in their understanding of psychological trauma and its impacts. However, less than 31% felt confident in applying trauma-informed principles within their work, many citing a lack of time to undertake training (Scottish Government, 2021).

Impact of homelessness & maintenance factors

Homeless healthcare research in Scotland has shown that people experiencing homelessness have five times the mortality rate of their housed counterparts in the least deprived areas of Scotland. Even when compared to housed people of a similar age and gender in the most deprived areas of Scotland, those experiencing homelessness still have double the mortality rates (Waugh et al, 2018). Additionally, conditions in homeless hostels have been noted to be disparate (Bramley et al, 2019), which can increase psychological distress (Alidoust & Huang, 2021).

Homelessness and neurodevelopmental conditions

Autism and ADHD may be over-represented in homeless populations. Studies with large samples (*n* =196-364) and robust measures of diagnostic clinical interviews using DSM criteria or validated assessment instruments found ADHD prevalence rates between 8-32% amongst participants experiencing homelessness (Salavera et al, 2014; Cauce et al, 2000). Studies of autism in homeless samples using screening tools such as the AQ-10 has indicated prevalence rates between 12-19% (Churchard et al, 2019; Kargas et al, 2019). Qualitative research into the experiences of homelessness amongst autistic [2] people is sparse, although some studies have been published in recent years. In their

[2] Identity-first language has been used in this report in reference to autism (i.e. 'autistic person', not 'person with autism'). There are differing views on person vs. identity first language, although a UK survey found that a large percentage of autistic adults preferred 'autistic' (Kenny et al, 2016). Additionally, identity-first language is adopted by the National Autistic Society (National Autistic Society, 2023). Participants in this study mainly used identity first language with occasional exceptions.

qualitative case series of two autistic adults who experienced homelessness, Stone (2019) revealed narratives characterised by resilience, susceptibility to socioeconomic disadvantage and disabling barriers to support (Stone, 2019). A more recent qualitative analysis of homelessness experiences amongst ten autistic adults in England revealed themes of reduced awareness of autism amongst services, early life adversity, social exclusion and employment barriers. This study recommended autism training for services, the removal of the requirement for a formal diagnosis to receive appropriate support and for homelessness to be recognised as a risk factor in the National Autism Strategy (Stone, Cameron & Dowling, 2022).

Secondary analysis of life mapping narratives of five adults reported to be autistic who experienced homelessness revealed themes of financial precarity, challenges living with others, autism as an additional risk factor for homelessness, reduced social networks, unmet needs in homeless hostels, and limited access to social housing (Garratt & Flaherty, 2021). However, only two of these five self-identified or were diagnosed as autistic, while the other three were thought to 'display autistic traits'. The majority of homelessness research involving autistic people or people with ADHD has been quantitative and focussed mainly on ADHD (Bihlar Muld, Bölte & Hirvikoski, 2015; García Murillo et al, 2016; Narendorf et al, 2017). While recent research has begun to address this gap, most has been in the form of case series or secondary analysis and there remains a lack of qualitative research into the experience of homelessness amongst people with ADHD. As these conditions often co-occur, this project aimed to qualitatively investigate the experiences of homelessness amongst autistic people and people with ADHD. To meet these aims, research questions were;

1. What are the participants' perceptions of their journeys in and out of homelessness?
2. How is accessing and using health and social care and homelessness support services experienced by this group?

Methods

Participants

Purposive sampling was used as the research questions related to a specific group of people (autistic and ADHD) within a group for whom research is often inaccessible (people who have experienced homelessness). Participants were recruited on the basis of having experienced homelessness in Scotland within the last five years and that they were autistic and/or had ADHD. Formal diagnoses were not required for inclusion. Homelessness included those residing in hostels, sofa-surfing, supported homelessness accommodation, temporary accommodation and experiencing street-homelessness. Participants were excluded if they had an intellectual disability, communication or other difficulties incompatible with the demands of a semi-structured interview (e.g. selective mutism), if they did not speak English or they otherwise did not have capacity to provide informed consent to participate.

Non-participation

A number of individuals made contact expressing initial interest. Of these people, two could not take part due not being based in Scotland. Another one could not take part due to their period of homelessness being over five years ago. Four further participants met inclusion criteria but did not respond to further correspondence. Correspondence from a further ten email addresses stating eligibility did not result in interviews due to non-attendance or potential participants not returning communications.

Design

Other qualitative research involving autistic participants has adopted a realist approach, assuming that meaning and experiences discussed by participants would have a straightforward relationship with the language they used to describe them (Garratt & Flaherty, 2021). While this could also be true for the participants in this project, it can also be said that autistic people and people with ADHD's perceptions of their experiences could be better understood when interpreted in the sociocultural contexts and systemic conditions in which they often experience exclusion. For that reason, a constructionist approach was adopted in the development of this project. The explanatory function of qualitative research lent itself to investigating why there may be increased risk of

homelessness in this population. Due to the complexities of the topic, qualitative methods were appropriate in gathering in-depth, detailed data exploring individual experiences. Qualitative methods were also appropriate to the expected sample size given the timescale and recruiting from a hard-to-reach group. Semi-structured interviews were used as they facilitate the collection of open-ended data in a manner that is appropriate for sensitive and personal topics. One-to-one interviews were chosen to encourage more open responses, especially in a participant group with neurodevelopmental conditions, who may find other qualitative methods of data collection, such as focus groups, stressful. The flexible format of this interview method acknowledges that respondents have unique interpretations of the subject matter and facilitates responsiveness to respondents' emerging views (Merriam & Tisdell, 2016).

Materials

A digital audio recorder was used to record interviews, which were transcribed and coded within NVIVO 12 software. Transcriptions, demographic and consent forms were stored on University of Glasgow OneDrive online storage, with audio recordings and physical copies of consent/demographic forms destroyed upon data transfer.

Recruitment

Third sector organisations with links to housing or supporting autistic people or people with ADHD across Scotland were contacted to display project advertisements in their physical and online spaces. Local authority housing services in cities throughout Scotland were contacted to advertise the project and pass on the project information directly to any clients who met the project inclusion criteria. Additionally, physical project advertisements were placed in community centres, related third sector offices and food banks across Glasgow and the Scottish Highlands. The main route through which eventual participants were recruited was by participants self-selecting after seeing the project advertisement on various Facebook pages of charities with links to autism and ADHD. Participants contacted the researcher through email or Facebook to arrange interviews. To take account of potential participants' neurodivergent needs, they were offered the choice of having a separate meeting with the researcher prior to the interview to familiarise themselves with the researcher and ask any questions about participation.

Two participants took up this offer. A participant information sheet (Appendix 2.1, page 76) and privacy notice was shared to familiarise participants with the project purpose, procedure, data governance compliance and researcher (including background, photo, interests) prior to interviews. Supermarket vouchers valuing £20 were offered as participation incentives.

Interviews

A semi-structured interview protocol (Appendix 2.2. page 77) was used flexibly across interviews. Each participant completed a consent and demographics form asking age, gender, ethnicity, sexual orientation, marital status, education level, employment status and physical or mental health conditions, (Appendix 2.3 & 2.4, pages 78-79). Interviews were conducted by the researcher (AG) face-to-face in university offices, public library rooms and rooms within charities advertising the project. Settings were chosen based on proximity to where participants were currently based. All interviews were conducted in private rooms, lasting between 50-90 minutes. Participants were offered the option of having a familiar person accompany them in interviews, with one participant taking up this offer.

Analysis plan

Reflexive thematic analysis was used for identification of themes and patterns relevant to the research questions of identifying patterns relating to this group's perceptions of their experiences of homelessness and patterns in the data relating to experiences of receiving support from services. This analysis plan was chosen as it is a flexible approach which can be applied independent of theory which fits with this project as there is relatively little qualitative research into homelessness in this group. Thematic analysis can highlight similarities and differences in the dataset, facilitating the analysis of data from a sample not entirely homogeneous. Adopting an approach which could help interpret data within social as well individual level contexts was important (Braun & Clarke, 2006). This is especially important given the additional social barriers this group faces. This followed the recommended phases of the researcher (AG) familiarising himself with the dataset through transcription, generating and collecting data for initial codes, and identifying themes from codes. Themes were then reviewed; checked against

the coded data and a 'map' of the data was generated before themes were defined/named. Initial and refined themes were discussed with supervisors during the refining stage. Lastly, excerpts were selected from the data which best related the themes to the research questions (Braun & Clarke, 2022). An inductive approach to coding was used as there are no existing theories about this group's experience of homelessness and theme development could be derived from the content of the data. Additionally, a latent approach to coding and theme identification was adopted, attempting to interpret beyond the explicit content of the data to identify underlying assumptions and conceptualisations of participants' experiences (Braun & Clarke, 2006).

Reflexive process

Some of the researcher's (AG) attributes that may have influenced the research process included demographics; being a white male, with no prolonged personal exposure to housing or financial insecurity. The researcher held an MA (Hons) in Psychology and was employed by the NHS as part of the Doctorate in Clinical Psychology at the time of this research. The researcher's background in working with autistic and ADHD adults in healthcare settings, in which satisfaction with accessing and using services often came up, will have somewhat shaped the approach to interviews, relationships with participants and analysis of the data. Working clinically with autistic people and people with ADHD has involved developing a shared understanding of difficulties and some of the researcher's perspectives influenced this. As a result, participants' experiences may have been analysed through the researcher's assumptions as well as being influenced by the researcher's understanding of autism and ADHD in clinical settings, which may not be wholly representative of this groups' experiences while facing homelessness. Participants were made aware of the researcher's reasons behind pursuing the research. Discussion of interview protocols and theme development with supervisors helped to maintain awareness of this and limit the influence.

Ethical approval

Ethical approval was granted by the University of Glasgow College of Medical, Veterinary and Life Sciences Ethics Committee (Appendix 2.5. pages 80-81).

Results

Demographics

Sociodemographic information of participants is shown in Table 2.1. Participants were allocated pseudonyms to protect sensitive data. Table 2.2 outlines details about each participant's homelessness journey. Participants (3 male, 3 female) were white, aged 24-42 (mean age 31). Three were autistic and had ADHD, two had ADHD alone and one was autistic alone. Most had formal diagnoses of either autism or ADHD at the time of data collection but most were undiagnosed when they first experienced homelessness. Participants estimated mean age when first experiencing homelessness was 26.

Table 2.1: Participant Demographics

Participant	Autism/ADHD	Age	Gender	Ethnicity	Sexual orientation	Martial status	Highest education level	Employment status	Other health conditions
William	Autism	30	M	White	Straight	Single	Bachelor's Degree	Unemployed (not looking for work)	None
Kenneth	ADHD	42	M	White	Straight	Divorced	High school	Unemployed (not looking for work)	Mixed, borderline & dependent personality disorder. Depression. Anxiety.
Peter	Autism & ADHD	39	M	White	Straight	Single	Bachelor's Degree	Unemployed (not looking for work)	Generalised anxiety disorder
Sarah	Autism & ADHD*	24	F	White	Unsure	Single	Partial Bachelor's Degree	Unemployed (not looking for work)	Anxiety. Depression.
Mairi	Autism & ADHD	26	F	White	Bisexual/ pansexual/queer	Single	High school	Unemployed (not looking for work)	Anxiety. Depression. Vulvodynia.
Siobhan	ADHD*	27	F	White	Straight	Single	High school	Part-time employment	ADHD Anxiety

*Sarah & Siobhan were awaiting an ADHD diagnosis. With the exception of this, all neurodevelopmental and other conditions were reportedly formally diagnosed at the time of interviews, according to participants' response on demographics forms.

Table 2.2: Type & duration of homelessness

Participant	Times homeless	Age at 1st period of homelessness	Autism/ADHD diagnosis at 1st period of homelessness	Estimated duration of homelessness	Type of homelessness	Current housing situation
William	2	Est. 25	Yes	3 weeks – several months	Street-living -3 weeks. Homeless hostel-unknown duration	Own tenancy
Kenneth	3	Est. 24	No	13 months split over 3 periods of homelessness	Hostel (owned by friend)-2 weeks. Sofa-surfing-2-3 weeks. Street-living (in garage)-7 weeks. Homeless hostel-4 months. Temporary accommodation-unknown duration	Own tenancy
Peter	1	Est. 37	No	3 years	Sofa-surfing & tourist hostels etc.-6 months. Homeless hostel-2.5 years. Street-living-1 week	Own tenancy
Sarah	1	24	Autism-yes. ADHD-no	1-2 months	Homeless hostel	Own tenancy
Mairi	1	23/24	No	13 months	Sofa-surfing – 4-5 months. Temporary accommodation - 8 months	Own tenancy
Siobhan	1	24	No	3 years, 2 months	Sofa-surfing, temporary accommodation	In private sector let, still reported to be experiencing homelessness

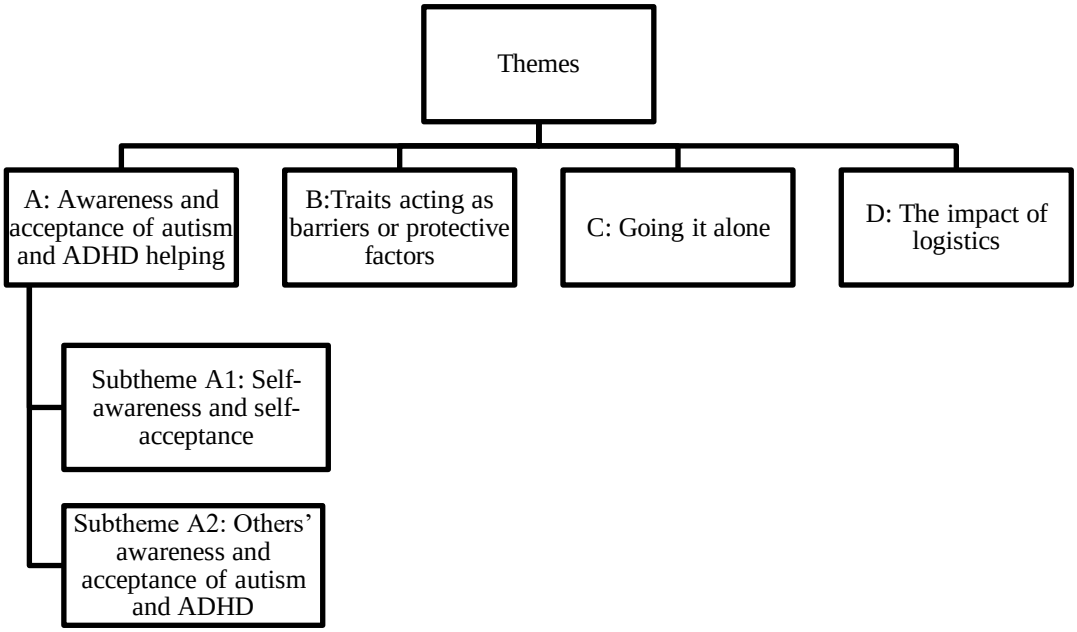

Figure 2:1: Thematic map

Analysis produced four themes; (A) awareness and acceptance of autism and ADHD helping. (B) traits acting as barriers or protective factors, (C) going it alone, and (D) the impact of logistics. Theme A was split into two subthemes; subtheme A1: self-awareness and self-acceptance and subtheme A2: others' awareness and acceptance of autism and ADHD.

Awareness and acceptance of autism and ADHD helping

Participants often evoked themes of awareness and acceptance relating to being autistic or ADHD and how this was helpful in their journey. This referred to both their own self-awareness and acceptance of being autistic/ADHD, analysed in subtheme A1, as well as others' awareness and acceptance of this, analysed in subtheme A2.

Subtheme A1: Self-awareness and self-acceptance

As table 2.1 shows, most participants did not have a diagnosis of autism or ADHD when they first experienced homelessness. Some explicitly related their lack of awareness about being ADHD or autistic as causal in experiencing homelessness. Kenneth believed an ADHD diagnosis would have provided some preventative function to becoming homeless: "I didn't have to get to that state in the first place because if I was actually diagnosed beforehand but, hey-ho I wasn't diagnosed". Mairi spoke of her misdiagnosis

of personality disorder and misdiagnoses in general amongst autistic people. She explained how this lack of self-understanding contributes to unhelpful coping; “They don't understand their own needs. Then they can't help themselves and then that leads to them not getting better in the way that they want to, which then just becomes a vicious cycle of becoming self-destructive because they don't know what they're missing in the first place”. Peter echoed this notion, describing how the discomfort of being unaware of what was causing him to feel this way led to coping through alcohol: “There was a lot of questioning, like; 'What is wrong with me?' And I remember just hating, I used to hate that feeling and alcohol was the best cure for that”. He discussed how his subsequent awareness of his autism related needs helped inform his housing needs: “Knowing that I'm autistic, I definitely should have a top floor flat because having people just constantly, like, make noise above me is, like, a big trigger”. William, who had a diagnosis while he was homeless discussed not accepting this when diagnosed: “I was like 'What on earth?! They must've made a mistake!' You know? I did well in school.” later describing not accepting this for for a few years after: “I was in denial”.

Subtheme A2: Others’ awareness and acceptance of autism and ADHD.

Participants journeys through homelessness were also impacted by the level of awareness and acceptance of autism and ADHD amongst their family and the services supporting them. Siobhan described her experience of living with her mother and being misunderstood. This relational tension led her to internalise negative perceptions of herself, triggering an urge to leave home; “Looking back, it definitely was cause I was undiagnosed…I remember when, talking about my mum and things like that, being really nasty about her. Cause it was like she didnae get me, she just didnae understand. It was like; ‘I cannae be near this house anymore. Because somebody keeps telling me I’m bad’”.

Sarah spoke of the acceptance of services when it comes to autism and ADHD. At the time of experiencing homelessness, she had a diagnosis of autism and self-identified as ADHD while awaiting formal assessment. She described her perception that services’ ability to tailor support is guided by formal diagnosis; “If I'm not diagnosed with ADHD they wouldn't take that into account”. Her familiarity with services informed her perception that services not only refuse to but are also restricted in their ability to adapt service provision without formal diagnoses; “I'm not stupid that, like, without a diagnosis

they can't take it seriously and refuse to take it seriously. Like, I don't have a reason. So that's just the way it works." She believed that her diagnosis of autism helped contextualise her distress to homeless hostel staff; "I did explain to them that I actually am autistic, so I think that helped them to sort of, like, frame my struggles a bit at that time". Mairi, who experienced psychical and emotional abuse in the context of an intimate relationship prior to experiencing homelessness, also highlighted her perception that services were not particularly accepting of her attempts to seek diagnostic assessment for ADHD and autism:

"They were kind of under the impression that I was just looking for things that were wrong with me. That was very hurtful because I don't see neurodivergence as something that's wrong. I see it as a difference, and I was just trying to understand my brain. And I wish that had been met with more curiosity…they're very much of the opinion that it's all trauma. But, you know, trauma's one thing; it doesn't mean that it's the whole picture."

Mairi explained her lack of faith in the awareness about autistic women amongst services as well as a reluctance to improve understanding: "It could've stemmed from medical misogyny of: 'female with big emotions that we don't quite understand. We're just kinda gonna go with personality disorder cause we don't know. We don't want to look into what else is happening'. So I think there's definitely an element of medical misogyny and just not understanding autism at its core". The issue of women being misdiagnosed is reflected in research findings that autistic women are more likely to be misdiagnosed than autistic men (Gesi et al, 2021). Mairi expressed the impact this lack of understanding amongst services had on her, namely feeling that the burden of educating services should not fall on her;: "Even now, being diagnosed, I have to do a lot of explaining about; 'This is what works for me, this is what doesn't work for me, this is what you need to do to be able to accommodate me'. So I'm very much the teacher in terms of; this is how to work with a traumatised autistic and ADHD woman. The knowledge isn't there. So yeah, it's quite difficult having to then take the labour of educating your support workers about how to support you in the correct way".

Traits acting as barriers or protective factors

Traits associated with autism and ADHD were framed as barriers to coping while experiencing homelessness as well as sometimes lessening the impact of adverse situations. These traits were often explicitly linked to autism or ADHD by participants. Peter described his journey to becoming homeless when his landlord decided to sell his property: “I didn't want another flat, I wanted this one. So it was this one or nothing. So, autistic people sort of, they cannot deal with change and they can be very black and white”. This singular focus was reflected in his subsequent decision to stay in a hostel for years when properties were available sooner in order to get a council house in which a landlord wouldn’t be able to evict him: “I just decided, I'm gonna bear staying at the B&B, being homeless for longer. But I won't lose my priority and I'll just be able to bid for flats on the website every week and I'll get a flat to myself”. While this ‘black and white’ thinking described by Peter helped him secure a flat with reduced uncertainty around eviction, it also contributed to a longer stay in the hostel, which he later described having a detrimental impact on his mental health; “The less you can be at those really rough places, the better for your mental health.”.

Kenneth, diagnosed with ADHD, partly related his homelessness journey to his decision-making tendencies: “It's the decision-making made without any consequences thought through. That's what led me to that there” . Siobhan, who was awaiting assessment for ADHD, described her reaction to being faced with big decisions involving housing as catastrophising: “It's like, somewhere inside me that is the end of the world, somewhere. Even though I know it's no. But I cannae see the light. It just shrinks”. Peter described a similar sentiment related to catastrophising and help-seeking:

“A lot of autistic people, me included, there's a big social anxiety. It's hard to deal with other people because you almost feel like a lot of the time like you don't fit in. And because of that you're gonna start assuming that: ‘Oh well, because okay so, they're not like me; I'm not like them. So they don't wanna deal with me, they don't wanna help me.'. So it's almost like, that catastrophising part of autism and the overthinking part of autism.”

Here, participants expressed how their thought patterns or impulsive tendencies either contributed to their experience of homelessness, their coping during that journey or their help-seeking. Some explicitly linked this to their autism or ADHD while others did not

explicitly label it as such. Peter evoked the notion that those different from him would not want to help him. This touches on the related idea that communication issues between autistic and non-autistic people are a two-way issue. Milton (2012) described this as the double-empathy problem, which challenges the notion that social communication issues are a result of autistic communication deficits. Instead, this concept situates the problem in the context of a mutual misunderstanding between autistic and non-autistic people in terms how the other interacts. In his example, Peter described how this mutual feeling of otherness can inhibit help-seeking.

Participants described traits also serving as protective factors, with some describing their thoroughness and affinity for researching as helpful while searching for properties when experiencing homelessness:

"I kind of accumulated a huge list of letting agencies and just sort of went through them all." [Sarah].

"The cool part about being autistic is the amount of research I do. So, I like to, when I was homeless I would just read everything about the [council housing list database], about how it works. So much research. And just became really knowledgeable about the whole thing. So, after I stopped being homeless I helped some people deal with that." [Peter].

Peter again discussed that singular focus, this time framing it as a means to achieve his one goal while experiencing homelessness: "Once you're there; your job, your task for the week is to log into the website every week and look for the flat". Mairi related her experience of being undiagnosed to resilience building, which she thought increased her ability to adapt to the adversity of experiencing homeless: "Growing up undiagnosed autistic and ADHD and having to go through things that you shouldn't have to go through and having to adapt to things that didn't work for my brain. It wasn't my first rodeo".

Going it alone

Participants spoke of coping on their own during their homeless journey. This was most often discussed in the context of feeling left to their own devices but some also spoke of

being alone by choice. Sarah spoke of her family deciding it was best she not return to the family home after being evicted from a private rented flat: “I kind of thought; ‘Okay seems like I'm a bit too much for them’”. Similarly, Peter spoke of the manner in which he coped with the change of becoming homeless leading to friends kicking him out while sofa-surfing. He described his friends not understanding why he didn’t want to find another flat: “They would bother me, like: 'Go look for a flat'. And I'm like: 'I don't wanna look for a flat. I want that old flat.' They're like: 'You're stupid!'”. This frustration in his friends eventually led to Peter being asked to leave the flat: “Cause I didn't wanna deal with looking for another flat. It was way too much for me. And I ended up being kicked out…because I didn't wanna deal with change”. Here, Peter attributed the rift to his readiness to cope with change, situating the reason for going it alone within himself and his resistance to change.

Mairi spoke of her perception of services being unprepared to support autistic people and people with ADHD: “It’s almost like services just want to brush them under the rug and not deal with that because it's not an easy fix. It's not something you can medicate, it's not something that you can therapise away. It's a lifelong condition and I think because that costs money and its complex, a lot of services just don't know how to interact with service users that have those conditions”. Her perception held the notion that services’ not adapting to autistic and ADHD needs was not only due to a lack of understanding but also an unwillingness to address the issue due to the complexity and related costs.

Siobhan spoke of the impact of staffing levels and how this left her unsupported: “I was kinda left and I had no support. I didnae have a housing officer to phone and say; 'Look, this is where I'm at now. I've just been offered this flat. I'm totally struggling’”. Both Kenneth and Siobhan strongly expressed the feeling of being left by services to cope themselves when experiencing homelessness. Siobhan was able to get some support from her family, which served as a protective factor to the lack of support she felt services provided; “My mum and my sister are very, they're good with things and then there's me”. However, Kenneth’s support from family while sofa-surfing at his cousin’s flat was tenuous, quickly ending when extended family suggested he find support elsewhere; “His cousin came up and told me: 'Gonna fuck off back to your own family!’”.

Kenneth spoke of being diagnosed in adulthood, and how he saw how this could result in many with ADHD isolating themselves: “The older you get the more you realise; ‘Aw there's consequences’, the more anxiety comes through, the more depression kicks in with it. And this is what it results...we will just slot out of society so we don't have to be a fucking burden. And that's a lot of the thing there, I didn't want to be a burden all the time”. Here, he expressed his perception of being burdensome and choosing to go it alone in reaction to this. This may also have been a reaction to feeling rejected by his extended family; choosing to go it alone as others left him alone.

The impact of logistics

Participants discussed how they coped with tasks related to navigating their experience of homelessness and through the housing process. This ranged from administrative paperwork, managing household tasks and finances, making housing related decisions and searching for flats. These demands will be referred to using the umbrella term of logistics for this theme. Half of the participants emphasised the pressures of the logistics of navigating the homeless/housing system and the additional demands these placed on them. Others felt the logistics were manageable, given their own strengths. For those who found logistics an issue, unfamiliarity with the system, combined with their own abilities and pressures from the system placed an emotional toll on them. Siobhan emphasised her unfamiliarity of navigating the homeless and housing services: “I've never had this sat and explained to me; 'So this is what happens when you do get offered a flat'.” A perceived lack of clarity from services regarding the consequences of decisions was combined with pressure: “You're giving me an hour to make a decision on a flat? Big decision. And I say to her; 'So if I take these keys today, when do I move in here?' 'Oh I don't know that' I'm like; 'Ahhhh!' They cannae answer these questions!”. The effect of this was substantial: “I was so stressed, like eyes were popping out ma head sorta stress.” [Siobhan]. This lack of clarity was reflected in Siobhan’s current housing status, who reported still experiencing homelessness as she was not sure about the permanency of the private sector let she was recently placed in.

Kenneth spoke of the demands the required paperwork placed on him: “I'm sitting there with a booklet about 16 pages long to go and do in the homeless shelter. Know what I mean? These simple things that make it almost impossible for us to go and access the

services and support we need". He went onto explain the criticism he received and internalised throughout his life relating to ADHD and the impact of this on his ability to perform these tasks; "It becomes hard-wired in you. So you don't expect you can get things done. If it's to do with paperwork, I'm never gonna be able to fill that in!". He further discussed how his reaction to demands like this can be misconstrued: "When we come across frustrated and all that, no we're not. We're just genuinely lost and confused about how we actually communicate over when people are put into systems that are…it's just not natural for us at all, some of these systems". Mairi also described the toll of completing paperwork when she did not yet know she was autistic: "As an autistic person, but not knowing at the time, I didn't understand the toll that had with the forms, all the information, all the appointments that I had to commit to. The same with the benefits stuff".

Others either did not mention logistics or discussed logistics as surmountable due to their own qualities. Sarah discussed her flat search being fast-tracked due to her impatience, which she attributed to her ADHD: "I'd only been looking for a week. And I'm just so impatient…like I said, I think I do have ADHD.". This impatience combined with her approach to the search strategy: "It was quite thorough to be fair" contributed to a brief duration of homelessness. Peter could see some instances in which others may be impacted by the logistical demands, but his computer skills served as a protective factor from requiring any support with this: "The support would have been maybe for some people who don't have access to a computer. But you can do it on your phone. I'm very tech savvy, I know, like, a lot about IT. It's not been a problem for me".

Discussion

By interviewing autistic people and people with ADHD who have experienced homelessness, this project aimed to understand their perceptions of their journeys through homelessness and their experience of using health, social care and homelessness support services.

Journeys through homelessness

Participants journeys through homelessness were characterised by a few common themes.

The most prevalent theme was how awareness and acceptance helped. Participants discussed their self-awareness of their autistic or ADHD needs developing throughout their experience of homelessness, several expressing the notion that earlier awareness of this would have been protective. All participants had the perception that they dealt with significant parts of their journeys alone. Most found this to be detrimental and would have welcomed specific supports. Another key theme related to journeys in and out of homelessness was traits related to autism and ADHD both contributing to participants experiencing homelessness and maintaining some difficulties while experiencing homelessness. This reflects previous themes of autism as a risk factor for experiencing homelessness found by Garratt & Flaherty (2021). Similarly, previous research has found reduced networks and social exclusion as themes in homelessness research with autistic people (Stone, Cameron & Dowling, 2022). Some participants also discussed traits and abilities such as thoroughness, resilience, and focus, which helped during their journey out of homelessness. Mairi's expression of resilience as a protective factor in her journey echoes previous research into autistic people's experience of homelessness (Stone, 2019).

Accessing and using support services

The other aspect of the most prevalent theme was awareness and acceptance of autism and ADHD amongst services. Some spoke of services whose awareness was helpful, while a more common perception was that services could improve awareness. This echoed the theme revealed by Stone, Cameron & Dowling (2022) of low awareness of autism amongst homelessness services. Half of the participants found that their experience of using services was made much more difficult by the associated logistical demands. This may be linked to executive functioning impairments in autism and ADHD, which refer to problems with higher order cognitive skills of planning, attention, prioritisation, initiation, task switching and task focus (Hill, 2004; Roselló et al, 2020). Additionally, it may be the case that reading and writing comprehension may be a barrier for some with ADHD when using homelessness services. School dropout has been shown to be significantly associated with increased odds of homelessness in participants with ADHD (García Murillo et al, 2016).While not an even split, two of the three participants who expressed difficulty with logistics were just diagnosed with ADHD alone, and the other one was diagnosed both autistic and with ADHD. Of those who reported no

significant difficulty or did not mention logistics, they were either both autistic and had ADHD or just autistic.

Comparison with existing literature

The results share similarities with other qualitative explorations of autistic peoples' experiences of homelessness. Similar to this sample, most participants in Stone, Cameron & Dowling's study did not have a formal diagnosis when they first experienced homelessness. Participants in both studies expressed how this could lead to misinterpretation of their behaviour amongst services. Even when participants in their study shared clinical diagnoses with local authorities, this did not always improve access to support, thought to be hindered by their ability to articulate their needs and services' autism awareness. Alongside services' awareness and acceptance of autism, some of the participants in this study expressed a lack of self-awareness/acceptance when they first experienced homelessness. Together, this suggests that services' autism or ADHD awareness alone will not reduce barriers to support. Other similarities include autistic participants in both samples experiencing problem substance use, abuse in intimate relationships, being reluctant to seek help, or being kicked out by friends of family when sofa-surfing. Participants in both samples also expressed difficulty accessing and navigating supports and hostel environments being detrimental to mental health.

The theme of going it alone in this study also represented similarities to those found by Garratt & Flaherty (2021), who reported that none of their five autistic participants had strong social networks. They also discussed autism as an additional risk factor for homelessness, which reflects the findings here that several participants thought aspects of being autistic or having ADHD was causal in their first experience of homelessness. Comparison of results to ADHD literature is limited by all ADHD studies in homelessness being quantitative. Although, there were some risk factors reported by participants with ADHD that have been noted as risk factors for homelessness in previous literature. For example, three participants with ADHD also reported depression, a significant correlate of ADHD youth experiencing homelessness (Narendorf et al, 2017). Substance use, also reported by three participants with ADHD, has also been identified as a risk factor associated with homelessness in people with ADHD (Lomas & Gartside, 1997; Hesse & Thiesen, 2013 García Murillo et al, 2016).

Wider contexts

Scottish housing policy, up until recently, asked social housing applicants for a 'local connection' which improves the likelihood of attaining local social housing. This connection could be a family member living in the council area, a work connection, applicants having lived in the area for at least six months or other reasonable connections. This changed in November 2022, with people being eligible to apply for housing in the local authority they present in without a local connection (Homeless Persons Order, 2022). Five participants in this study experienced homelessness prior to this policy change, with one noting it as an obstacle to gaining housing. As alluded to in the results, many autistic people or people with ADHD may have relational difficulties with their families and limited social networks, reducing their chance of having a local connection and impacting their housing opportunities. This change in policy will hopefully reduce the likelihood of social difficulties contributing to housing difficulties.

Regarding the fact that most participants were undiagnosed when homeless; this could indicate undiagnosed autism and ADHD as a risk factor for homelessness. However, this cannot be conclusive. Often, diagnosis of mental health or neurodevelopmental conditions is provided in the context of support services. It may be that being supported by services is the protective factor rather than diagnoses. Without further research, it cannot be concluded whether undiagnosed ADHD or autism is any greater a risk factor than other undiagnosed conditions.

Strengths & limitations

This is the first qualitative exploration of experiences of homelessness amongst people with ADHD. While recent research has begun to explore these experiences amongst autistic participants, this study has addressed a gap in the literature relating to people with ADHD's experience of homelessness. This study builds upon recent research highlighting autistic strengths of resilience and self-advocacy in relation to homelessness by exploring participants protective traits such as thoroughness, focus and resilience (Stone, 2019; Stone, Cameron & Dowling, 2022). The inclusion of self-identification and various types of homelessness (sofa-surfing, street-living, hostels) increases the generalisation of findings to a wider population. Most participants being currently housed allowed for exploration of pathways out of homelessness and what helped in their journeys in addition to barriers faced when experiencing homelessness.

Generalisation of findings may be limited by only having recruited participants within Scotland; with most participants experiencing homelessness in the same city. Recruitment was limited in this way due to the time and resource constraints of the project, but also as a way to ensure as much as possible that participants' perceptions were based on services operating within the same sociocultural and policy context. Due to time limits, interviews didn't address trauma explicitly and focussed more on autism, ADHD and circumstances around the time of homelessness. Trauma and adverse childhood experiences are highly prevalent in homeless populations and warrant awareness in research and service provision (Fitzpatrick, Bramley & Johnsen, 2013; Bramley et al, 2019). It is hoped that these findings will be considered alongside, not in place of, research into trauma and homelessness. As Mairi said; it's part of the picture but may not be "the whole picture" for many. Possible risk factors were indicated by participants such as problem substance use and relational conflict. As the focus of this project was not on identifying risk factors and more focussed on participants' perceptions of their journeys and support form services, these potential risk factors were not explored in detail. Future research can identify these and explore their mechanisms.

Implications & conclusions

Given the heightened prevalence of ADHD and autism amongst those experiencing homelessness indicated in research (Salavera et al, 2014; Cauce et al, 2000: Churchard et al, 2019; Kargas et al, 2019), it is possible that many people are not having their needs met. Given the prevalence of the theme of awareness and acceptance across all participants, increased awareness and acceptance of ADHD and autism could improve relationships between services and those they are supporting. This would require gaining an understanding of existing levels of awareness of autism and ADHD amongst frontline workers in services before using this information to provide awareness training. Some participants expressed how their strengths related to thoroughness, affinity for research, and resilience helped them navigate the logistics of exiting homelessness. While not all explicitly related these strengths to autism or ADHD, most did. Several participants described their perception that services appeared unwilling to address challenging issues in relation to autism and ADHD due to the perceived complexity and costs. Training incorporating both the strengths and difficulties of these conditions will facilitate the

adoption of a strengths-based approach, improving relationships amongst services and those they support while highlighting what can help.

Services may also underestimate people's support needs related to autism or ADHD, resulting in a longer and more difficult journey through homelessness. Of course, many participants themselves were unaware of being autistic or ADHD when they experienced homelessness. So it may be the case that even if services are more aware of autism or ADHD, they still may be working with undiagnosed autistic people or people with ADHD. As Sarah discussed, many services don't take self-identification seriously and diagnosis can be very lengthy. As already recommended by Stone, Cameron & Dowling (2022), less reliance amongst services on formal diagnoses to inform support would reduce barriers to appropriate support.

Given a number of participants cited undiagnosed ADHD and autism as causal in their journey into homelessness, increased recognition of ADHD and autism amongst services will prevent homelessness. This can be supported by the use of screening tools in homeless services. An autism screening tool, the DSM 5 Autistic Traits in the Homeless Interview (DATHI) has been shown to have adequate reliability and validity when used in this population (Churchard et al, 2019). The ADHD Self-Rating Scale-6 has shown that self-ratings on this tool have adequate agreement with rating by nurses with clinical experience of ADHD (Hesse & Thiessen, 2013). These tools present positive steps to increasing recognition of ADHD and autism in homeless populations in order to direct them to formal diagnosis or adapt support in the absence of diagnoses. As mentioned earlier, awareness amongst services will not reduce the barriers in itself, as some participants expressed a lack of self-awareness/acceptance, which may hinder their ability to express their needs. Having access to advocacy services which can support people to express their needs may help reduce the impact of this barrier. This recommendation is in alignment with the NICE guidance on health and social care for people experiencing homelessness, which asks services to consider the involvement of advocates when required (NICE, 2022).

Statements and Declarations

The author(s) have no competing interests to declare.

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Appendices

Appendix 1.1 PRISMA 2020 Reporting Checklist

Section and Topic	Item #	Checklist item	Location where item is reported
TITLE			
Title	1	Identify the report as a systematic review.	Title, page 11
ABSTRACT			
Abstract	2	See the PRISMA 2020 for Abstracts checklist.	Page 12
INTRODUCTION			
Rationale	3	Describe the rationale for the review in the context of existing knowledge.	Page 14
Objectives	4	Provide an explicit statement of the objective(s) or question(s) the review addresses.	Page 14
METHODS			
Eligibility criteria	5	Specify the inclusion and exclusion criteria for the review and how studies were grouped for the syntheses.	Pages 15-17
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.	Pages 14-15
Search strategy	7	Present the full search strategies for all databases, registers and websites, including any filters and limits used.	Pages 14-15 Appendix 1.3, page 75
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.	Page 15
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.	Page 16
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.	Page 16

Section and Topic	Item #	Checklist item	Location where item is reported
	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.	Page 16
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.	Pages 16-17
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)).	Page 15 & 18
	13b	Describe any methods required to prepare the data for presentation or synthesis, such as handling of missing summary statistics, or data conversions.	Page 17
	13c	Describe any methods used to tabulate or visually display results of individual studies and syntheses.	Pages 18 & 20-24. & Figure 1.1 & Tables 1.1, 1.2, 1.3
	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.	Page 17
	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).	Page 16
Certainty assessment	15	Describe any methods used to assess certainty (or confidence) in the body of evidence for an outcome.	Page 16
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.	Page 18
	16b	Cite studies that might appear to meet the inclusion criteria, but which were excluded, and explain why they were excluded.	Page 19

Section and Topic	Item #	Checklist item	Location where item is reported
Study characteristics	17	Cite each included study and present its characteristics.	Pages 20-22
Risk of bias in studies	18	Present assessments of risk of bias for each included study.	Pages 20-22
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.	Pages 20-24
Results of syntheses	20a	For each synthesis, briefly summarise the characteristics and risk of bias among contributing studies.	Pages 25-27
	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.	Pages 20-22. Table 1.1 Page 27
Certainty of evidence	22	Present assessments of certainty (or confidence) in the body of evidence for each outcome assessed.	Table 1.1 Pages 20-22. Page 27
DISCUSSION			
Discussion	23a	Provide a general interpretation of the results in the context of other evidence.	Pages 28-30
	23b	Discuss any limitations of the evidence included in the review.	Pages 29-30
	23c	Discuss any limitations of the review processes used.	Page 30
	23d	Discuss implications of the results for practice, policy, and future research.	Pages 30-31
OTHER INFORMATION			
Registration and protocol	24a	Provide registration information for the review, including register name and registration number, or state that the review was not registered.	Page 12
	24b	Indicate where the review protocol can be accessed, or state that a protocol was not prepared.	Page12
	24c	Describe and explain any amendments to information provided at registration or in the protocol.	Page 15
Support	25	Describe sources of financial or non-financial support for the review, and the role of the funders or sponsors in the	Page 12

Section and Topic	Item #	Checklist item	Location where item is reported
		review.	
Competing interests	26	Declare any competing interests of review authors.	Page 31
Availability of data, code and other materials	27	Report which of the following are publicly available and where they can be found: template data collection forms; data extracted from included studies; data used for all analyses; analytic code; any other materials used in the review.	Pages 20-24. Tables 1.1, 1.2 & 1.3. None publicly available.

From: Page MJ, McKenzie JE, Bossuyt PM, Boutron I, Hoffmann TC, Mulrow CD, et al. The PRISMA 2020 statement: an updated guideline for reporting systematic reviews. BMJ 2021;372:n71. doi: 10.1136/bmj.n71

For more information, visit: http://www.prisma-statement.org/

Appendix 1.2 PRISMA 2020 for Abstracts Checklist

Section and Topic	Item #	Checklist item	Reported (Yes/No)
TITLE			
Title	1	Identify the report as a systematic review.	Y
BACKGROUND			
Objectives	2	Provide an explicit statement of the main objective(s) or question(s) the review addresses.	Y
METHODS			
Eligibility criteria	3	Specify the inclusion and exclusion criteria for the review.	Y
Information sources	4	Specify the information sources (e.g. databases, registers) used to identify studies and the date when each was last searched.	Y
Risk of bias	5	Specify the methods used to assess risk of bias in the included studies.	Y
Synthesis of results	6	Specify the methods used to present and synthesise results.	Y
RESULTS			
Included studies	7	Give the total number of included studies and participants and summarise relevant characteristics of studies.	Y
Synthesis of results	8	Present results for main outcomes, preferably indicating the number of included studies and participants for each. If meta-analysis was done, report the summary estimate and confidence/credible interval. If comparing groups, indicate the direction of the effect (i.e. which group is favoured).	Y
DISCUSSION			
Limitations of evidence	9	Provide a brief summary of the limitations of the evidence included in the review (e.g. study risk of bias, inconsistency and imprecision).	Y
Interpretation	10	Provide a general interpretation of the results and important implications.	Y
OTHER			
Funding	11	Specify the primary source of funding for the review.	Y
Registration	12	Provide the register name and registration number.	Y

Appendix 1.3:Systematic review search strategy

OVID (Medline & Embase) Search Strategy		Ebscohost (PsycInfo & CINAHL) Search Strategy	
Line	**Search term**	**Line**	**Search term**
1	Autis*.mp.	S1	TX autis*
2	ASD.mp.	S2	TX ASD
3	ASC.mp.	S3	TX ASC
4	Asperger*.mp.	S4	TX Asperger*
5	Kanner*.mp.	S5	TX Kanner*
6	(Pervasive Developmental*).mp.	S6	TX Pervasive developmental*
7	((delay* or disorder* or impair* or disab*) adj3 (development*)).mp.	S7	TX (delay* OR disorder* OR impair* OR disab*) N3 (development*)
8	(ADHD or (attention deficit hyperactivity disorder*)).mp.	S8	TX ADHD
9	((disorder* or deficit* or impair*) adj3 (attent* or hyperactiv* or hyperkinetic* or impulsiv*or inattentiv* or overactiv*)).mp.	S9	TX attention deficit hyperactivity disorder*
10	Neuro-atypical.mp.	S10	TX (disorder* OR deficit* OR impair*) N3 (attent* OR hyperactiv* OR hyperkinetic* OR impulsiv*OR inattentiv* OR overactive*)
11	Neurodevelop*.mp.	S11	TX Neuro-atypical
12	Neurodivers*.mp.	S12	TX neurodevelop*
13	PDD-NOS.mp.	S13	TX Neurodivers*
14	Autism Spectrum Disorder/	S14	TX PDD-NOS
15	Attention Deficit Disorder with Hyperactivity/	S15	DE autism spectrum disorders
16	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 or 14 or 15	S16	DE attention deficit disorder with hyperactivity
17	(bed and breakfast).mp.	S17	S1 OR S2 OR S3 OR S4 OR S5 OR S6 OR S7 OR S8 OR S9 OR S10 OR S11 OR S12 OR S13 OR S14 OR S15 OR S16
18	(couch-surfing or couch surfing).mp.	S18	TX (bed and breakfast)
19	fixed abode.mp.	S19	TX (couch-surfing or couch surfing)
20	Homeless*.mp.	S20	TX fixed abode
21	hostel.mp.	S21	TX homeless*
22	housing.mp.	S22	TX hostel
23	((hous* or living or accom*) adj3 (marginal* or street* or supported or temporary)).mp.	S23	TX housing
24	vagrant.mp.	S24	TX ((hous* OR living OR accom*) N3 (marginal* OR street* OR supported OR temporary))
25	Homeless Persons/	S25	TX vagrant
26	17 or 18 or 19 or 20 or 21 or 22 or 23 or 24 or 25	S26	DE Homeless
27	16 and 24	S27	S18 OR S19 or S20 OR21 OR S22 OR S23 OR S24 OR S25 OR S26
28	exp animals/ not humans.sh.	S28	S17 AND S27
29	27 not 28		

Appendix Two: Major Research Project

Appendix 2.1: Participant information sheet

Open-source link to Participant information sheet

Appendix 2.2: Semi-structured interview protocol

Open-source link to Semi-structured interview protocol

Appendix 2.3: Consent form

Open-source link to Consent form

Appendix 2.4: Demographics form

Open-source link to Demographics form

Appendix 2.6: Consolidated criteria for reporting qualitative studies (COREQ): 32-item checklist

No	Item	Guide questions/description	Result
Domain 1: Research team and reflexivity			
Personal Characteristics			
1.	Interviewer/facilitator	Which author/s conducted the interview or focus group?	AG
2.	Credentials	What were the researcher's credentials? *E.g. PhD, MD*	MA (Hons)
3.	Occupation	What was their occupation at the time of the study?	Trainee Clinical Psychologist
4.	Gender	Was the researcher male or female?	Male
5.	Experience and training	What experience or training did the researcher have?	Doctorate in Clinical Psychology (pending)
Relationship with participants			
6.	Relationship established	Was a relationship established prior to study commencement?	No. Not prior to recruitment stage. Offer of introductory phone calls and Zoom to familiarise participants with researcher and project was accepted by 2/6 participants prior to data collection.
7.	Participant knowledge of the interviewer	What did the participants know about the researcher? e.*g. personal goals, reasons for doing the research*	Reason for conducting research, work background, some personal background/interests detailed in Participant Information Sheet.
8.	Interviewer characteristics	What characteristics were reported about the interviewer/facilitator? e.g. *Bias, assumptions, reasons and interests in the research topic*	Demographics (gender, ethnicity, socioeconomic), work background relating to possible bias.
Domain 2: study design			
Theoretical framework			
9.	Methodological orientation and Theory	What methodological orientation was stated to underpin the study? *e.g. grounded theory, discourse analysis, ethnography, phenomenology, content analysis*	Reflexive thematic analysis through a constructionist approach.
Participant selection			

No	Item	Guide questions/description	Result
10.	Sampling	How were participants selected? *e.g. purposive, convenience, consecutive, snowball*	Purposive
11.	Method of approach	How were participants approached? e*.g. face-to-face, telephone, mail, email*	Advertising (social media and physical posters in related services).
12.	Sample size	How many participants were in the study?	6
13.	Non-participation	How many people refused to participate or dropped out? Reasons?	17; did not meet criteria or participants ceased contact.
Setting			
14.	Setting of data collection	Where was the data collected? e*.g. home, clinic, workplace*	Council & third sector offices
15.	Presence of non-participants	Was anyone else present besides the participants and researchers?	Family member accompanied one participant.
16.	Description of sample	What are the important characteristics of the sample? *e.g. demographic data, date*	Included in tables
Data collection			
17.	Interview guide	Were questions, prompts, guides provided by the authors? Was it pilot tested?	Semi-structured interview protocol with prompts. No pilot.
18.	Repeat interviews	Were repeat interviews carried out? If yes, how many?	No
19.	Audio/visual recording	Did the research use audio or visual recording to collect the data?	Audio
20.	Field notes	Were field notes made during and/or after the interview or focus group?	Yes, during.
21.	Duration	What was the duration of the interviews or focus group?	50-90 minutes
22.	Data saturation	Was data saturation discussed?	No
23.	Transcripts returned	Were transcripts returned to participants for comment and/or correction?	On request, one participant requested. Participant was satisfied this reflected her discussion.
Domain 3: analysis and findings			
Data analysis			
24.	Number of data coders	How many data coders coded the data?	1

No	Item	Guide questions/description	Result
25.	Description of the coding tree	Did authors provide a description of the coding tree?	No
26.	Derivation of themes	Were themes identified in advance or derived from the data?	Refined through exploration of the data with research questions in mind.
27.	Software	What software, if applicable, was used to manage the data?	Nvivo12
28.	Participant checking	Did participants provide feedback on the findings?	No
Reporting			
29.	Quotations presented	Were participant quotations presented to illustrate the themes / findings? Was each quotation identified? e.*g. participant number*	Yes
30.	Data and findings consistent	Was there consistency between the data presented and the findings?	Yes
31.	Clarity of major themes	Were major themes clearly presented in the findings?	Yes
32.	Clarity of minor themes	Is there a description of diverse cases or discussion of minor themes?	Subthemes in one theme discussed.

Appendix 2.7: Final Approved MRP Proposal

Open Source Link to Final Approved MRP Proposal