

Evidence of raised levels of autistic traits in a homeless population.

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Thesis declaration form

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

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Overview

This thesis focuses on the relationship between autism spectrum condition (ASC) and homelessness.

Part 1 is a systematic review of whether and how ASC overlaps with the personality disorders (PDs) schizoid PD and schizotypal PD. There was little evidence for the nature of the overlap between schizoid PD and ASC, but some studies did suggest that having ASC may be a risk factor for the development of this PD. There was more evidence for the relationship between schizotypal PD and ASC, with studies showing that overlap was minimal, although differentiating the conditions could be challenging. The findings informed decision making in the empirical study reported in part 2 of the thesis.

Part 2 is a study into whether rates of ASC were raised in a homeless population. As there was no previous peer-reviewed research in this area the study aimed to begin to develop an evidence base. It did this by identifying what proportion of the homeless population studied presented with the full range of traits associated with ASC, rather than by seeking to make confirmed diagnoses. It found that a relatively high proportion did show strong evidence of ASC traits, which suggests that rates of this condition may be raised in this population and that further investigation is required. This was part of a joint study (Ryder, 2017) with Morag Ryder, trainee clinical psychologist also at University College London (UCL).

Part 3 is a critical appraisal of the systematic review and empirical study. It discusses the dilemmas inherent in carrying out research into homelessness, where data collection is difficult and there are many risks to validity, and argues that despite this it was important to carry out the empirical study. It also details measures taken to increase the impact of the research and reflections on how this was carried out.

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Part 1: Literature Review

The overlap of autism spectrum condition with schizoid and schizotypal personality disorders: a review of the literature.

Abstract

Objective: Differential diagnosis of autism spectrum condition (ASC) and the personality disorders (PDs) schizoid PD and schizotypal PD can be challenging. A better understanding of whether and how ASC and these two PDs overlap would allow for greater diagnostic clarity, and potentially improve the assessment and care of people with these conditions.

Method: A systematic review was carried out to investigate the extent to which symptoms of the conditions co-occurred in both clinical and non-clinical populations. The PsycINFO, PubMed and Web of Science databases were searched and 1443 potentially relevant studies were found. Of these 34 studies met inclusion criteria for the review.

Results: There was limited evidence on the nature of the relationship between ASC and schizoid PD. Consistent findings were that a substantial proportion of people with ASC met criteria for this PD, but no studies looked at rates of ASC among people with a confirmed diagnosis of schizoid PD, and no studies explored how ASC and schizoid PD inter-related in any great depth. There was more evidence concerning schizotypal PD and ASC. While this was somewhat conflicting it appears that there is little overlap between the conditions, although it can be difficult to differentiate the psychotic symptoms associated with schizotypal PD and the repetitive and restrictive behaviours associated with ASC.

Conclusions: There is a limited evidence base in this area. It seems clear that people with ASC are more likely to meet criteria for schizoid PD, but more research is required. There was stronger evidence that there is little overlap between ASC and schizotypal PD, but the conditions can be difficult to differentiate and there is a danger of mis-diagnosis.

Introduction

Autism spectrum condition (ASC)¹ was first identified in the mid-20th century, but as there is no reliable biomarker for this condition (Ruggeri, Sarkans, Schumann, & Persico, 2014) its diagnosis continues to rely on behavioural criteria which can be challenging to assess. Differentiating it from other conditions can be problematic, and this is particularly the case with schizoid personality disorder and schizotypal personality disorder. These are both characterised by social and behavioural difficulties which are similar to some of the symptoms of autism. This review will examine whether or not autism overlaps with either of these conditions, and if so what the nature of the overlap is.

ASC is a neurodevelopmental condition that emerges in infancy and early childhood. It is characterised by social deficits, and also restrictive and repetitive behaviours (RRBs) such as inflexibility, very fixated interests, and sensory differences (American Psychiatric Association, 2013). It has a population prevalence of about 1% and is associated with poor outcomes in many areas (Howlin & Moss, 2012; Steinhausen, Mohr Jensen, & Lauritsen, 2016).

Personality disorders (PDs) are defined by difficulties with managing emotions and relating to others (American Psychiatric Association, 2013). Schizoid PD and schizotypal PD are both characterised by similar social deficits and flat affect, the main point of differentiation between them is that schizotypal PD is also characterised by milder variants of the positive and disorganised symptoms of schizophrenia (Chemerinski, Triebwasser, Roussos, & Siever, 2013). Table 1 lists the diagnostic criteria for both PDs. The degree of similarity between schizoid and schizotypal PD has been recognised by many experts in the field (eg. Krueger et al., 2015), and it has even been suggested that schizoid PD might be

¹ Throughout this paper I will use the term autism spectrum condition rather than autism spectrum disorder as used in the DSM-5 (American Psychiatric Association, 2013), although these do refer to the same diagnostic entity. This follows the recommendation of Lai and Baron-Cohen (2015) who argue that 'condition' is more neutral and respectful, and less stigmatising.

better considered as a mild variant of schizotypal PD (Triebwasser, Chemerinski, Roussos, & Siever, 2012). These two PDs are therefore considered jointly in this review as they share so many features in common.

Table 1: *DSM-5 diagnostic criteria for schizoid PD and schizotypal PD*

Condition	DSM-5 diagnostic criteria
Schizoid PD	<p>A pervasive pattern of detachment from social relationships and a restricted range of expression of emotions in interpersonal settings, beginning by early adulthood and present in a variety of contexts, as indicated by four (or more) of the following:</p> <ol style="list-style-type: none"> 1. Neither desires nor enjoys close relationships, including being part of a family. 2. Almost always chooses solitary activities. 3. Has little, if any, interest in having sexual experiences with another person. 4. Takes pleasure in few, if any, activities. 5. Lacks close friends or confidants other than first-degree relatives. 6. Appears indifferent to the praise or criticism of others. 7. Shows emotional coldness, detachment, or flattened affectivity.
Schizotypal PD	<p>A pervasive pattern of social and interpersonal deficits marked by acute discomfort with, and reduced capacity for, close relationships as well as by cognitive or perceptual distortions and eccentricities of behaviour, beginning by early adulthood and present in a variety of contexts, as indicated by five (or more) of the following:</p> <ol style="list-style-type: none"> 1. Ideas of reference (excluding delusions of reference). 2. Odd beliefs or magical thinking that influences behaviour and is inconsistent with subcultural norms (e.g., superstitiousness, belief in clairvoyance, telepathy, or “sixth sense”; in children and adolescents, bizarre fantasies or preoccupations). 3. Unusual perceptual experiences, including bodily illusions. 4. Odd thinking and speech (e.g., vague, circumstantial, metaphorical, overelaborate, or stereotyped). 5. Suspiciousness or paranoid ideation. 6. Inappropriate or constricted affect. 7. Behaviour or appearance that is odd, eccentric, or peculiar. 8. Lack of close friends or confidants other than first-degree relatives. 9. Excessive social anxiety that does not diminish with familiarity and tends to be associated with paranoid fears rather than negative judgments about self.

This Review’s Conceptualisation of Overlap

The social deficits seen in both schizoid PD and schizotypal PD, combined with unusual behaviours, mean that there is much apparent overlap with ASC. This is recognised in the DSM-5 and earlier versions of this manual, as criteria for both PDs state that ASC should be ruled out before a diagnosis is made (American Psychiatric Association, 2000, 2013). However, experts in the field of ASC note that making this differential diagnosis can be very challenging (Lai & Baron-Cohen, 2015). This has serious implications, as the type of

care needed by someone with ASC might be quite different to the type of care given to someone with either of these PDs.

This review considers five ways in which the overlap between ASC and schizoid PD or schizotypal PD can be conceptualised, on a continuum from only trivial overlap to total overlap. The first possibility is that DSM-5 is correct and they are distinct conditions, which if measured properly can be differentiated. The second is that they are distinct conditions, but some or all symptoms manifest in the same way and differentiation is challenging or in some cases impossible. The third is that they are distinct conditions, but ASC is a risk factor for the development of either of these PDs (as ASC is well evidenced to be a condition which emerges early in development having any PD could not be a risk factor for the development of ASC). The fourth is that they are distinct conditions, but they have a shared aetiology which leads to high co-morbidity. The fifth is that one or both of these PD is not a distinct condition to ASC, but different approaches to diagnosis lead to them being inappropriately distinguished.

Hypotheses About How and Where Overlap May Occur

This review has a number of hypotheses about how and where overlap between the conditions might occur. At a more general level the potential overlap between ASC and both PDs relates to underlying questions about the distinction the DSM system makes between neurodevelopment and personality development. Neurodevelopmental conditions such as ASC are generally characterised by early onset and deficits are related to differences at a neural level (O’Hearn, Asato, Ordaz, & Luna, 2008). PDs are by contrast not diagnosed until much later, and it is thought that they arise at least partly in relation to psychosocial factors (Livesley, Jang, Jackson, & Vernon, 1993). However, processes affected by ASC are thought to include mentalizing, self-perception, self-control, and interpersonal skills (David et al., 2008; Lai & Baron-Cohen, 2015). Impairments in these will affect the ability of the person to regulate themselves and interact successfully with others,

and as such would be expected to impact on their personality development. Researchers have also identified that people with some PDs, who do not have a neurodevelopmental diagnosis, still demonstrate neurocognitive problems which might suggest neurodevelopmental difficulties (Burgess, 1992; Dinn & Harris, 2000). It is therefore unclear whether the broad areas of neurodevelopment and personality development should be as clearly demarcated as they are in the DSM-5, and this makes it more likely that the overlap between ASC and either schizoid PD or schizotypal PD may be substantial. If the neurodevelopmental processes behind ASC do affect personality development this may mean that having ASC is a risk factor for having either of the PDs. It could even be that the overlap is total and people with either of the PDs actually have ASC which has not been recognised in childhood.

This review will focus on a number of areas which seem likely to provide evidence of whether or not the conditions do overlap. The withdrawal and reduced affect of schizoid PD shows clear similarities with ASC in terms of social deficits, but it seems that the RRBs characteristic of ASC may allow differentiation as these are not a feature of the diagnostic criteria for schizoid PD. We will therefore examine whether schizoid PD and ASC can be distinguished on the basis of RRBs. Another key question is whether the social deficits that characterise both conditions can be differentiated, as this will provide evidence as to whether they are truly distinct conditions or whether they can co-occur in some fashion.

Social deficits are also a central part of diagnostic criteria for schizotypal PD, and whether or not these deficits overlap with those seen in ASC will be explored. The positive and disorganised symptoms of schizotypal PD also bear a marked resemblance to ASC diagnostic criteria beyond social deficits, in that they emphasise odd and eccentric behaviours, preoccupations, and stereotyped speech (American Psychiatric Association, 2013). Therefore a question for the review is whether the positive and disorganised symptoms of schizotypal PD can be differentiated from the RRBs seen in ASC.

Aims and Scope of This Review

This review will examine the overlap between ASC and the two PDs. There have been no previous systematic reviews in this particular area, with other researchers looking at differential diagnosis of ASC in general with little specific information about either schizoid PD or schizotypal PD (Lehnhardt et al., 2013; Takara, Kondo, & Kuba, 2015). This review will therefore provide evidence about the exact nature of any overlap.

There are a range of studies which will be relevant to this research question. These include studies into the prevalence of either of the two PDs among people with ASC, and prevalence of ASC among people with either of the two PDs. These will help show whether or not there is evidence of any kind of overlap at a diagnostic level. Also relevant are studies which focus on the occurrence of traits of one condition among people with a confirmed diagnosis of the other (ie. schizoid or schizotypal traits among people with ASC). These will provide information as to whether there are traits and symptoms which do seem to be shared between the conditions. Both ASC and PDs in general are thought to be dimensional constructs (Dell’Osso et al., 2016; Widiger, 2011), so studies in non-clinical populations which look at the inter-relation of traits of ASC and either of the PDs will also be included. These will provide evidence as to whether traits do or do not co-occur. All these studies will provide evidence as to whether there is any degree of overlap between ASC and either schizoid PD or schizotypal PD, and if so what the nature of that overlap is.

Method

Search Strategy

Articles were identified by (a) searching PsycINFO, PubMed and Web of Science electronic databases and (b) screening for references in relevant articles. Year limits were set to after 1994, as this was the year when DSM-IV (American Psychiatric Association, 1994) was published and ICD-10 (World Health Organization, 1992) was put into use, and a greater degree of consensus was reached on criteria for diagnosing ASC. These criteria are

much more similar to current criteria for ASC than pre-1994 criteria, so the findings of this review should be more generalisable to current practice.

In this review ASC refers to any of the diagnoses previously listed as distinct categories in DSM-IV, which were autistic disorder, Asperger’s disorder, childhood disintegrative disorder and pervasive developmental disorder not otherwise specified (PDD-NOS). In DSM-5 these are now all included in the overall category autism spectrum disorder, as the current consensus is that it is more valid to consider these diagnoses as all being part of one autistic spectrum (American Psychiatric Association, 2013).

Search Terms

The search focused on literature about the following two areas: 1) schizoid personality disorder / schizotypal personality disorder and 2) autism spectrum condition.

Table 2: *Search terms for first search*

Any of following terms for schizoid PD / schizotypal PD (Combined with “OR”)	Combined with “AND”	Any of following terms for autistic spectrum condition (Combined with “OR”)
Schizoid personality disorder/ Schizotypal personality disorder/ schizotyp* schizoid*		Autism spectrum disorders/ autis* asperger* HFA ASC ASD "pervasive developmental disorder*" PDD

Note: Phrase ending with / indicates that Medical Subject Heading term was used.
* Indicates that search was for multiple endings on truncated word.
Text in quotation marks indicates that specific phrases were searched for.

Two searches were carried out, and these differed in the terms they used for the PD part of the search. The first search focussed specifically on terms relating to schizoid PD and/or schizotypal PD. The second search used terms for PD in general. This second search was to identify any papers which focussed on all PDs and would not have been captured by the initial search, but which did report on schizoid PD and/or schizotypal PD.

Scoping the literature identified appropriate search terms. Table 2 shows the terms for the first search, table 3 the terms for the second search.

Table 3: search terms for second search

Any of following terms for personality disorder (Combined with "OR")	Combined with "AND"	Any of following terms for autistic spectrum condition (Combined with "OR")
Personality disorders/ "personality disorder*"		Autism spectrum disorders/ autis* asperger* HFA ASC ASD "pervasive developmental disorder*" PDD

Note: Phrase ending with / indicates that Medical Subject Heading term was used.
 * Indicates that search was for multiple endings on truncated word.
 Text in quotation marks indicates that specific phrases were searched for.

Selection Strategy

Titles and abstracts for all articles were screened by the author and were evaluated against the following basic inclusion criteria:

- It had human subjects.
- It was written in English.
- It was published in a peer-reviewed journal.
- It was published in or after 1994.

If the study met these criteria it was evaluated for whether it fit into one of the following categories:

- It measured prevalence of schizoid PD and/or schizotypal PD in a population with a diagnosis of ASC, using at least one measure of schizoid PD or schizotypal PD with satisfactory psychometric properties. Satisfactory psychometric properties were defined as published evidence of reliability and validity.
- It measured prevalence of ASC in a population with a diagnosis of schizoid PD or schizotypal PD, using at least one ASC measure with satisfactory psychometric properties.

- It measured schizoid PD and/or schizotypal PD traits or symptoms in a population with a diagnosis of ASC, using at least one measure of schizoid PD or schizotypal PD with satisfactory psychometric properties.
- It measured ASC traits or symptoms in a population with a diagnosis of schizoid PD or schizotypal PD, using at least one ASC measure with satisfactory psychometric properties.
- It investigated associations between traits or symptoms of both ASC and schizoid PD and/or schizotypal PD in a non-clinical population. using at least one measure of ASC with satisfactory psychometric properties and one measure of schizoid PD and/or schizotypal PD with satisfactory psychometric properties.

Selection Process and Study Evaluation

The searches identified studies with at least one search term from each of the two areas in the title, abstract or keywords. The first search on PsycINFO, PubMed and Web of Science found 280, 145 and 227 results respectively. The second search on PsycINFO, PubMed and Web of Science found 649, 470 and 412 results respectively. After overlapping results were removed there were 1443 papers to evaluate. Figure 1 shows the selection process.

Given the wide range of studies included in the search there was no one formal tool for quality appraisal which would have been appropriate, but the quality of studies was critically evaluated throughout.

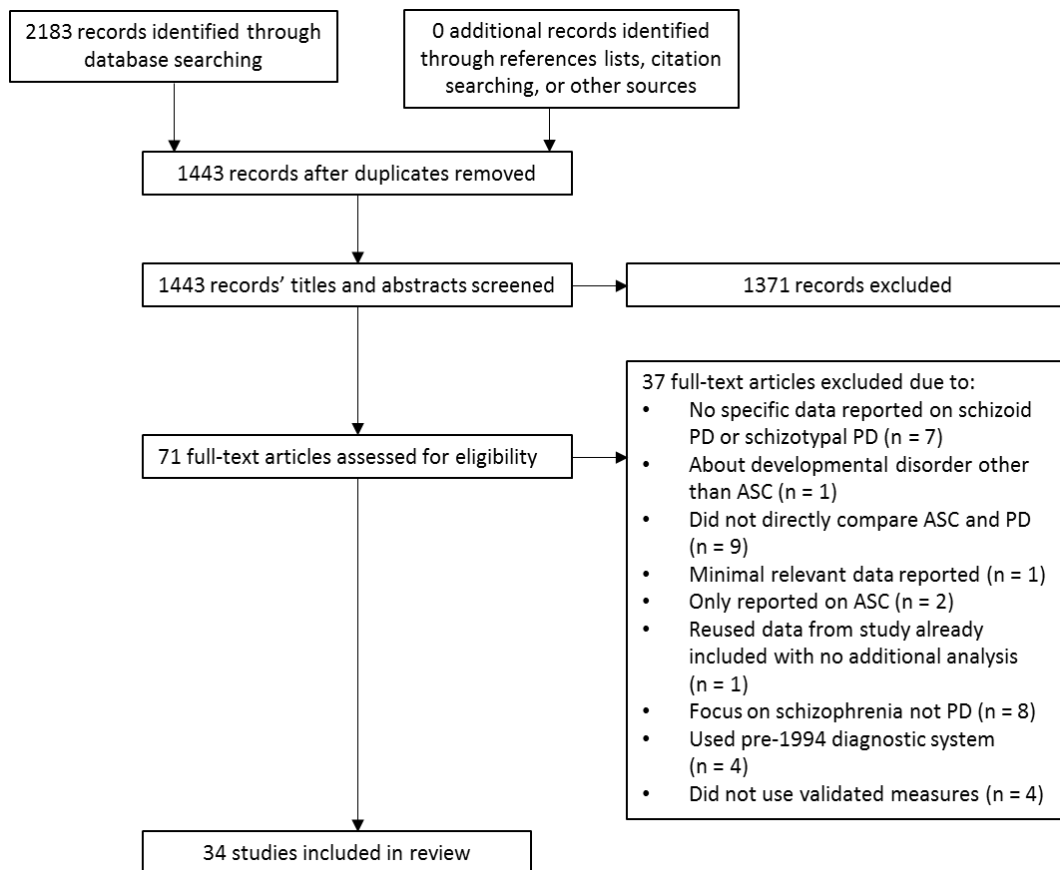


Figure 1: Flow chart of study selection process

Results

Measures Used in Studies

A large number of different measures were used in the studies examined in this review. For ease of reference details of these measures have been summarised in tables 4 and 5.

Table 4: *ASC-related measures used in studies*

Measure	Purpose	Direct or informant	Process	Type of results	NICE approved
Autism Diagnostic Interview-Revised (ADI-R; Lord, Rutter, & Le Couteur, 1994)	Diagnosis of ASC	Informant	Interview about developmental history and current presentation	Scores for following ASC related domains: communication and language; quality of reciprocal social interaction; restricted and repetitive, stereotyped interests and behaviours	For diagnosis
Autism Diagnostic Observation Schedule (ADOS; Lord et al., 2000)	Diagnosis of ASC	Direct	Structured activities to assess ASC related behaviours	Overall score indicates likelihood of presence of ASC	For diagnosis
Autism-spectrum quotient (AQ; Baron-Cohen, Wheelwright, Skinner, Martin, & Clubley, 2001)	Screening and assessment of level of ASC traits	Direct	Questionnaire	Higher scores indicate higher levels of ASC traits, contains five subscales: Social skills; Communication skills; Imagination; Attention to detail; Attention switching/tolerance of change	For screening
Autism-spectrum quotient - 10 items (AQ-10; Allison, Auyeung, & Baron-Cohen, 2012)	Screening and assessment of level of ASC traits (shorter version of AQ)	Direct	Questionnaire	Higher scores indicate higher levels of ASC traits	For screening
Asperger Syndrome Diagnostic Interview (ASDI; Gillberg, Gillberg, Rastam, & Wentz, 2001)	Diagnosis of ASC	Informant	Interview about presentation	Scores indicate presence of ASC traits	For diagnosis
Asperger Syndrome and high functioning autism Screening Questionnaire (ASSQ; Ehlers & Gillberg, 1993)	Screening for ASC	Informant	Questionnaire	Cutoff scores indicate potential presence of ASC	No
Broad Autism Phenotype Questionnaire (BAPQ; Hurley, Losh, Parlier, Reznick, & Piven, 2007)	Assessment of level of ASC traits	Direct	Questionnaire	Higher scores indicate higher levels of ASC traits	No

Measure	Purpose	Direct or informant	Process	Type of results	NICE approved
Child & Adolescent Symptom Inventory-4R (CASI-4R; Gadow & Sprafkin, 2005)	Assessing symptoms of DSM-IV disorders, can be used to inform diagnosis	Informant	Questionnaire	Scores indicate whether symptoms associated with DSM-IV disorders are present, severity of symptoms, and impairment caused	No
Diagnostic Interview for Social and Communication Disorders (DISCO; Wing, Leekam, Libby, Gould, & Larcombe, 2002)	Diagnosis of ASC	Informant	Interview about developmental history and current presentation	Diagnostic algorithms indicate likelihood of presence of ASC	For diagnosis

Table 5: *Schizoid PD and schizotypal PD related measures used in studies*

Measure	Purpose	Direct or informant	Process for participant	Type of results
Child & Adolescent Symptom Inventory-4R (CASI-4R; Gadow & Sprafkin, 2005)	Assessing symptoms of psychiatric disorders, can be used to inform diagnosis	Informant	Questionnaire	Scores indicate whether symptoms associated with DSM-IV disorders are present, severity of symptoms, and impairment caused
Coolidge Personality and Neuropsychological Inventory (CPNI; Coolidge, Thede, Stewart, & Segal, 2002)	Assessment of PD, anxiety, depression, ADHD and executive functioning in children	Informant	Questionnaire	Separate scale for each disorder, with higher scores indicating higher levels of traits
International Personality Disorder Examination (IPDE; Loranger, Sartorius, Andreoli, & Berger, 1994)	Diagnosis of PD	Direct	Screening questionnaire and interview	Definite, probable, or negative diagnosis of PD
The Oxford-Liverpool Inventory of Feelings and Experiences (O-LIFE; Mason, Claridge, & Jackson, 1995)	Assessment of schizotypal traits	Direct	Questionnaire	Overall score for schizotypal PD traits, contains four factors: Unusual Experiences; Cognitive Disorganisation; Introvertive Anhedonia; Impulsive Nonconformity
The Personality Diagnostic Questionnaire (PDQ-4; Hyler, 1996)	Screening for PD	Direct	Questionnaire	Indicate likelihood of presence of individual PD
Structured Clinical Interview for DSM-IV Axis II Disorders (SCID-II; First, Gibbon, Spitzer, Williams, & Smith, 1997)	Diagnosis of PD	Direct	Interview	Diagnosis of PD
SCID-II screener (First et al., 1997)	Screening for PD	Direct	Questionnaire	Screening for PD
Structured Interview for DSM-IV Personality (SIDP-IV; Pfohl, Blum, & Zimmerman, 1997)	Diagnosis of PD	Direct	Interview	Diagnosis of PD
The Short Oxford-Liverpool Inventory of Feelings and Experiences (sO-LIFE; Mason, Linney, & Claridge, 2005)	Assessment of schizotypal traits, shorter version of O-LIFE	Direct	Questionnaire	Overall score for schizotypal PD traits, contains four factors: Unusual Experiences; Cognitive Disorganisation; Introvertive Anhedonia; Impulsive Nonconformity

Measure	Purpose	Direct or informant	Process for participant	Type of results
Schizotypal Personality Questionnaire (SPQ; Raine, 1991)	Assessment of schizotypal PD traits	Direct	Questionnaire	Overall score for schizotypal PD traits, contains three factors: positive schizotypy, negative schizotypy, disorganised schizotypy
SPQ-Brief revised (SPQ-BR; Cohen & Matthews, 2010)	Assessment of schizotypal traits, revised and shorter version of SPQ	Direct	Questionnaire	Overall score for schizotypal PD traits, contains three factors: positive schizotypy, negative schizotypy, disorganised schizotypy
SPQ-L (Wuthrich & Bates, 2005)	Assessment of schizotypal traits, version of SPQ with likert scale	Direct	Questionnaire	Overall score for schizotypal PD traits, contains three factors: positive schizotypy, negative schizotypy, disorganised schizotypy
SPQ-Revised (SPQ-R; Vollema & Hoijtink, 2000)	Assessment of schizotypal traits, revised version of SPQ	Direct	Questionnaire	Overall score for schizotypal PD traits, contains three factors: positive schizotypy, negative schizotypy, disorganised schizotypy
Temperament and Character Inventory (TCI; Cloninger, Przybeck, & Svrakic, 1993)	Measurement of personality traits	Direct	Questionnaire	Provides scores for character maturity and temperament. If character is immature this indicates probable presence of PD, and type of temperament indicates which PD.

Prevalence of Schizotypal PD and Schizoid PD in Individuals Diagnosed With ASC

Six studies were included (table 6). Higher quality studies consistently found that a relatively high proportion of people with ASC met criteria for schizoid PD. Findings were more mixed for schizotypal PD, with reasonable quality studies of equivalent methodology reporting widely varying rates.

Sampling details. All studies collected data in one or more specialist ASC or neuropsychiatric clinics, and all participants were adults.

Quality of studies. Quality was considered in terms of sampling methodology, sample size, and measures used for diagnosis of ASC and PD. Based on these criteria four studies (Anckarsater et al., 2006; Hofvander et al., 2009; Lugnegard, Hallerback, & Gillberg, 2012; Strunz et al., 2015) were of reasonable quality. These studies used measures recommended by NICE for the diagnosis of ASC, structured tools for diagnosis of a PD, and had sample sizes ranging from 47 (Anckarsater et al., 2006) to 117 (Hofvander et al., 2009). The highest quality study was Hofvander et al. (2009), as they had the largest sample size and also sampled from consecutive referrals which reduces the risk of bias. Two studies were of lower quality (Ketelaars et al., 2008; Soderstrom, Rastam, & Gillberg, 2002). Ketelaars et al. (2008) used validated measures for ASC and the two PDs, but had a very small sample size of 15. Soderstrom et al. (2002) did not report using any measures recommended by NICE for the diagnosis of ASC, only used a patient-completed questionnaire for the PD diagnosis, and had a relatively small sample of 31. All studies were in clinical settings which may have increased rates of psychiatric co-morbidity.

Findings. All studies apart from Soderstrom et al. (2002) found a relatively high proportion of people with ASC met criteria for schizoid PD, and their research was of a lower quality compared to other studies. For schizotypal PD the findings were mixed. If only better quality studies (Anckarsater et al., 2006; Hofvander et al., 2009; Lugnegard et al., 2012; Strunz et al., 2015) are considered, very similar methodologies found widely varying rates from 0% (Strunz et al., 2015) to 23.4% (Anckarsater et al., 2006).

Table 6: Summary table of studies of prevalence of schizotypal PD and schizoid PD in individuals diagnosed with ASC

Study	n	Country	Sample and recruitment details	Method for assessing ASC and (diagnostic criteria)	Method for assessing PD and (diagnostic criteria)	Prevalence
Anckarsater et al., 2006	47	Sweden	Consecutive referrals to adult neuropsychiatric clinic	Clinical assessment, record review, informant interview where possible. ASSQ ASDI (DSM-IV)	Clinical assessment, record review, informant interview where possible TCI SCID-II (DSM-IV)	Schizoid: 31.9% Schizotypal: 23.4%
Hofvander et al., 2009	117	France and Sweden	Consecutive referrals to adult ASC clinic	Clinical assessment, record review, informant interview where possible. ASDI for 87% of subjects (DSM-IV / Gillberg & Gillberg (1989) criteria for AS)	81% of subjects SCID-II 15% structured DSM-IV based clinical interview 4% not assessed (DSM-IV)	Schizoid: 21% Schizotypal: 13%
Ketelaars et al., 2008	15	Netherlands	Patients assessed as adults at ASC clinic	Semi-structured interview with parents, clinical assessment. ADI-R ADOS-G (DSM-IV)	IPDE (DSM-IV)	Schizoid: 20% of subjects complete or partial diagnosis Schizotypal: 6.7% of subjects partial diagnosis

Study	<i>n</i>	Country	Sample and recruitment details	Method for assessing ASC and (diagnostic criteria)	Method for assessing PD and (diagnostic criteria)	Prevalence
Lugnegard et al., 2012	54	Sweden	Patients known to adult ASC clinic	Previous diagnosis by ASC clinic. 83% DISCO interview with close relative. (DSM-IV)	SCID-II (DSM-IV)	Schizoid: 26% Schizotypal: 2%
Soderstrom et al., 2002	31	Sweden	Patients known to adult ASC clinic	Psychiatric interviews, clinical examinations, neuropsychological testing (DSM-IV / ICD-10 / (Gillberg & Gillberg (1989) criteria for AS)	TCI	Schizoid temperament type: 6.4% mild, 0% severe
Strunz et al., 2015	59	Germany	Patients known to adult ASC clinic	ADOS Semi-structured clinical interview ADI-R for parents (DSM-IV)	SCID-II (DSM-IV)	Schizoid: 36% Schizotypal: 0%

Schizotypal PD traits and Schizoid PD Traits in Individuals Diagnosed With ASC

Nine studies were included (table 7). Studies from both child and adult populations have been considered together, as while a PD should not be diagnosed until late adolescence many of the traits associated with PD are evident earlier in development (Asarnow, 2005; Cohen, Crawford, Johnson, & Kasen, 2005; Johnson et al., 2000).

All studies found raised overall levels of the traits of the PD they investigated. Studies did not investigate schizoid PD any further, but there was more in-depth investigation of schizotypal traits. Studies uniformly found that negative traits of schizotypy were raised among people with ASC, while there was less consistent evidence for whether psychotic traits were also raised in this population.

Quality of studies. Quality was considered in terms of measures used for diagnosis of ASC, sample size, and the appropriateness of any control group used. All studies used validated measures of either schizoid PD or schizotypal PD, as this was part of the inclusion criteria for the literature search. Four studies (Barneveld et al., 2011; Barneveld, de Sonnevile, van Rijn, van Engeland, & Swaab, 2013; Gadow, 2012, 2013) were of reasonable quality. These studies used measures recommended by NICE for the diagnosis of ASC, had sample sizes ranging from 57 (Barneveld et al., 2011) to 482 (Gadow, 2012), and had appropriate control groups. One study (Spek & Wouters, 2010) was of lower quality, as it used measures recommended by NICE for the diagnosis of ASC and a validated measure of schizotypal PD, but had a small sample size of 21 and no control group. Four studies (Fagel et al., 2013; Kanai et al., 2011; Rydén & Bejerot, 2008; Thede & Coolidge, 2007) were of lower quality, as while they used validated measures of the two PDs and had appropriate control groups, they did not detail the use of any NICE approved measures in their assessment of ASC.

Findings in relation to schizoid PD traits. The four studies (Gadow, 2012, 2013; Rydén & Bejerot, 2008; Thede & Coolidge, 2007) which investigated schizoid PD traits in

individuals with ASC varied in quality, but all found raised levels of these traits. Ryden and Bejerot (2008) did not find a significant difference between the ASC group and controls on their measure of schizoid traits, but as more than one third of the ASC group were above the cut-off for schizoid PD this suggests a high level of these traits in both groups.

Findings in relation to schizotypal PD traits. Seven studies (Barneveld et al., 2011, 2013; Fagel et al., 2013; Kanai et al., 2011; Rydén & Bejerot, 2008; Spek & Wouters, 2010; Thede & Coolidge, 2007) investigated schizotypal PD traits. Despite studies varying in quality they consistently found a link between ASC and raised levels of schizotypal PD traits. Barneveld et al. (2013) stated that 41% of their ASC group would have met criteria for schizotypal PD, although they gave little detail as to how they had come to this conclusion beyond reporting that a psychiatrist had given this opinion. It does not therefore seem that they followed as systematic a protocol as the prevalence studies described above.

The strongest associations between ASC and schizotypal traits was seen in the general area of social deficits. The highest positive correlations of measures of ASC were with subscales of the SPQ relating to negative schizotypy, which is the part of the schizotypy construct relating to social relationships and affect (Barneveld et al., 2011; Kanai et al., 2011; Spek & Wouters, 2010). Findings were more inconsistent for the other subscales of the SPQ, which relate to the more psychotic symptoms of schizotypal PD. One study of better quality (Barneveld et al., 2011) and one of lower quality (Kanai et al., 2011) found that positive and disorganised symptoms of schizotypal PD also correlated with symptoms of ASC; one study of lower quality contradicted this finding (Spek & Wouters, 2010). The most sophisticated statistical analysis was by Barneveld et al. (2013), and their exploratory factor analysis found that only the 'negative schizotypy' subscale loaded with any AQ subscales. This would suggest that for their sample the bulk of the association between the AQ and the SPQ was accounted for by negative aspects of schizotypy.

Table 7: Summary table of studies into schizotypal PD traits and schizoid PD traits in individuals diagnosed with ASC

Study	n	Country	Sample	Method for assessing ASC and (diagnostic criteria)	Method for assessing PD traits	Results
Barneveld et al., 2011	57	Netherlands	Adolescents aged 11-18 years from ASC clinic (<i>n</i> = 27) and community controls (<i>n</i> = 30).	Diagnostic agreement between 2 psychiatrists. ADI-R used to validate diagnosis. AQ. (DSM-IV-TR)	SPQ-R	SPQ-R score higher in ASC group than controls, both as a total and in three subscales. Within the ASC group significant correlations between total scores on AQ and SPQ-R (<i>r</i> = .38*). Also significant correlations between some AQ and SPQ subscales, largest correlations with 'negative schizotypy' SPQ subscale.
Barneveld et al., 2013	69	Netherlands	Adolescents aged 10-18 years from ASC clinic (<i>n</i> = 29) and community controls (<i>n</i> = 40)	Diagnostic agreement between 2 psychiatrists. ADI-R used to validate diagnosis. AQ. (DSM-IV-TR)	SPQ-R	SPQ scores significantly raised in ASC group (M=31.21; SD=16.8) versus controls (M=11.20; SD=7.7), $F(1,60)=31.21, p<.0001$ 41% of ASC group met criteria for schizotypal PD. In ASC group significant correlation between total scores on SPQ and AQ (<i>r</i> = .35*). Exploratory factor analysis carried out on all subscales of AQ and SPQ-R, three factors extracted explaining 83% of variance. AQ and SPQ-R items loaded onto separate factors, apart from 'negative schizotypy' subscales of SPQ-R which loaded with most AQ subscales.

Study	<i>n</i>	Country	Sample	Method for assessing ASC and (diagnostic criteria)	Method for assessing PD traits	Results
Fagel et al., 2013	811	Netherlands	Adult psychiatric outpatients (<i>n</i> = 731) and community controls (<i>n</i> = 80)	Semi-structured clinical interview, developmental history, review of medical records and child obs.	SPQ-R	People diagnosed with PDD scored significantly higher than controls on negative and disorganised subscales of SPQ-R, but not positive subscale (full statistics not reported in paper).
Gadow, 2012	482	USA	Two groups from child psychiatric clinic: ASC group (<i>n</i> = 147); controls from clinic (<i>n</i> = 335)	(DSM-IV-TR) Clinical assessment, informant interview, child observations CASI-4R ADOS (DSM-IV)	CASI-4R	ASC group had more severe schizoid symptoms than controls (large number of results reported which cannot be reproduced here).
Gadow, 2013	339	USA	2 groups of children: ASC group (<i>n</i> = 147) and psychiatry outpatient controls (<i>n</i> = 339)	Clinical assessment, informant interview, child observations CASI-4R ADOS (DSM-IV)	CASI-4R	Higher levels of schizoid personality symptoms in ASC group (large number of results reported which cannot be reproduced here).
Kanai et al., 2011	112	Japan	Adults from ASC clinic (<i>n</i> =55) and non-clinical controls (<i>n</i> =57)	Clinical interview of patient and informant. AQ (DSM-IV)	SPQ	ASC group scored significantly higher on SPQ total and all subscales than control group. In ASC group significant correlations between AQ and SPQ total, and between total AQ score and almost all SPQ subscales. Largest correlation of AQ ($r = .65^{***}$) with 'excessive social anxiety' subscale of SPQ.

Study	<i>n</i>	Country	Sample	Method for assessing ASC and (diagnostic criteria)	Method for assessing PD traits	Results
Ryden & Bejerot (2008)	115	Sweden	ASC psychiatric outpatients (<i>n</i> = 74) and psychiatry outpatient controls (<i>n</i> = 41)	Clinical assessment, informant interview ASSQ (DSM-IV)	SCID-II screen	Authors report that over a third of ASC group reached cut-off score for schizoid PD, and that over a third of ASC group reached cut-off score for schizotypal PD. ASC group were significantly more likely to score higher on measure of schizotypal PD than controls (<i>p</i> = .009), but not on measure of schizoid PD.
Spek & Wouters, 2010	21	Netherlands	Adult ASC outpatients	Evaluation of current symptomatology. ADI-R AQ (DSM-IV-TR)	SPQ	Reported on subscales of SPQ and not overall score. 'Negative schizotypy' subscale correlations: AQ social skill <i>r</i> = .462* AQ attention switching <i>r</i> = .437* AQ communication <i>r</i> = .465* Other SPQ subscales did not significantly correlate with any AQ scales.

ASC Traits in Individuals Diagnosed With Schizotypal PD

Two studies were included (table 8). Both were from the same research team and used a similar methodology, sampling from adolescents and comparing individuals with Schizotypal PD with controls on domains of the ADI-R (Lord et al., 1994). Their diagnostic procedure for schizotypal PD was of reasonable quality using a validated instrument, and the ADI-R is a psychometrically sound measure of autistic traits.

The studies were consistent with each other in raised scores on the ADI-R relative to controls on multiple domains, except for communication deficits where no significant differences were found to controls. While Esterberg et al. (2013) compared against non-clinical controls, Esterberg et al. (2008) found that scores were raised even if controls were diagnosed with another PD.

Unfortunately, the results of the ADI-R were reported in a non-standard manner. This means it is impossible to compare them against norms (Risi et al., 2006) and evaluate whether people with schizotypal PD scored as highly as on the ADI-R as people with a confirmed diagnosis of ASC, or just relatively higher than the controls in the studies.

It is unclear whether the individuals in these two studies were the same population, and the researcher has not responded to personal communications enquiring about this.

Table 8: Summary table of studies into ASC traits in individuals diagnosed with schizotypal PD

Study	<i>n</i>	Country	Sample	Method for assessing Schizotypal PD and (diagnostic criteria)	Method for assessing ASC traits	Results
Esterberg et al., 2013	77	USA	All adolescents aged 11-18 years. Two groups: schizotypal PD community sample (<i>n</i> =30) and non-clinical community controls (<i>n</i> =47).	SIDP-IV (DSM-IV)	ADI-R administered to participant's guardian	<p>Schizotypal PD group had significantly more severe scores on ADI-R domains: current social interaction; childhood social interaction; current repetitive interests and behaviors; childhood repetitive interests and behaviors.</p> <p>No significant differences on following domains: current communication deficits; childhood communication deficits.</p>
Esterberg et al., 2008	121	USA	All adolescents aged 11-18 years. Three groups: community sample of schizotypal PD (<i>n</i> = 35); No PD (<i>n</i> = 48); and Other PD (<i>n</i> = 38).	SIDP-IV (DSM-IV)	ADI-R administered to participant's guardian	<p>Schizotypal PD group had significantly higher scores than both other groups on following ADI-R domains: childhood social impairment; childhood unusual interests and behaviours; current social impairment; current unusual interests and behaviours.</p> <p>No significant difference between groups on following ADI-R domains: childhood communication; current communication.</p> <p>Autistic symptoms significantly predicted variance in total symptoms of schizotypal PD, and also negative, positive, and disorganised symptoms.</p>

Relationship Between ASC Traits and Schizotypal PD Traits or Schizoid PD traits in Non-Clinical Samples

Seventeen papers were included (table 9). These all gave measures of ASC traits and schizoid PD and/or schizotypal PD traits to a non-clinical sample, and examined the relationships between these variables.

One study looked at schizoid PD and ASC, and found an association between traits of the two conditions. The remaining 16 papers focussed on schizotypal PD and ASC, and all these studies found a relationship between schizotypal and ASC traits. However, more sophisticated methodologies found that the relationship seemed to be accounted for by shared social deficits. Positive traits of schizotypal PD, that is more psychotic traits, seemed to differentiate ASC and schizotypy.

Sampling details. Twelve studies sampled from university students. Two studies used a community sample, one study sampled professionals, and two studies used a mixed sample of university students and professionals.

Quality of studies. All studies were of similar quality, in that they had taken medium to large samples from non-clinical populations using validated measures. The smallest sample size was 70 (Rawlings & Locarnini, 2008) and the largest was 921 (Sierro, Rossier, & Mohr, 2016).

Findings for schizoid traits. Wainer et al. (2011) found that their measure of the autism phenotype correlated positively with a measure of schizoid traits.

Schizotypal traits: findings for simple correlational studies and regression study. Nine studies (Blain, Peterman, & Park, 2016; Claridge & McDonald, 2009; Del Giudice, Angeleri, Brizio, & Elena, 2010; Rawlings & Locarnini, 2008; Rawlings, 2008; Russell-Smith, Maybery, & Bayliss, 2011; Sierro et al., 2016; Wainer, Ingersoll, & Hopwood, 2011; Wakabayashi, Baron-Cohen, & Ashwin, 2012) calculated simple correlations between measures of ASC and measures of schizotypal PD traits. All found moderate to large

positive correlations between these measures. One study (Russell-Smith, Bayliss, & Maybery, 2013) carried out a regression which found a strong association between factors measuring social deficits on the O-Life and the AQ.

Schizotypal traits: findings for controlled correlational studies. Two studies (Hurst, Nelson-Gray, Mitchell, & Kwapil, 2007; Mealey, Abbott, Byrne, & McGillivray, 2014) carried out more sophisticated analyses involving controlled correlations. They first calculated simple correlations, and replicated the results found by the simple correlational studies described above. Mealey et al. (2014) found that when correlations were controlled for the 'negative' subscale of the SPQ was the only subscale of this measure that still correlated positively with the AQ total score, although some subscales of the AQ were still correlated positively with either the 'disorganised' or 'positive' subscales of the SPQ. Hurst et al. (2007) found that after the other SPQ subscales were partialled out only the 'negative' subscale explained more than a small amount of variance in the AQ total score.

Schizotypal traits: findings for factor analytic and principal components analysis studies. One study (Zabelina, Condon, & Beeman, 2014) used exploratory factor analysis, two studies used principal components analysis (PCA; Del Giudice, Klimczuk, Traficante, & Maestripieri, 2014; Dinsdale, Hurd, Wakabayashi, Elliot, & Crespi, 2013), and one study carried out both a factor analysis and a PCA (Ford & Crewther, 2014). All studies applied their analysis to all subscales from the AQ and variants of the SPQ rather than including individual items in the analysis.

All studies found that subscales from both scales relating to social/interpersonal areas loaded in the same direction on one factor. Subscales relating to psychotic symptoms from the SPQ and subscales relating to repetitive and restrictive behaviours (RRBs) from the AQ either loaded in opposite directions on one factor (Del Giudice et al., 2014; Dinsdale et al., 2013) or loaded onto separate factors (Ford & Crewther, 2014), suggesting that these were measuring different constructs. Factor analytic and PCA studies therefore suggested

that the positive association between the AQ and SPQ was accounted for by social/interpersonal areas.

Schizotypal traits: finding for cluster analysis study. One study (Choteau, Raynal, Goutaudier, & Chabrol, 2016) found four clusters of students on the AQ and SPQ, and one of these clusters scored highly on both measures. The authors argued that this shows that ASC and schizotypal PD can overlap. However, they only used the total SPQ score and did not investigate whether or not the 'negative' subscale was responsible for the majority of the overlap, as would be predicted given the results of other studies. No other cluster analysis studies were found.

Areas Where no Studies Were Found

No studies attempted to estimate prevalence of ASC in individuals with either schizotypal PD or schizoid PD. No studies examined ASC traits in individuals with schizoid PD.

Table 9: Summary table of studies into relationship between ASC traits and schizotypal PD traits or schizoid PD traits in non-clinical samples

Study	<i>n</i>	Country	Sample	Method for assessing ASC traits	Method for assessing PD traits	Results
Blain et al., 2016	107	USA	University students	AQ-10	SPQ	AQ-10 total significantly correlated with SPQ total ($r = 0.40^{***}$) and all SPQ subscales: positive ($r = 0.28^{**}$); negative ($r = 0.36^{***}$); disorganization ($r = 0.36^{***}$).
Choteau et al., 2016	347	France	University students	AQ	SPQ (french version)	Cluster analysis on all AQ and SPQ items, four clusters identified: low in all traits; moderate ASC traits but no schizotypal PD traits; moderate schizotypal PD traits but no ASC traits; high in both schizotypal PD and ASC traits.
Claridge & McDonald, 2009	77	UK	University students	AQ	O-LIFE	Significant correlations between 'Introvertive Anhedonia' subscale of O-LIFE and total AQ score ($r = .50^{***}$), and with 3 of 5 AQ subscales: Social skill ($r = .59^{***}$); Attention switching ($r = .031^{**}$); Communication ($r = .51^{***}$). Other correlations of O-LIFE subscales with AQ not reported.
Del Giudice et al., 2010	200	Italy	University students and professionals.	AQ (Italian version)	SPQ (Italian version)	SPQ split into two factors: 'positive' and 'negative'. AQ split into two factors: 'interpersonal' and 'attention to detail'. Large positive correlations between AQ-Interpersonal and SPQ-Negative, smaller positive correlations AQ-Interpersonal and SPQ-Negative.
Del Giudice et al., 2014	152	USA	University students and community sample	AQ	SPQ	Principal components analysis of AQ and SPQ subscales. Two components found, accounted for 51.8% of variance: PC1: 'social difficulty'. Substantial loadings from all AQ subscales except 'attention to detail'. Substantial loadings from SPQ subscales 'negative', 'disorganised', and smaller loadings from 'positive' subscales. PC2: 'autism-schizotypy axis'. Negative loading from all AQ subscales except 'attention to detail'. Positive loading from SPQ 'positive' subscale.

Study	<i>n</i>	Country	Sample	Method for assessing ASC traits	Method for assessing PD traits	Results
Dinsdale et al., 2013	605	Canada & Japan	University students	AQ	SPQ-BR	Factor analysis on all AQ and SPQ-BR subscales, found two factors: Factor 1: 'Social interest/aptitude'. Both AQ and SPQ-BR items loading in same direction. Factor 2: 'Autism-positive schizotypy axis'. AQ and SPQ-BR items loading in opposite directions.
Ford & Crewther, 2014	449	Australia	Community sample	AQ	SPQ-L	Factor analysis on all AQ and SPQ subscales. Three factors found: 1: 'Social disorganisation'. Subscales from both AQ and SPQ-L. 2: 'Perceptual oddities'. Almost all subscales from SPQ-L. 3: 'Social rigidity'. Subscales from AQ. No relationship between factors 1 and 2.
Hurst et al., 2007	607	USA	University students	AQ	SPQ	Significant correlation ($r = .47^*$) AQ total and SPQ total, and significant correlations between all subscales of SPQ, AQ total, and AQ subscales. Calculated semi-partial r^2 of AQ total and subscales of SPQ, with other SPQ subscales partialled out: only 'negative' subscale of SPQ explained more than small amount of variance ($r^2 = .209^*$) in AQ total score.
Mealey et al., 2014	144	Australia	University students	AQ	SPQ-L	Significant correlation ($r = .54^{***}$) AQ total and SPQ total. Significant correlations between all subscales of SPQ, AQ total, and some AQ subscales. After other SPQ subscales controlled for in multivariate analysis only SPQ 'Negative' factor was significantly correlated with AQ total ($r = .59^*$). In same multivariate analysis significant correlations between 4 of 5 individual AQ subscales and 'Negative' SPQ subscales, and some significant correlations with 'Positive' and 'Disorganised' SPQ subscales.

Study	<i>n</i>	Country	Sample	Method for assessing ASC traits	Method for assessing PD traits	Results
Rawlings & Locarnini, 2008	70	Australia	Professionals	AQ	O-LIFE	Significant correlation AQ total score and O-LIFE 'introvertive anhedonia' subscale ($r = 0.52^{**}$). All other AQ total correlations with O-LIFE subscales non-significant and small or very small correlations.
Rawlings, 2008	126	Australia	University students	AQ	O-LIFE	Positive correlations between 3 of 4 O-LIFE scales and AQ: Unusual experiences: $r = .32^{***}$ Cognitive disorganisation: $r = .51^{***}$ Introvertive anhedonia: $r = .62^{***}$ Impulsive nonconformity: $r = .13$
Russell-Smith et al., 2011 (2 studies reported in this paper)	Study 1: 362 Study 2: 639	Australia (same for both studies)	University students (same for both studies)	AQ (same for both studies)	Study 1: sO-LIFE Study 2: additional items from O-LIFE added to sO-LIFE	Study 1: Significant correlation AQ total score and sO-LIFE total score ($r = .46^{***}$), multiple significant positive correlations between subscales. Strongest correlation AQ social skills subscale and sO-LIFE introvertive anhedonia subscale ($r = .62^{***}$). No negative correlations between any subscales. Study 2: Significant correlation AQ total score and O-LIFE total score ($r = .51^{***}$), multiple significant positive correlations between subscales. Strongest correlation AQ social skills subscale and sO-LIFE introvertive anhedonia subscale ($r = .74^{***}$). Some negative correlations between subscales.

Study	<i>n</i>	Country	Sample	Method for assessing ASC traits	Method for assessing PD traits	Results
Russell-Smith et al., 2013	284	Australia	University students	Social skills factor of AQ	Introvertive anhedonia factor of O-LIFE	When O-LIFE:IntAnh scores and other variables relating to social deficits were entered as predictors of AQ:Social factor, O-LIFE:IntAnh was most powerful individual predictor (Beta = .50**) When AQ:Social scores and other variables relating to social deficits were entered as predictors of O-LIFE:IntAnh, AQ:Social was most powerful individual predictor (Beta = .44**).
Sierro et al., 2016	921	Switzerland	University students	AQ (French)	sO-LIFE	Significant correlation between AQ total score and sO-Life total score ($r = .419^{**}$). Large number of other correlations reported between subscales.
Wainer et al., 2011	680	USA	University students	AQ BAPQ	SPQ-BR Schizoid PD scale from PDQ-4	Factor analysis on all ASC scales to create a measure of broader autism phenotype (BAP). Significant correlations between BAP overall score and SPQ-BR ($r = .62^{**}$) and Schizoid PD scale from PDQ-4 ($r = .55^{**}$). Subscales of BAP also correlated with these scales.
Wakabayashi et al., 2012	662	Japan	University students	AQ (Japanese)	SPQ (Japanese)	Significant correlation between AQ total score and SPQ total score ($r = .483^*$). Significant correlations between all SPQ subscales and AQ, largest were positive correlations with SPQ social subscales.
Zabelina et al., 2014	100	USA	Community sample	AQ	SPQ	Exploratory factor analysis carried out: AQ and SPQ social items loaded in same direction onto one factor. Otherwise no association.

Discussion

This review investigated the overlap between ASC and schizoid PD or schizotypal PD. Diagnostic criteria for these conditions appear similar, and it is explicitly stated for both PDs that ASC should be ruled out before a diagnosis is made (American Psychiatric Association, 2013). My conceptualisation of overlap ranged from trivial overlap, where symptoms appeared similar but could be easily differentiated, to total overlap where the same underlying condition was being labelled as either ASC or one of the two PDs.

Prevalence Rates

Studies only considered prevalence of the two PDs among individuals with ASC, and not prevalence of ASC among individuals with either of the PDs. While appropriate methodologies were used sample sizes were generally rather small, which means the quality of evidence for prevalence is not strong. The results reported here should not therefore be taken as accurate estimates of what proportion of people with ASC meet criteria for either of the PDs; rather they should be considered in terms of evidence for or against overlap between the conditions.

A consistent finding was that a substantial proportion of people with ASC met criteria for schizoid PD, with estimates in better quality studies ranging from 21-36% (Hofvander et al., 2009; Strunz et al., 2015). This is only partial evidence given the lack of prevalence studies of ASC among people with schizoid PD, but it does suggest that the conditions do overlap in some fashion.

For schizotypal PD the prevalence results were much more mixed. The highest quality study (Hofvander et al., 2009) did show rates of 13%, but other studies of not substantially lower quality showed widely varying results ranging from 0% (Strunz et al., 2015) to 23.4 % (Anckarsater et al., 2006). Prevalence studies did not therefore provide consistent evidence as to whether ASC and schizotypal PD do overlap.

All prevalence studies were carried out in a clinical setting, which may have inflated the rates of the two PDs as people would be expected to have more complex presentations in these environments.

The Overlap Between Schizoid PD and ASC

Based on prevalence studies it would seem that there is a subgroup of people with ASC who meet criteria for schizoid PD. However, only a small number of other studies reported data relevant to the relationship between ASC and schizoid PD (Gadow, 2012, 2013; Rydén & Bejerot, 2008; Thede & Coolidge, 2007; Wainer et al., 2011), so it is impossible to reach any firm conclusions about the nature of the overlap between the conditions. One major problem with the evidence base is that no studies measured ASC prevalence or traits in a population of people with a confirmed diagnosis of schizoid PD. This means that we do not know whether or not people with schizoid PD do actually have raised levels of ASC traits in general, or even undiagnosed ASC.

The relatively large proportion of people with ASC who met criteria for schizoid PD suggests that there is more than trivial overlap between the conditions. Prevalence studies involved in-depth clinical interviews, and Lugnegard et al. (2012) note that they had observed clear evidence of the schizoid traits of social disinterest and detachment in their sample of people with ASC. Given the lack of more in-depth studies into schizoid traits and ASC this does not show conclusively that the same pattern of social deficits is present, but it does provide some evidence that this is the case.

According to my conceptualisation of overlap this would suggest that ASC is a risk factor for the development of schizoid PD. As schizoid traits are generally agreed to be dimensional (Triebwasser et al., 2012) it would also be expected that a much greater proportion of people with ASC would show at least some evidence of these traits. This would fit with questions that have been raised about whether neurodevelopment and personality development should be as strongly demarcated as they are in the DSM-5

(Burgess, 1992; Dinn & Harris, 2000). However, the majority of the people with ASC sampled in prevalence studies did not meet criteria for schizoid PD. Therefore, it does not seem that the schizoid traits of withdrawal and detachment are universal among people with ASC, and this suggests that the overlap between the conditions is not total.

In order to substantiate this conclusion, it would be necessary to have studies of rates of ASC and ASC traits among people with schizoid PD. It was hypothesised that the repetitive and restricted behaviours (RRBs) associated with ASC might allow differentiation between ASC and schizoid PD, but there is no evidence as to whether or not this is the case. The current evidence base does not therefore show whether or not it is possible to have schizoid PD without either an underlying diagnosis of ASC or a raised level of ASC traits.

The studies in this review have shown that there may be a subgroup of people with ASC who present with the schizoid traits of detachment, diminished affect, and lack of interest in relationships. These traits were not seen in every person with ASC, and this fits with speculation that ASC may present in a number of different ways. One model splits the ASC social phenotype into the following three categories: 'aloof', 'passive', and 'active but odd' (Borden & Ollendick, 1994). People with ASC who meet criteria for schizoid PD may fall into the 'aloof' group, and a question for future researchers is whether schizoid PD is a useful clinical category to understand this potential subgroup.

The Overlap Between Schizotypal PD and ASC

Schizotypal PD is characterised by the social deficits of schizoid PD, and also less severe variants of the psychotic symptoms associated with schizophrenia (American Psychiatric Association, 2013). There was much more evidence for the extent and nature of the overlap between schizotypal PD and ASC than there was with schizoid PD. Some of the evidence is contradictory, but tentative conclusions can be drawn. The majority of studies suggest that the overlap between the two conditions is more trivial, that it is driven by higher scores on measures of social deficits, and that the RRBs of ASC and the psychotic

symptoms of schizotypal PD can be differentiated. These studies also suggest that shared higher scores on social deficits may be the result of measurement error.

Most studies which investigated this area used measures of schizotypal PD which had separate factors relating to social deficits versus positive and disorganised symptoms, and studies which reported on individual factors showed that the social deficits factor was the most pronounced area of overlap. Studies with more sophisticated statistical analyses such as controlled correlations and factor analytic methods provided evidence that these shared social deficits explained the vast majority of total overlap between schizotypal PD and ASC (Barneveld et al., 2013; Del Giudice et al., 2014; Dinsdale et al., 2013; Ford & Crewther, 2014; Hurst et al., 2007; Mealey et al., 2014; Zabelina et al., 2014). This was the case in studies of schizotypal traits in individuals with ASC and in studies in non-clinical populations.

Shared higher scores on measures of social deficits do not provide convincing evidence that the same pattern of social deficits is present in both conditions. The questionnaires which generated this evidence include quite generic items: compare for instance the SPQ item 'I have little interest in getting to know other people,' (Raine, 1991) and the AQ item 'I enjoy meeting new people' (Baron-Cohen et al., 2001). Scoring more highly on items such as these does not show that the same exact pattern or cause of social deficits was present. Del Giudice et al. (2010), researching the diametric model of ASC and psychosis (Crespi & Badcock, 2008), suggest that quite different processes could lead to high scores for schizotypal PD and ASC on measures of social deficits. They argue that individuals with schizotypal PD may have a tendency towards hyper-mentalization, a characteristic of psychotic disorders which results in the over-interpretation of other peoples' behaviour and as a consequence feeling anxious and ill at ease in social situations. People with ASC on the other hand may show social deficits because of hypo-mentalization, a poor understanding of how others are thinking and feeling. Both groups would score

higher on measures of social deficits, but for very different reasons. While this an interesting hypothesis, the studies reviewed here do not provide any evidence for or against it. It is therefore unclear whether the social deficits seen in both conditions are actually the same types of deficits, or whether the similarity is superficial.

The majority of studies suggest that the overlap between the conditions is fairly minor. It is either trivial, with differentiation being possible on the basis of differences between psychotic symptoms and RRBs, or perhaps in some cases more difficult if the clinical picture is complex. There are however some studies which disagree with this conclusion. While two of the better-quality prevalence studies found little evidence of schizotypal PD among people with ASC (Lugnegard et al., 2012; Strunz et al., 2015), the other two studies of similar or slightly higher quality found rates of this PD to be raised (Anckarsater et al., 2006; Hofvander et al., 2009). Also, two studies which sampled people with schizotypal PD found raised scores on the ADI-R (Esterberg, Ousley, Cubells, & Walker, 2013; Esterberg et al., 2008). However, this evidence is only partial. The two studies by Esterberg et al. (2008, 2013) reported the scores of the ADI-R in such a way that comparison with norms for people with a confirmed diagnosis of ASC is impossible. It may be that people with schizotypal PD showed slightly raised scores on the ADI-R, but not to the level expected for someone with pronounced ASC traits. The conflicting evidence on prevalence studies makes it difficult to draw any firm conclusions from these, beyond it being clear that assessment of schizotypal PD in the context of ASC can be very difficult.

The finding that ASC and schizotypal PD can be differentiated disagrees with an older understanding of schizotypal PD summarised in Wolff (2000). They had carried out research into children who they described as meeting criteria for schizotypal PD (Wolff & Barlow, 1979, 1980; Wolff, 1989), and they thought these children also showed strong signs of Asperger's syndrome, the diagnosis formerly given to people with ASC with higher levels of IQ and general functioning. This would suggest a high degree of overlap between

schizotypal PD and ASC. However, it seems that much of their research was based on older diagnostic understandings, where autism was only beginning to be recognised among people with higher IQ. It is possible that their work was identifying individuals with ASC and higher IQ, but who under the diagnostic system of the time were classified as having schizotypal PD.

The findings of this review would fit better with the diametric model of ASC and psychosis (Crespi & Badcock, 2008), where these conditions are on opposite ends of a continuum. Schizotypal PD is also on this continuum, on the other side from ASC but not as far away as psychosis. According to this model, social cognition is under-developed among people with ASC and over-developed among people with schizotypal PD, leading to social deficits which may appear similar and clear divergences in terms of RRBs and positive symptoms.

Some studies included in this review carried out further investigation into this diametric model beyond what is described above. These studies investigated areas as diverse as socio-sexual behaviour (Del Giudice et al., 2010, 2014), handedness and mental rotation (Dinsdale et al., 2013), or analysed results from questionnaires in more detail than can be fully described here (Ford & Crewther, 2014; Russell-Smith et al., 2011). Findings were mixed, with some studies finding support for the diametric model (Del Giudice et al., 2010, 2014; Dinsdale et al., 2013) and some not (Ford & Crewther, 2014; Russell-Smith et al., 2011). Those studies which did not find support for the diametric model did not however show a higher degree of overlap between ASC and schizotypal PD, but instead suggested that these conditions are independent of each other rather than being on opposite ends of a spectrum. It is therefore unclear whether the diametric model of psychosis and ASC does explain the apparent lack of substantial overlap between schizotypal PD and ASC, but research into this model does not so far contradict the overall conclusions of this review.

Limitations and Further Research

When comparing ASC and schizoid PD it would have been helpful to have more studies, so findings can only be provisional. Most studies included did not focus specifically or even primarily on this PD, and the data presented was often quite minimal. This reflects the general lack of research into this PD (Triebwasser et al., 2012). Given the lack of studies of ASC prevalence and traits in people with a confirmed diagnosis of schizoid PD it was impossible to reach any firm conclusions as to the nature of the overlap between the conditions. The tentative conclusion of this review is that while there is a large degree of overlap between the conditions, this overlap does not seem to be total and the best evidence is that having ASC can lead to a person meeting criteria for schizoid PD. Further research should be carried out in this area, and if this is done it would be helpful if researchers could use a validated measure specifically of schizoid PD such as the Interpersonal Measure of Schizoid Personality Disorder (Kosson et al., 2008).

Many more studies included in this review focussed on ASC and schizotypal PD. However, there were some areas where there were either no or very few studies. This was particularly the case for rates of ASC or ASC traits among individuals with schizotypal PD. Studies in the latter area did not fully agree with the conclusions of this review, so it would be helpful to have more empirical evidence. If more research was carried out it would be beneficial if it went beyond the results of standardized questionnaires and gathered more in-depth evidence about the exact nature of symptoms, so that an assessment could be made of whether these or not these are only superficially similar. More research into the diametric model of psychosis and ASC (Crespi & Badcock, 2008) would also be helpful.

This review did not carry out a meta-analysis as study quality was in general quite low, and it was felt that carrying out meta-analysis would not provide any substantial additional information. It was clear for instance that prevalence rates varied widely in similar quality studies, and that the most substantial correlation between measures of ASC

and schizotypal PD was on social deficits. However, if study quality does improve and findings become more nuanced future reviews in this area could consider using meta-analytic methods.

Clinical Implications

With regards to diagnosis it seems probable that there could be confusion between ASC and either of the PDs in clinical practice. This is a particular risk in a general adult psychiatric setting, where there may be lack of specific knowledge about differential diagnosis of ASC. It is entirely possible that in these settings someone with ASC could receive a diagnosis of either of the PDs which would not meet their needs.

The risk of someone with either of the PDs being misdiagnosed as having ASC is present. However, a diagnosis of ASC should always rely on a developmental history (NICE, 2011, 2012). While two studies (Esterberg et al., 2013, 2008) did find reports of some ASC symptoms in childhood among a sample with schizotypal PD, they did not find the full range of ASC symptoms. This suggests that if symptoms were present in early childhood then ASC would be the most appropriate diagnosis. The current DSM-5 criteria which give ASC priority as a diagnosis over either of the PDs would therefore seem sensible (American Psychiatric Association, 2013).

The studies reviewed here suggest that the RRBs of ASC are the best point of comparison between ASC and schizotypal PD. The results of prevalence studies suggest that it can however be very difficult to differentiate between psychotic symptoms and RRBs. This may in some cases be an intractable problem, in which case a developmental history would be crucial. However, Lai and Baron-Cohen (2015) suggest that RRBs are often pedantic and logical, while psychotic symptoms are more characterised by vagueness, lack of clarity, and circumstantiality. It may be that paying attention to the specific quality of symptoms can in some cases allow the conditions to be differentiated.

While there was not any evidence as regards RRBs among people with schizoid PD, the general lack of support for the validity for this condition (Krueger et al., 2015; Triebwasser et al., 2012) suggests that if there is clear evidence of RRBs then ASC would be the most appropriate diagnosis. The finding that levels of schizoid traits are raised among people with ASC may be helpful in clinical practice, as it could allow for a finer-grained understanding of the personality profiles that people with ASC can present with.

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Part 2: Empirical Paper

Evidence of raised levels of autistic traits in a homeless population.

Abstract

Objective: Having autism spectrum condition (ASC) may raise the risk of becoming homeless, but there has been no previous peer-reviewed research into whether or not this is the case. This study sought to provide initial evidence as to whether rates of ASC might be raised in a homeless population, by investigating what proportion of a group of long-term homeless people had traits of ASC.

Method: The entire caseload of a homeless outreach team was screened ($n = 106$), excluding individuals born outside of the UK or Republic of Ireland. A new measure, the DSM-5 based ASC traits in homeless individuals semi-structured interview (DATHI), was developed. This used informant report from keyworkers to identify those individuals who showed strong signs of ASC traits. The reliability and validity of the DATHI was checked.

Results: The DATHI showed adequate reliability and correlated strongly with another measure of ASC. It identified 13 individuals who showed strong evidence of the full range of traits associated with ASC, which as a proportion of the overall sample was 12.3%, 95% CI [7.0%, 20.4%].

Conclusions: This study has provided initial evidence that rates of ASC may be raised among homeless people. A substantial proportion of this homeless population showed strong evidence of all traits associated with ASC, and this suggests that further investigation is required in this area.

Introduction

Autism spectrum condition² (ASC) may increase the risk of homelessness, as it is associated with poor adult outcomes in multiple areas (Howlin & Moss, 2012). If this is the case then this has important implications for how to work with some of the potentially most vulnerable people in our society, but there has been little research into this area. The focus of this study is on providing initial evidence as to whether there is a link between ASC and homelessness, by estimating what the prevalence of ASC is in a homeless population.

ASC is a neurodevelopmental condition characterised by difficulties in social interaction and understanding, in addition to rigidity, inflexibility and sensory differences (American Psychiatric Association, 2013). While people with ASC can lead successful lives if they are in a supportive environment which meets their needs, a very high proportion of individuals with this condition do not have good adult outcomes (Howlin & Moss, 2012; Steinhausen, Mohr Jensen, & Lauritsen, 2016). Particular difficulties adults with ASC face include attaining independence and stable living arrangements without support, and one study found that the majority of participants with ASC were still living with their parents well into adulthood (Gray et al., 2014). These poor outcomes in terms of accommodation would seem likely to raise the risk of homelessness. Poor outcomes in general could also be linked to homelessness; people with ASC on average have lower incomes and higher rates of mental health co-morbidity (Hofvander et al., 2009; Joshi et al., 2013), both of which are known risk factors for homelessness (Fazel, Geddes, & Kushel, 2014). Having ASC may therefore make a person more likely to become homeless.

Homelessness is an umbrella term which covers a range of different situations. It refers to rough sleepers, but it can also include people who have no legal title to their

² Throughout this paper I will use the term autism spectrum condition rather than autism spectrum disorder as used in the DSM-5 (American Psychiatric Association, 2013), although these do refer to the same diagnostic entity. This follows the recommendation of Lai and Baron-Cohen (2015) who argue that 'condition' is more neutral and respectful, and less stigmatising.

accommodation and do not have access to any private spaces for their social relations (Fazel et al., 2014). Homelessness has extremely negative effects on physical and mental health, with the average age of death for someone who dies while homeless being between 40-44 years (Office of the Chief Analyst, 2010). Fazel et al. (2014) detail the numerous other problems and concerns which are also observed amongst homeless people, such as high rates of physical health conditions and unintentional injuries. If having ASC does make someone more likely to become homeless, then it is necessary to document this so that this potential subset of the homeless population can be identified and appropriate resources extended to them. This may also help with the implementation of measures to help prevent people with ASC becoming homeless in the first place.

There has however been little research into whether ASC and homelessness are associated, with no work published in peer-reviewed journals. In one small-scale NHS internal audit a psychiatrist carried out interviews with a group of homeless adults, gathered information from keyworkers, and reviewed case notes (NHS Devon, 2011). They found that 50% of this group of homeless adults showed strong signs of ASC, but this does not provide a good estimate of prevalence as it appears that the group was deliberately selected as being at high risk of having this condition, and it was a very small sample of 14 people. In terms of other investigations the homelessness charity Shelter carried out qualitative research into experiences of homelessness among a group of people with ASC (Shelter Cymru, 2015), and a survey of adults with ASC in Wales found that 12% had been homeless for a period since leaving school (Evans, 2011). These all suggest that there may be a link between ASC and homelessness, but none of these pieces of work provides firm evidence for the overall scale of the problem. Key limitations are that no study has surveyed a sufficiently large population of homeless people for ASC in a way which will reduce the risk of bias, and there is not therefore a good estimate of prevalence at present.

The aim of this research is to provide an initial estimate of the prevalence of ASC in a homeless population. Gathering this data presents a number of challenges, as diagnosing ASC in adults in general can be difficult (Lai & Baron-Cohen, 2015), and homelessness complicates assessment further. The normal process of assessing ASC in adults (NICE, 2012) involves an interview, carrying out behavioural tests such as the Autism Diagnostic Observation Schedule (Lord et al., 2000), and gaining a developmental history from an informant who knew the person being assessed as a child. This is time-consuming and requires quite a high degree of engagement from the person being assessed. Difficulties with engagement are ubiquitous in work with homeless people (Kryda & Compton, 2009; Olivet, Bassuk, Elstad, Kenney, & Jassil, 2010) and gaining any kind of history can be extremely difficult in this group, as they have often lost contact with family and friends (Roll, Toro, & Ortola, 1999). Other factors such as high rates of substance misuse, mental health problems, and a disjointed social environment all also complicate the process of assessment (Fazel et al., 2014).

These are very substantial hurdles to making diagnoses which could then serve as the basis for an estimate of prevalence. Given the difficulties with engagement it would be predicted that a large proportion of the study population would not be willing to take part in the study, and people with social communication difficulties of the type seen in ASC would probably be among the most likely to refuse to participate. This would introduce a substantial level of bias into the estimate of prevalence. Carrying out a study on the model of the NHS Devon (2011) audit, but on a larger scale with a more robust sampling methodology, would therefore be impractical. There are also not any screening measures which are validated with and appropriate for use with this population (Sappok, Heinrich, & Underwood, 2015), so our research has had to take a different approach.

An alternative methodology is to use informant report rather than seeking to assess individuals in person. This was the approach of Fraser et al. (2012) who attempted to

estimate prevalence of ASC on the caseload of a youth mental health service by asking clinicians to identify which individuals they worked with showed symptoms of ASC. This does not provide as high quality information as a full ASC assessment, and the focus is not on making definitive diagnoses. The aim is rather to identify those individuals who show good evidence of traits of ASC, and thereby provide initial evidence as to what proportion of a population may have this condition. An advantage of this methodology is that it reduces sampling bias as the entire caseload can be screened.

Using this type of study design with a homeless population will begin the process of building an evidence base in this area. Our aim is therefore to screen a homeless population for traits of ASC using informant report.

Method

Procedure

We screened the entire caseload of an outreach team in southern England who work with long-term homeless people, carrying out interviews with keyworkers to identify whether or not individuals on their caseload showed evidence of traits of ASC. The entire caseload was screened to reduce bias, for example arising from cases being selected by keyworkers as being particularly likely to have ASC. The only exclusion criterion was that the person must have been born in either the UK or Republic of Ireland, as we suspect that the causes of and trajectory into homelessness for migrants (including refugees) is distinct from that of people who become homeless in their country of birth (Fitzpatrick, Johnsen, & Bramley, 2012; Phillips, 2006). As such we did not seek to investigate whether ASC could be a risk factor for homelessness in those born outside the UK and Republic of Ireland. Further, cultural and linguistic factors would also have introduced additional difficulties into the assessment of ASC traits and symptoms.

The decision to use informant report was based on ethical grounds and methodological considerations outlined in the introduction. Consultation with keyworkers

in the service where this research was based indicated that carrying out individual interviews with service users could be distressing for some, due to difficulty with engagement and building up trust and rapport with a new person. Keyworkers believed that approaching these individuals and attempting to explain our study to them would have carried the risk of increasing their distress, and could in some cases have potentially led to them disengaging from the team. Given these challenges, we anticipated that involving homeless individuals would in many cases be impractical and would likely lead to a bias in the research, with lower recruitment of those individuals with social and communication difficulties. This would impact on the validity of the study and the meaningfulness of the findings. We were informed that keyworkers built up long-lasting relationships with clients and were familiar with their presentations, and after piloting our measure we felt that they knew their clients sufficiently well to be able to provide good quality information about whether or not they had traits of ASC. We therefore decided to use informant report from keyworkers of whether or not their clients presented with traits of ASC.

We followed procedures to protect the privacy and confidentiality of the homeless people being screened. The homeless people were not identifiable to the research team: we were not told names or any other identifying information such as date of birth, and each person screened had a unique identifying number which did not provide any personal information.

Prior to conducting the interviews we provided a training workshop for the outreach team about ASC to improve the quality of reporting, and to reduce biases that could arise from variations in keyworkers' knowledge of ASC.

If a person showed good evidence of autistic traits we considered that there would be a clear need for additional support for that person. We were advised that there was an existing clinical pathway that keyworkers could use which had proved effective in the past. This pathway linked up keyworkers with a clinical psychologist who specialised in working

with adults with ASC, and therefore provided them with consultation and potentially further intervention for the adult in question. Our protocol was to advise keyworkers that they should use this pathway if a client they worked with did screen positive for ASC.

After all interviews were completed we gave the team £300 in food vouchers to thank them for their participation in the study. These were to be used to support their clients.

Ethics

This study received ethical approval from the UCL Research Ethics Committee, reference 8359/001 (see appendix 1). All keyworkers were provided with an information sheet and consent form (see appendix 2).

Participants

Nine keyworkers took part in the study. Six were female, they ranged in age from 36-57 years, and their average age was 42.6 years (SD = 6.4). The amount of time they had worked in homelessness services in general ranged from 6-26 years, with the average length of time worked being 15 years (SD = 7.3). The amount of time they had worked in their current role ranged from 2.5-8 years, with the average being 3.8 years (SD = 2.0).

Of 137 people on the caseload, 106 met inclusion criteria and were screened. For those who met criteria 85.8% were male, the average age was 48.9 years (SD = 12.7), and 87.7% were White British. Average length of homelessness was 11.7 years (SD = 8.5). The most common accommodation situations were as follows: 43.4% were street homeless; 18.9% were in a homeless hostel; 9.4% were in independent accommodation; 9.4% were in semi-independent accommodation; 8.5% were in prison. A small number of people were either in emergency accommodation, with friends and family, had disappeared for more than 90 days, or had their accommodation situation listed as 'other'. 59.4% were known to use drugs or alcohol, and 32.1% had a diagnosed mental health condition (a much higher percentage were suspected of having a mental health condition).

Measures

DSM-5 based ASC traits in homeless individuals semi-structured interview (DATHI)

Following Fraser et al. (2012), we intended to use keyworkers' knowledge of their clients to identify those homeless individuals with observable traits of ASC. Informant report has been used in homelessness studies before (Crane et al., 2005), and gathering data in this way is well established in ASC diagnosis where many measures are designed for completion by informants (Ehlers & Gillberg, 1993; Lord, Rutter, & Le Couteur, 1994). However there were not any existing informant report tools which were appropriate for use in this study, as none had been validated in this population and they also generally assumed that the informant was someone very close to the individual, such as a family member or long term friend (Sappok et al., 2015).

We therefore created a new measure for this study, the DSM-5 based ASC traits in homeless individuals semi-structured interview (DATHI). This allowed us to gather in-depth information about the individual's presentation. The DATHI was developed through the following six-step process: 1) The trainee consulted with an expert in ASC and homelessness; 2) The trainee went through the DSM-5 criteria in detail and created a draft; 3) This draft was shown to their supervisors; 4) The London Adult Autism Special Interest Group was consulted and their feedback integrated into the measure; 5) The measure was piloted with the homeless outreach team; 6) the final measure was agreed with the supervisors.

The DATHI was based on DSM-5 criteria for ASC, asking questions about the individual's behaviour to assess if they presented with autistic traits (for a copy of the DATHI and its rubric see appendix 3). The seven DSM-5 criteria are split into two groups: three are in group A, 'Persistent deficits in social communication and social interaction', and four are in group B, 'Restricted, repetitive patterns of behaviour, interests, or activities'. Table 1 has further details of these criteria.

Table 1: *DSM-5 criteria for ASC*

Group	Criterion	Examples given in manual
A: Persistent deficits in social communication and social interaction	A1: Deficits in social-emotional reciprocity	Range includes: abnormal social approach and failure of normal back-and-forth conversation; reduced sharing of interests, emotions, or affect; failure to initiate or respond to social interactions
	A2: Deficits in nonverbal communicative behaviours used for social interaction	Range includes: poorly integrated verbal and nonverbal communication; abnormalities in eye contact and body language or deficits in understanding and use of gestures; total lack of facial expressions and nonverbal communication
	A3: Deficits in developing, maintaining, and understanding relationships	Range includes: difficulties adjusting behaviour to suit various social contexts; difficulties in sharing imaginative play or in making friends; absence of interest in peers
B: Restricted, repetitive patterns of behaviour, interests, or activities	B1: Stereotyped or repetitive motor movements, use of objects, or speech	Simple motor stereotypies, lining up toys or flipping objects, echolalia, idiosyncratic phrases
	B2: Insistence on sameness, inflexible adherence to routines, or ritualized patterns or verbal nonverbal behaviour	Extreme distress at small changes, difficulties with transitions, rigid thinking patterns, greeting rituals, need to take same route or eat food every day
	B3: Highly restricted, fixated interests that are abnormal in intensity or focus	Strong attachment to or preoccupation with unusual objects, excessively circumscribed or perseverative interest
	B4: Hyper- or hyporeactivity to sensory input or unusual interests in sensory aspects of the environment	Apparent indifference to pain/temperature, adverse response to specific sounds or textures, excessive smelling or touching of objects, visual fascination with lights or movement

The DATHI had separate questions for each criterion, with questions about general areas followed by specific prompts. For example the question about eye contact in criterion A2 was followed by prompts about whether eye contact was absent, or whether the individual had a fixed gaze. Notes were taken of keyworkers' answers, and this allowed us to gather detailed information about the person's presentation in terms of autistic traits. Some questions were adapted to the homelessness context, using the information provided by the expert in ASC and homelessness and feedback from the outreach team. An example of this was that ritualised behaviour in criterion B2 was considered in relation to

sleep sites; the focus here was on whether there were unusual patterns of sleep site selection, or if the person set up their sleep site in a particularly ritualistic fashion. The interview was ordered so that measures used by the other trainee (more details of which are below), which gathered information about the homeless individual's history, were used before the DATHI. This allowed the researchers to consider contextual factors such as substance misuse when deciding whether or not the person showed evidence of autistic traits.

The DATHI was scored by rating whether ASC traits were present for each of the seven DSM-5 criteria. A range of scoring options was included to ensure that a criterion was only classified as 'Present' – that is, the person had screened as positive for this ASC trait – if there was good evidence that this was the case, as we expected that there would be a wide variety in presentations and it would be very difficult in some cases to decide whether or not a particular behaviour was a trait of ASC. The other potential scoring options were: 'Possibly present', 'Not present', 'Present but attributable to cause other than ASD', and 'Insufficient information to classify'. These were applied according to a rigorous and transparent set of rules detailed in the scoring rubric.

Scores on individual criteria were combined to make an estimated overall classification for each homeless person. To do this we followed the DSM-5 system, where to receive a diagnosis of ASC the person has to meet all three criteria in group A, and any two of the four criteria in group B. Table 2 shows how this was operationalised for the measure. This included some margin for error and allowed for judgment on the part of the rater. We considered this to be the best compromise between type 1 and type 2 error. In terms of avoiding type 1 error, to screen positive for ASC traits the individual would have to show a wide range of ASC related behaviours. In terms of avoiding type 2 error this scoring system meant that the overall presentation of the individual could be considered, and if

there was strong evidence of ASC traits in most areas they would not be screened out on the basis of a marginal score on one criterion.

Table 2: *Scoring criteria for overall classification*

Classification	Scoring criteria
Screened positive / present	Section A: <ul style="list-style-type: none"> • 3 items = present OR • At least 2 items = present AND 1 item = possibly present
	AND Section B: <ul style="list-style-type: none"> • At least 2 items = present OR • 1 item = present AND at least 2 items = possibly present
Screened marginal / possibly present	Section A: <ul style="list-style-type: none"> • At least 3 items = possibly present
	AND Section B: <ul style="list-style-type: none"> • At least 2 items = possibly present
Screened negative / not present	<ul style="list-style-type: none"> • Does not meet criteria for 'Possibly present'
Screened negative / insufficient information to classify	<ul style="list-style-type: none"> • Client is so poorly known to services that any attempt to match their behaviour to criteria would be a guess (this same classification will be seen on individual items).

Autism Spectrum Disorder in Adults Screening Questionnaire (ASDASQ)

This is an informant report screening measure for ASC, initially developed for use among psychiatric out-patients (Nylander & Gillberg, 2001). This asks questions about the person's current presentation, with answers in a yes/no format. Potential scores range from 0-9, with higher scores indicating a higher probability of having ASC. See appendix 4 for a copy of the ASDASQ.

Given the prevalence of mental health conditions among homeless people (Fazel et al., 2014) we considered that the ASDASQ could be an appropriate instrument to use with this population. In the original study detailing its development it did not show high

sensitivity or specificity (Nylander & Gillberg, 2001), but as our aim in the study was to begin the development of an evidence base in this area we decided to use it as a partial test of the criterion validity of the DATHI.

Demographic information and information about keyworker relationship

Data was gathered about the homeless peoples' age, gender, and length of time they had been homeless. We also collected data about the length of time they had known their keyworkers.

Joint project and measures used by other trainee

This was a joint project, and the other trainee carried out research into the characteristics of homeless people with elevated levels of ASC traits (Ryder, 2017). They developed measures which gathered additional data about the homeless people's history, and also about their current presentation and needs. These measures are in appendix 5. Both trainees did all parts of the screening interview including the DATHI, ASDASQ, and the additional measures detailed immediately above. The workload was split so each trainee screened approximately half of all cases on the caseload, further details are in appendix 6.

Data Analysis

Sample size calculation

This is a study designed to assess the prevalence of suspected ASC. It does not seek to test for the relationships between variables. As such, no power calculation was carried out. Instead, our main concern was to minimise sampling bias, so sample size was dictated by the need to collect data for the entire case load who met study inclusion criteria.

Reliability checking and assigning final classification

After classifications were made by the primary researchers (myself and the other trainee in this joint project) the reliability of the DATHI was investigated. This was done by selecting all those cases which had screened positive for ASC traits, all cases which had screened as marginal, and a random selection of cases which had screened negative.

The decision to over-select positive and marginal cases, rather than take a random selection from all cases screened, was made to provide a more rigorous test of the reliability of the measure. In the majority of cases screened it was clear that no or minimal traits of ASC were in evidence. For this group keyworkers reported clear evidence of social reciprocity, non-verbal communication, and little or no evidence of inflexibility and sensory needs. We expected that it would be obvious in these cases that they would not screen positive. Making a random selection of all cases screened would therefore have meant that most reliability checking was on those cases which showed very little evidence of ASC traits, and we suspected that this would have been a relatively easy test of the reliability of the DATHI. Our interest was rather in how reliably it could classify people as screening positive for ASC traits. We therefore selected an approximately equal mix of cases which screened as positive, marginal, and negative.

The procedure for reliability checking was that all written information collected in the assessment was shared with the raters, who then individually made classifications on the DATHI with no knowledge of our original classification. Scans of the DATHI, the ASDASQ, and the measures used by the other trainee were sent with the classification redacted. Reliability was checked for each of the seven DSM-5 criteria and for the overall classification made, using the scoring options detailed above. The statistic computed was Fleiss's kappa (Fleiss & Cohen, 1973). This was used instead of Cohen's kappa (Cohen, 1960) as Cohen's kappa assumes that there are only two raters, but Fleiss's kappa is robust when more raters than this are used. The reliability raters (the two supervisors of this project) are experts in the field of ASC with substantial experience of assessing this condition, and each classified half of all cases sent for reliability checking.

After reliability checking was complete, decisions were made about classification for those cases where there was a disagreement between the original classification and that made by the reliability rater.

Scoring DATHI and using the ASDASQ for criterion validity

In addition to generating an overall classification for each individual, classifications for individual criteria were converted into numerical scores. This was so the overall score on the DATHI, and overall scores in the two groups (the A and B items), could be correlated with the ASDASQ to investigate criterion validity. If an item on the DATHI screened positive (classified as 'Present') it was given a score of 2; if it screened marginal (classified as 'Possibly present') it was given a score of 1; if it screened negative (classified as 'Not present', 'Present but attributable to cause other than ASD', or 'Insufficient information to classify') it was given a score of 0.

Data analysis software

All analyses were computed in IBM SPSS Statistics version 24. Fleiss's kappa was calculated using a plug-in for SPSS downloaded from the IBM developerWorks website (IBM SPSS, 2015).

Results

Figure 1 shows the process of carrying out interviews and classification. It has details of total numbers screened, how many did not meet inclusion criteria, and when reliability checks were carried out and final classifications made.

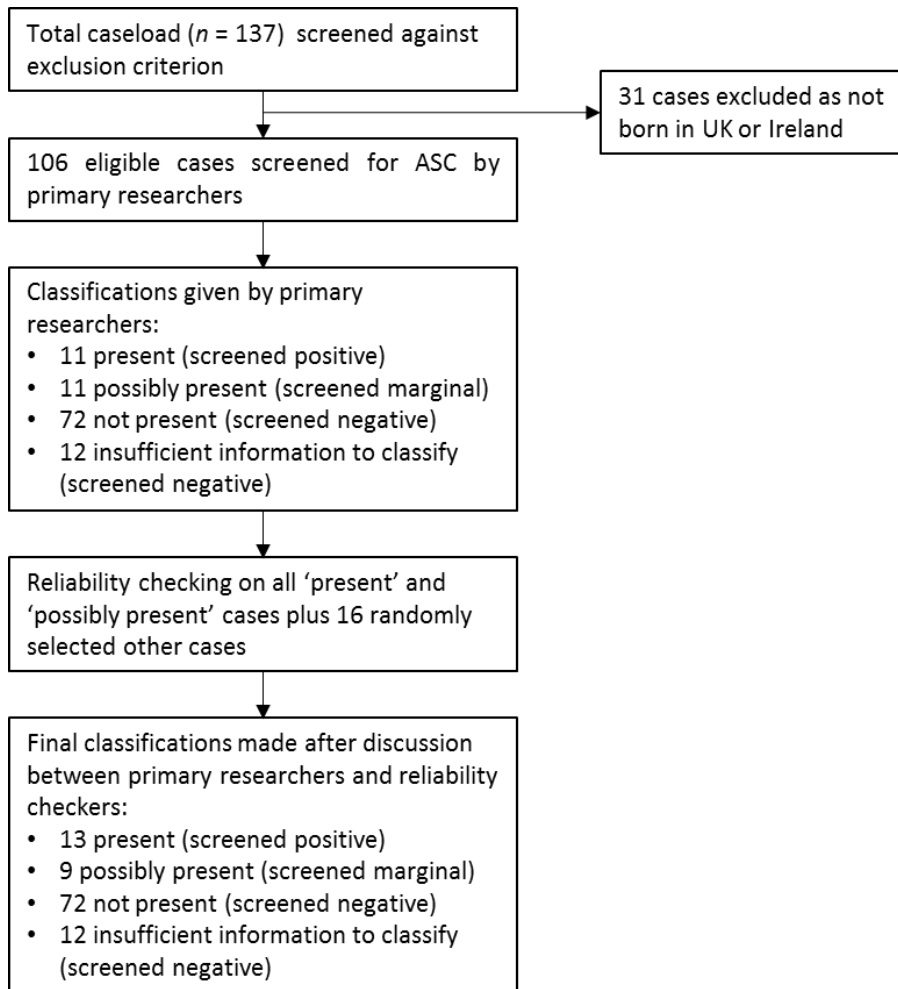


Figure 1: Screening, reliability checking, and classification process

Interviews With Keyworkers

We interviewed nine keyworkers, screening their entire individual caseloads. Keyworkers had between two and 19 cases each, with the average number of cases being 11.78 (SD = 4.52). The amount of time clients had been known by their keyworkers ranged from 0-19 years, with the average being 2.92 years (SD = 3.50 years).

DATHI Results

Findings for individual items

The DATHI provided classifications for each of the criteria making up the diagnosis of ASC. Table 3 shows average scores for each criterion, the percentage of cases who were classified into each category, and the inter-rater reliability as measured by Fleiss's kappa.

Table 3: *Details for individual criteria on DATHI*

Criterion	Average score (SD)	Percentage of cases in each classification					Fleiss's kappa ^a [95% CI]
		Present	Possibly present	Not present	Present but [...]	Insufficient information	
A1: social-emotional reciprocity	0.50 (0.78)	17.9	14.2	55.7	0.9	11.3	0.51 [0.30, 0.71]
A2: nonverbal communication	0.48 (0.73)	14.2	19.8	53.8	0.9	11.3	0.65 [0.44, 0.87]
A3: relationship	0.58 (0.79)	18.9	19.8	48.1	0	13.2	0.62 [0.40, 0.84]
B1: stereotyped / repetitive behaviours	0.33 (0.66)	10.4	12.3	66.0	0	11.3	0.64 [0.42, 0.85]
B2: inflexibility	0.39 (0.68)	11.3	16.0	57.5	1.9	13.2	0.69 [0.47, 0.90]
B3: fixated interests	0.29 (0.65)	10.4	8.5	67.9	1.9	11.3	0.64 [0.43, 0.85]
B4: sensory differences	0.25 (0.59)	7.5	10.4	69.8	0	12.3	0.65 [0.44, 0.87]

^a All results significant $p < .001$

A substantial minority showed evidence of ASC traits on every item, although average scores were low as the majority of individuals did not show any evidence of these traits. Scores were higher for criteria in group A, indicating that the sample as a whole was more likely to show evidence of social deficits rather than repetitive and restrictive behaviours. However, the average was still below one, meaning that the majority of the sample did not show even marginal evidence of any ASC trait. For every item apart from A1 Fleiss's kappa was above 0.6, indicating a substantial level of agreement between raters (Landis & Koch, 1977). For A1 the level of agreement was moderate.

Table 4: *Qualitative description of behaviours which screened as positive for ASC traits*

Criterion	Examples of behaviours considered consistent with ASC traits		
A1: Deficits in social-emotional reciprocity	Many pauses in conversation, would not say hello to someone they do not know.	Cannot say “how are you?” as finds this insincere. One-sided conversations and does not respond to a smile.	Does not initiate social interaction and displays rigid smile when greeted. Gives tangential responses and speaks in stilted sentences.
A2: Deficits in nonverbal communicative behaviors used for social interaction	Peculiar expression with eyes closed and mouth open, displays what appears to be a learnt smile.	No eye contact, blank facial expression, has to be told when interactions are finished as would not pick up on this otherwise.	Difficult to tell how they are feeling from their facial expression, does not use or pick up on body language.
A3: Deficits in developing, maintaining, and understanding relationships	Acts the same in different contexts. Difficulties in social interaction led to leaving accommodation.	No friendships or interest displayed in making friends, acts the same to everyone they meet.	No interest shown in making friends, small talk. Often rude and aggressive in interactions.
B1: Stereotyped or repetitive motor movements, use of objects, or speech	Plays with cuffs and rubs legs all the time, moves papers repeatedly in and out of envelope. Seems like there is a rhythm to these behaviours.	Repeatedly moves arms in a very particular way. Speaks in an old-fashioned way, stereotyped old-fashioned way of saying goodbye.	Described as talking like a character from a nineteenth century novel. Consistently uses unusual name for people in authority.
B2: Insistence on sameness, inflexible adherence to routines, or ritualized patterns of verbal or non-verbal behavior	Room precisely ordered with similar items placed in rows, but extremely dirty.	Items organised in rows in room. Day follows precise routine of when they sleep, watch TV. Always take same route to shop and has rules about where shopping can be placed in flat.	Possessions organised very precisely on shopping trolley, would take this on same route each day. When trolley was stolen was devastated.
B3: Highly restricted, fixated interests that are abnormal in intensity or focus	Talks a lot about food, very picky about foods, when shopping will stare at one product for a long time reading all ingredients.	Everything they buy has a particular animal on it. Likes one colour a great deal, painted their room an intense shade of this colour.	Makes lists of obscure musicians, has a large collection of broken electronics.
B4: Hyper- or hyporeactivity to sensory input or unusual interests in sensory aspects of the environment	When fire alarm went off unexpectedly seemed like they would scream, always has curtains closed, burnt hand badly but seemed under-reactive to pain (waited one week to seek treatment).	Sensitive to texture of clothing, checks before purchasing anything. Attracted by flashing light. Has TV on very loud, while in hospital would have TV screen very close to face.	Oversensitive to sound and light, does not like TV being left on when is in office with keyworker, refused own TV. Complains about noises others cannot hear.

Table 4 gives examples of the types of presentations on individual criteria which screened as positive for ASC traits. This has been included to provide information about the types of behaviours that were classified as being consistent with traits of ASC. In some instances superficial details in this table have been altered slightly to maintain the confidentiality of clients.

Overall classifications

Based on the results on individual criteria, an overall classification for each individual was made. As figure 1 shows these classifications were first checked for reliability, then a final classification agreed between the primary researchers and the reliability checkers. If all potential classification categories were included in the reliability check then the level of agreement was moderate (Landis & Koch, 1977), with a Fleiss's kappa of 0.52, 95% CI [0.31, 0.74], $p < .001$. However, the aim of this study was to identify those individuals who showed strong evidence of ASC traits. When the data was recoded so the only two classifications were 'Screened positive' or 'Screened negative', with all marginal cases in the second group, Fleiss's kappa was 0.69, 95% CI [0.37, 1.0], $p < .001$. This indicated a substantial level of agreement between raters (Landis & Koch, 1977).

Table 5: *Demographic details and length of homelessness by classification on DATHI*

DATHI classification	Gender		Mean age (SD)	Mean length of homelessness in years (SD)
	Female	Male		
Screened positive / present	2	11	53.5 (14.6)	11.8 (10.9)
Screened marginal / possibly present	0	9	50.4 (10.1)	17.8 (9.9)
Screened negative / not present	12	60	46.8 (12.4)	11.0 (8.1)
Screened negative / insufficient information to classify	1	11	55.9 (11.9)	11.4 (6.3)

After the final classification 13 of the 106 cases screened positive for ASC traits. This equates to a prevalence in this population of 12.3%, 95% CI [7.0%, 20.4%]. Nine cases were screened as showing marginal evidence of ASC traits, 72 as not showing any evidence of these traits, and 12 as being insufficiently well known to services to be given a

classification. Table 5 gives basic demographic details and length of homelessness for each classification.

Table 6 shows classifications on all criteria for each individual who screened positive for ASC traits and each individual who screened marginal for ASC traits.

Findings of ASDASQ

When the DATHI was converted into a numerical score the ASDASQ was significantly correlated with the overall score on this measure, $r = .81, p = .01$ (2-tailed). The ASDASQ was also significantly correlated with the overall score for social deficits, $r = .71, p = .01$ (2-tailed), and with the overall score for restrictive and repetitive behaviours, $r = .81, p = .01$ (2-tailed).

Table 6: Classifications on DATHI individual items for 13 cases which screened overall as positive, and 9 cases which screened overall as marginal

Classification	A1	A2	A3	B1	B2	B3	B4
Positive	●	●	●	●	●	●	●
	●	●	●	●	●	●	●
	●	●	●	●	●	●	●
	●	●	●	●	●	●	●
	●	●	●	●	●	●	●
	●	●	●	●	●	●	●
	●	●	●	●	●	●	●
	●	●	●	●	●	●	●
	●	●	●	●	●	●	●
	●	●	●	●	●	●	●
	●	●	●	●	●	●	●
	●	●	●	●	●	●	●
	●	●	●	●	●	●	●
Marginal	●	●	●	●	●	●	●
	●	●	●	●	●	●	●
	●	●	●	●	●	●	●
	●	●	●	●	●	●	●
	●	●	●	●	●	●	●
	●	●	●	●	●	●	●
	●	●	●	●	●	●	●
	●	●	●	●	●	●	●
	●	●	●	●	●	●	●

Note: blue = present; orange = possibly present; black = not present.

Exploratory Analysis of ASDASQ as a Screening Tool

Given the high correlations between the ASDASQ and the DATHI we were interested as to whether the ASDASQ could be a useful screening tool which could identify those cases which had been classified as positive or marginal on the DATHI. We initially calculated this on the basis of a score of six or above, the level defined by the measure's developers as a high score (Nylander & Gillberg, 2001). Table 7 shows how many cases which screened as positive or marginal, as opposed to cases which screened as negative, had a score of six or above on the ASDASQ. Based on these results the sensitivity of the ASDASQ was 0.63, 95% CI [0.41, 0.83] and specificity was 0.98, 95% CI [0.92, 1.0]. In this sample, the positive predictive value was 0.88, 95% CI [0.63, 0.97] and the negative predictive value was 0.91, 95% CI [0.85, 0.95].

Table 7: *Sensitivity and specificity data when cut-off score of 6 used*

ASDASQ score	Classification	
	Screened negative	Screened marginal or positive
Less than 6	82	8
6 or greater	2	14

Given the relatively low scores for sensitivity if a cut-off of six was used, we explored whether a lower cut-off could provide better discrimination. A cut-off point of four was found to maximise sensitivity and specificity. Table 8 shows results for this lower cut-off point. Based on these results the sensitivity of the ASDASQ was 0.86, 95% CI [0.65, 0.97] and specificity was 0.87, 95% CI [0.78, 0.93]. In the current sample, the positive predictive value was 0.63, 95% CI [0.49, 0.75] and the negative predictive value was 0.96, 95% CI [0.89, 0.99].

Table 8: *Sensitivity and specificity data when cut-off score of 4 used*

ASDASQ score	Classification	
	Screened negative	Screened marginal or positive
Less than 4	73	3
4 or greater	11	19

Discussion

Having ASC may increase the risk of becoming homeless, but there has been no previous peer-reviewed research into this area. This study gathered initial evidence as to whether rates of ASC are raised among homeless people. The DATHI, a new measure developed for this study, was used to screen a population of long-term homeless people for autistic traits. The proportion of the sample classified as having the full range of traits associated with ASC was 12.3%, which is substantially higher than the general population prevalence of 1% (Brugha et al., 2016). Rates of ASC may therefore be raised in this homeless population, and it seems clear that further investigation is required into links between ASC and homelessness in general.

Reliability and Validity of DATHI

The prevalence finding is based on the DATHI, a semi-structured interview developed specifically for this study. Given this novel methodology it is important to consider initial findings on whether the results of the measure are reliable and valid.

The DATHI provided classifications for all individual criteria for ASC in the DSM-5, and also an overall classification for whether the person screened positive for ASC traits. For all but one of the individual criteria the level of agreement was substantial, with the 'social-emotional reciprocity' criterion showing a moderate level of agreement.

For the overall classification the level of agreement was moderate if all potential classifications were included, but substantial if agreement was calculated for whether or not someone screened as positive for ASC traits. The latter reliability analysis was carried out because the aim of the DATHI was ultimately to identify those individuals who showed good evidence of ASC traits. The reliability was lower in the first analysis because there was more disagreement about whether or not individuals showed marginal evidence of ASC traits.

One important consideration is that the reliability analysis was carried out on a sample deliberately selected to be a stronger test of reliability. All cases which were screened as positive or marginal by the primary researchers were included, in addition to a random selection of other cases. If a random sample had been taken from the entire data set it would be expected that about 80% of the cases would have been those screened as negative by the primary researchers, rather than 42% in this analysis. The primary researchers found that most of the individuals who screened as negative showed very little or no evidence of ASC traits. For instance, on criterion A2 (nonverbal communication) in most cases keyworkers reported that the individual made good eye contact, had a normal range of facial expressions, and picked up on body language and implicit social cues. We expected that it would be obvious that cases such as these should screen negative on this criterion, and it was similarly evident for other criteria that ASC traits were not present. We would therefore predict that the DATHI would have shown higher reliability if a random sample of cases had been taken. For the cases which screened as positive or marginal the presentation was much more complex, and the good performance of the measure in relation to these cases would suggest that it is a reliable instrument.

One key threat to validity was the use of informant report, with the informants in this case being keyworkers rather than the family members who would be involved in a more standard ASC assessment context (NICE, 2012). However, the service we carried out our research with was an outreach service where keyworkers had relatively small and stable caseloads, and therefore had the opportunity to get to know their clients quite well. This is shown in the average amount of time keyworkers had known each of their clients, which was almost three years. Some clients had been known for a much shorter period of time, so in these cases keyworkers were not always able to provide an in-depth description of the client's presentation. In cases such as these the person was generally screened as

negative for ASC traits and this should not therefore be a threat to validity, unless the person did have ASC traits which were missed.

Homeless individuals often have complex presentations, with high levels of substance misuse and mental health problems (Fazel, Khosla, Doll, & Geddes, 2008). We were concerned that this would translate into people appearing autistic, and the DATHI would in effect be a measure of complexity. However, the DATHI classified most individuals as not showing good evidence of ASC traits, both on individual items and for the overall classification. This provides evidence that the DATHI could manage the chaotic presentations of the majority of the homeless individuals screened, in that complexity did not automatically lead to the person being classified as having autistic traits. While some individuals might have scored up erroneously on some traits, all cases which screened overall as positive presented with good evidence of the full range of traits associated with ASC.

Best practice in a formal assessment of validity would have been to compare our results against those of a 'gold standard' measure of ASC, but the lack of previous research in this population meant that this was not possible. Criterion validity was therefore initially investigated through the ASDASQ. This does not provide a strong test, as in its original development study it did not show especially high sensitivity or specificity (Nylander & Gillberg, 2001). However, as our aim was to begin to develop an evidence base in this area we considered that results from the ASDASQ would at least provide some information regarding the validity of the DATHI. Positive correlations with the overall score on the DATHI and both sets of criteria were very large, which provides some evidence for criterion validity.

It is also possible to consider the measure in terms of content validity, the degree to which it identified traits specific to ASC rather than other differential diagnoses. The

qualitative descriptions in table 4 show what behaviours were considered to be good evidence of ASC traits for individual criteria. These match up closely with DSM-5 criteria, showing evidence of pronounced social deficits and restrictive and repetitive behaviours (RRBs). Individuals were identified who had very well developed fixations, such as the person who made lists of obscure musicians, and there was good evidence of sensory differences in about half of all cases which screened as positive.

The examples given in table four can also be compared to the behaviours which would be expected for other conditions which have similarities to ASC. The key differential diagnoses for ASC in adults are: the personality disorders (PDs) schizoid PD, schizotypal PD, and obsessive-compulsive PD (OCPD); obsessive compulsive disorder (OCD); attention deficit and hyperactivity disorder (ADHD); schizophrenia; and social anxiety disorder (Lai & Baron-Cohen, 2015).

For many of these diagnoses there are clear points of differentiation. While social deficits are common to many conditions, the RRBs seen in ASC do not have such a great overlap with other diagnoses. Social anxiety disorder and schizoid PD are not characterised by any such behaviours (Triebwasser, Chemerinski, Roussos, & Siever, 2012; Tyson & Cruess, 2012), and can therefore be rejected as explanations for the presentations picked up by the DATHI. Positive and disorganised symptoms of schizotypal PD and schizophrenia can appear similar to RRBs (Churchard, 2017; Dossetor, 2007), but we would argue that the RRBs described in table four do not appear psychotic in nature, but seem closer to traits of ASC in that they are very precise, pedantic, and inflexible. With regards to OCPD this has so much overlap with ASC that it has been questioned whether this should be diagnosed at all before the presence of ASC is ruled out, so this has less relevance as a differential diagnosis (Fitzgerald, 2002).

It is more difficult to differentiate ASC from OCD and ADHD. The rigidity and inflexibility which characterises OCD overlaps with the RRBs seen in ASC (Russell, Mataix-Cols, Anson, & Murphy, 2012), and the inattentiveness seen in ADHD can also lead to a person appearing to have ASC (Johnston et al., 2013). We acknowledge that ruling out these differential diagnoses is challenging without a full assessment including a developmental history, and it is possible that the traits detailed in table four are in fact explained by these other conditions. However, important to consider here is that up to 40% of adults with ASC have co-morbid ADHD (Hofvander et al., 2009; Johnston et al., 2013), and up to 30% have co-morbid OCD (Buck et al., 2014; Hofvander et al., 2009). It is entirely possible that some of the individuals who were screened as positive on the DATHI could have these other conditions in addition to ASC.

We cannot conclusively rule out the differential diagnoses outlined above. However, the in-depth information gathered by the DATHI does allow us to detail the types of behaviours which led to a person being screened as positive on this measure. These match quite closely the behaviours which characterise ASC, and we would argue that they provide good evidence for content validity.

Prevalence Statistic

The key finding from the current study is that a relatively large group of individuals were classified as showing good evidence of having traits of ASC. The prevalence statistic of 12.3% is much higher than in the general population, where about 1% of people are thought to have ASC (Brugha et al., 2016). Even if several individuals have been misclassified as screening positive, or the statistic should actually be at the lower end of the 95% CI at 7.0%, the prevalence would still be markedly higher than in the general population. This provides some evidence that rates of ASC may be raised in this homeless population. This is only however an initial finding. What our research does clearly show is

that a large proportion of this group of homeless people would benefit from a full ASC assessment, and that further research should be carried out in this area.

Limitations

This study identified individuals who showed the range of symptoms associated with ASC, but this does not equate to a diagnosis of ASC. To make this would require much more in-depth assessment including a full developmental history and the use of validated measures. One major limitation was that we did not meet individuals, but relied entirely on informant report. This was the best choice from an ethical and methodological standpoint, as it did not intrude on individuals and lowered the risk of bias. However, it did make it more difficult to gather information relevant to differential diagnosis.

The reliability checking process was carried out on scans of the questionnaires filled out by the primary researchers. Classifications were made by the primary researchers on the basis of notes written on these questionnaires, but it is possible that some information was lost and the reliability raters were making judgments on the basis of slightly different information to that held by the primary researchers.

There was a sizeable group of participants who were so poorly known to services that no data could be gathered about the presence of ASC symptoms, and who received the classification 'insufficient information to classify'. These individuals in general actively avoided contact with keyworkers, and while this could have a wide variety of causes it seems plausible that this would be the type of behaviour someone with ASC might display due to difficulties with any kind of social interaction. This may mean that our estimate of prevalence is too low. Also important to consider is that due to social pressure adults with ASC can mask their symptoms as they get older (Lai & Baron-Cohen, 2015). While our measure did gather detailed information it is quite possible that individuals who engaged in this type of behaviour might have been missed.

With regards to the generalisability of the prevalence statistic, this sample was from a population of long-term homeless people with complex needs. They are not therefore representative of the general homeless population. It seems likely that people with ASC who become homeless would tend to be more vulnerable and less able to engage with services, and it is therefore possible that there might be more people with ASC traits among the long-term homeless sampled from in this study.

ASDASQ as Screening Tool

If rates of ASC are raised among homeless people then it would be useful to have a screening tool. The ASDASQ is a short measure which takes little time to complete, and which showed some evidence of validity and utility in its development study (Nylander & Gillberg, 2001).

When the results of the ASDASQ were compared against final classifications our focus was on whether it could successfully identify cases which had screened as positive and marginal. Marginal cases were included in the analysis as these were often the cases which required the most thought as to whether or not they showed evidence of ASC, and which we would therefore expect to benefit from a more in-depth assessment rather than being screened out. When a cut-off point of six was used the ASDASQ showed high specificity, but low sensitivity. When a lower cut-off point of four was used sensitivity was much better, although specificity had dropped somewhat. Given these results it seems that the ASDASQ could be a useful screening tool, but using the lower cut-off of four.

One consideration with the ASDASQ is that the keyworkers who filled it out had had training in ASC, and had also had extensive discussions with us about whether or not their clients showed evidence of autistic traits. Further investigation is required as to whether the ASDASQ could be used as a screening tool with keyworkers who have little or no knowledge of ASC.

Clinical Implications and Future Directions

This study has provided initial evidence that rates of ASC may be raised in homeless populations. While this cannot be more than a tentative conclusion, this would be consistent with the well-evidenced poor outcomes for adults with ASC (Howlin & Moss, 2012; Steinhausen et al., 2016). Lai and Baron-Cohen (2015) refer to a 'lost generation' of adults with ASC who did not receive a diagnosis because of lack of knowledge about the condition, and the individuals we have identified may be part of this group.

If rates of ASC are raised among homeless populations this has important implications. Many people are homeless in the UK; the most recent estimate is that there are over 4000 rough sleepers at any one point (Department for Communities and Local Government, 2016), and there is a much larger group of people with no stable accommodation who are termed the 'hidden homeless' (Crisis, 2017). There may therefore be a considerable number of homeless adults with ASC who are not having their needs met, and who are in an extremely vulnerable position.

Some organisations have recently developed ways of supporting homeless adults with ASC, and they have provided anecdotal evidence of success (Homeless Link, 2015). These interventions have used expertise from the ASC field to inform keyworking, and relatively straightforward adaptations have allowed the engagement of adults who had previously refused support. The model of consultation used in our study, where keyworkers can speak to an expert in ASC about their clients, has been found to be helpful.

There are also implications in terms of earlier identification of ASC and better support in housing services. The qualitative study on ASC and homelessness by the charity Shelter found that a lack of knowledge about ASC on the part of professionals working in housing was a substantial barrier to obtaining help (Shelter Cymru, 2015), and this would seem to be a significant factor in increasing the risk of homelessness for someone with ASC.

It is important that further research be carried out in this area to test our findings and identify the potential scope of the problem. This could be done through using a similar methodology in another homeless population. In this context one more general question to investigate could be whether ASC has directly caused homelessness, or whether this research has just suggested correlation and not causation. The trainee with who I carried out this research (Ryder, 2017) has gathered data about routes into homelessness which is relevant to this question.

Further validation of DATHI against better tests of criterion validity would be appropriate. This could be done with non-homeless adults with a confirmed diagnosis of ASC who have support workers, as while the DATHI has homelessness specific questions most of its items relate to the overall ASC presentation. Further research could also be carried out into the validity and utility of the ASDASQ, as this would potentially allow services to have access to a quick screening tool for ASC. As some services are already working with homeless people with ASC, it would be useful to evaluate the effectiveness of this support.

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Part 3: Critical Appraisal

Introduction

This critical appraisal will discuss the relationship of this research to my pre-training clinical experiences of working with homeless people. It will also consider methodological issues and challenges in carrying out the research, and detail actions taken to increase the 'impact' of the study.

Impact of Personal Experience on the Research

Before commencing clinical training I had been employed as a support worker in hostels for homeless people. Working in this role made me want to find out more about the psychological needs of the people I was supporting, which ultimately led to applying to clinical training.

It was while working in homeless hostels that I first encountered the statistic that the average age of death for someone who died while homeless was 40-44 years (Office of the Chief Analyst, 2010). Figures like this show how significant the health needs of homeless people are, but there was relatively little high quality evidence for how to work with this group (Bassuk, DeCandia, Tsertsvadze, & Richard, 2014; Fitzpatrick-Lewis et al., 2011). The chance to help develop the evidence base strongly appealed to me and led to me choosing this piece of research.

Before choosing this project I had had little experience of working with autism spectrum condition (ASC) and I was not familiar with research in this area. Reading about the poor outcomes for adults with ASC (Howlin & Moss, 2012) it seemed plausible that they would be at increased risk of homelessness, but I was also aware that it would be a challenge to gather empirical evidence as to whether or not this was the case. During my time as a support worker I had had many clients who had extremely complex presentations, and I was curious as to whether it would be possible to identify specifically autistic traits. One client I had worked closely with came to mind: they were quite socially

awkward with limited facial expressions, and their preferred activity was to sit in the hostel computer room and watch long videos of train journeys. I wanted to see whether this type of presentation might be best explained as autistic, and if so whether more appropriate support could be offered to homeless people with autism.

The Empirical Paper and Considerations Around Carrying out Research in a Homelessness Setting

This section will first focus on general issues around conducting research about homelessness, given the many challenges and dilemmas which this type of research presents. It will then go into greater depth about the methodology employed in this study, as our experience may be helpful for potential future researchers in this field.

One major consideration in research into homelessness is the difficulty of gathering valid data in this area, and from the beginning we were aware that this would particularly apply to trying to assess ASC in this population. The empirical paper outlines the methodological issues we faced such as the lack of any developmental history, the multiple co-morbidities and general complexity, and it not being possible to actually meet the homeless people in person. The question we found ourselves facing was whether the challenges and risks to validity inherent in this doing this research outweighed the potential benefit of beginning to develop an evidence base in this area.

Previous studies into analogous areas had not been uniformly successful. While the Fraser et al. (2012) study had suggested a useful methodology, there was also a study which screened for ASC in prisoners which had found that the measure they had developed did not show good validity (Robinson et al., 2012). This raised concerns about whether we would be able to draw any conclusions at all. Another danger was that if the methodology was not rigorous then our hypothesis that rates of ASC would be raised in this population

would be either falsely confirmed or falsely disproved. This is of course a concern in any research, but given the many complexities in this area it was particularly pressing for us.

Given the many challenges to researching the relationship of ASC and homelessness it might be suggested that an appropriate way to tackle this question would be to carry out a more intensive and in-depth study, rather than our exploratory attempt to begin to develop an evidence base with its associated risks to validity. Possibilities might be a diagnostic study using experts in the assessment of ASC, or even a longitudinal study of outcomes for people with ASC. The latter study would provide convincing evidence as to whether ASC was a genuine risk factor for homelessness, and this has been done among people with Attention Deficit and Hyperactivity Disorder (Garcia Murillo, Ramos-Olazagasti, Mannuzza, Castellanos, & Klein, 2016). However these studies are resource intensive, and there is relatively little funding for research in homelessness in general. This is reflected in the relative lack of research in many areas of homelessness, as is discussed in reviews of cognitive functioning among young homeless people (Fry, Langley, & Shelton, 2016) and of the prevalence of childhood abuse in homeless populations (Sundin & Baguley, 2015). Given these challenges it did not seem likely that more in-depth studies would be conducted in this field at any point in the near future. A more standard diagnostic study, which would probably involve meeting homeless people in person, would also face the same challenges around engagement and bias which were discussed in the empirical paper as reasons for using informant report.

Probably the most significant limitation to the study is the lack of any developmental history in our assessment of ASC traits. Guidelines for diagnosis of ASC in adults state that this is crucial (NICE, 2012), and experts in the field note that differential diagnosis often relies on having such a history (Lai & Baron-Cohen, 2015). This can show whether the behaviours being assessed emerged at an early age, which would support a diagnosis of

ASC, or whether they emerged later and would therefore seem more likely to be related to another psychiatric condition. The question is whether this is such a major limitation that it throws all the findings of the study in doubt. Relevant here is that the explicit aims of the study were to identify those individuals who showed strong signs of ASC traits, not to make diagnoses of ASC. I would argue that this is a sufficiently important finding to justify the study, as it provides some evidence at least that there may be a link between ASC and homelessness, and this may then act as the basis for further research. Our study is not alone in using this type of methodology: the Autism Mental State Examination (Grodberg, Weinger, Kolevzon, Soorya, & Buxbaum, 2012) focusses entirely on observable traits of ASC, and the authors argue that it may be used as a quick initial measure to identify which people are likely to go on to receive a diagnosis of ASC in a full assessment.

It therefore seemed appropriate to conduct our exploratory study, even with its many risks to validity. These have been discussed in the empirical paper, so this section will consider how these risks relate to broader problems with conducting research into homelessness.

Another major challenge was the difficulty of gathering information. The unstable situations of homeless people means that engagement is often challenging (Joly & Crane, 2015; Olivet, Bassuk, Elstad, Kenney, & Jassil, 2010), and even just locating them can be very difficult. Our use of informant report from keyworkers was in part intended to address this, but it did raise additional concerns about whether the information they gave would be of sufficiently high quality. When we contacted the authors of the Fraser et al. (2012) study to enquire about their methodology they questioned whether keyworkers would be reliable informants, but this does not seem to be borne out by our experience. The team of keyworkers we worked with had in general worked in the field of homelessness for a long time, and we found that for most clients they were able to give a rich and detailed picture

of at least the person's current presentation. It was still difficult at times to gather information, but keyworkers did have enough knowledge of their clients to manage this concern.

Related to the difficulty in gathering information were questions about what type of measure we should use. Our final decision was to develop the DATHI semi-structured interview, rather than using a previously validated screening questionnaire. This was partly a result of necessity, as of the screening measures listed in a recent review (Sappok, Heinrich, & Underwood, 2015) none apart from the ASDASQ (Nylander & Gillberg, 2001) were appropriate as they expected the informant to be a close family member or friend of the person being screened. We also considered screening measures used with individuals with an intellectual disability such as the Diagnostic Behavioral Assessment for ASD – Revised (Sappok et al., 2014), a recently developed measure which would have needed to be translated from German. This was developed for use with staff and measures observable behaviours, which we thought was an advantage as it would not require keyworkers to make inferences about participants' mental states. However upon further reflection we decided that it would make little sense to use a measure designed for a completely different population, as results would be difficult to interpret.

Our decision not to use a screening measure was also informed by the awareness that this would not give in-depth information about homeless people's presentations. Given the exploratory nature of this project we wanted to find out as much as possible about whether and how ASC traits might present in a homeless population, and we felt that the simple numerical scores provided by screening questionnaires would not be particularly useful as they would not give any detail about how traits presented. They would also be vulnerable to the objection that people with complex presentations were scoring up for ASC traits simply because of this complexity, rather than the presence of actual ASC traits.

The DATHI allowed us to gather much more in-depth information which did seem to show that it was not simply a measure of complexity and chaotic presentations.

Another concern was about how far we would be able to reach any kind of clarity in our assessment of ASC traits. Other studies of mental health and homelessness note the difficulties in making diagnoses (Connolly, Cobb-Richardson, & Ball, 2008; Fazel, Khosla, Doll, & Geddes, 2008), and based on my personal experience of working in the field this is also a concern often stated by keyworkers when faced with a client with a complex presentation. Ultimately however the DATHI produced reliable results and there was evidence for validity. It was based closely on DSM-5 criteria, with adaptations only being made to make the criteria more relevant to a homelessness context. This is supportive evidence for the validity of the DATHI, in that it maps onto DSM-5 criteria which have extensive evidence for validity (American Psychiatric Association, 2013; Mandy, Charman, & Skuse, 2012). We were struck by how clearly some behaviours seemed to match up with the DSM-5 criteria for ASC, particularly in terms of fixated interests and sensory behaviours. Again, this is not conclusive evidence of ASC, but it does seem suggestive enough to justify carrying our further research into this area.

Ethical considerations were also quite prominent in this study. Our use of informant report meant that we did not gain consent from the individuals we were screening. We considered carefully whether or not this was unethical. Other researchers in the homeless field have emphasised the importance of fully involving homeless people in any research being carried out (Cloke, Cooke, Cursons, Milbourne, & Widdowfield, 2000), and this was not something we were able to do. Our questionnaires were designed to not gather any personally identifiable information about individuals, but we were still recording quite detailed information about their presentation. We felt that the measures we were taking to maintain confidentiality, combined with the potential benefits of developing an evidence

base in this area, justified our research design. However future research in this area would benefit from more service user involvement.

Focussing more closely on the study methodology, there are several learning points which may be helpful for any future researchers in this field.

Starting with the DATHI, the mixture of more general questions and prompts allowed us to gather a large amount of information to draw on when making classifications. The classification system for individual items seemed to work well, apart from the 'Present but attributable to causes other than ASD' classification which was little used. It also required us as researchers to make more inferences than when making other classifications, which did not seem helpful. For instance, we had to consider whether or not socially inappropriate behaviour which occurred in the context of continuous substance misuse was evidence of ASC traits. In cases such as these the most appropriate classification would have been 'Possibly present', as we could not be sure that ASC traits were not present and we could also not be sure that they were better explained by substance misuse. It could therefore be appropriate to drop 'Present but attributable to causes other than ASD' as a classification from any future versions of the DATHI. When making classifications in general one particularly helpful feature of the rubric was the instructions about whether to score up or down when uncertain about a particular classification.

The scoring process mainly involved using the information gathered by the DATHI. However it was also very helpful to have the information about the client which we explored in the initial more general interviews. This allowed us to contextualise details of the individual's presentation and gain a greater understanding of how any autistic traits they displayed could cause impairment. Our focus in using this information was to use it primarily as contextual information for making classifications on the DATHI, rather than formulating. As clinical psychologists we were aware of the temptation to make a

formulation, especially for the social items of the DATHI where multiple clients presented with traumatic histories which seemed directly related to their interpersonal style and relationships. However we tried to as far as possible maintain a focus on observable behaviours rather than making inferences about psychological processes and historical factors behind a particular presentation.

The actual interview process was easier than we expected. It was relatively straightforward to arrange times with the team, which may have reflected the fact that their manager's manager was extremely interested in the research. Above and beyond this though, the team did seem actually quite happy to be involved in the research. This may be a positive side-effect of homelessness being under-researched, in that it seemed to be a welcome experience for keyworkers to have discussions about clients with us.

The Systematic Review

The systematic review topic was deliberately chosen to support the empirical analysis. Given my previous experiences of working with homeless people, combined with knowledge of the research literature in this field (Connolly et al., 2008), I was aware that personality disorders (PDs) would be very common in the population we were studying. The aim in carrying out the review was to gain more knowledge about the status of these as differential diagnoses for ASC, to inform the analysis and discussion of the data gathered by the DATHI.

At first the plan was to do a systematic review of the overlap between all PDs and ASC, as an initial search showed that the number of papers included would be manageable. However, as I refined my search terms it quickly became clear that a large number of papers were not identified by this initial search. In the area I eventually chose to focus on there were a large number of papers on schizotypy and ASC which used measures of schizotypal PD, but which did not mention PD in their title or abstract. This might reflect

the unclear boundaries of PDs in general, which many researchers argue should be considered on a dimensional and not categorical basis (Widiger, 2011) .

Once I had decided to focus just on schizoid PD, schizotypal PD and ASC the search was relatively straightforward. It was surprising that there were so few papers in some areas, and that schizoid PD in general was so under-researched. This was a major limitation of the review as evidence in some areas was so limited.

The concept of overlap required a great deal of thought. My final conceptualisation of it as a continuum deliberately left out various possibilities. This continuum ranged from trivial overlap, with symptoms appearing similar but being easily differentiable if measured properly, to total overlap where a single underlying condition had been given two different names. Deliberately excluded as possibilities were more in-depth considerations of aetiology, such as shared genetic risk factors or shared social risk factors. These were excluded as the evidence was so limited, so the review had to instead focus on more basic understandings of how overlap might occur.

Unlike many systematic reviews a quality appraisal tool was not used. This was because studies were so varied in terms of methodology, so any single tool would not have been appropriate. My aim throughout the analysis was to make explicit the criteria I used to analyse the quality of studies, for instance whether or not studies involving participants with ASC had used appropriate measures to make a confirmed diagnosis.

The conclusions of the review could only be tentative, given the lack of evidence in some areas. However, these conclusions were helpful in guiding thinking in the empirical paper. What they showed specifically was the importance of focussing on the exact nature of the restrictive and repetitive behaviours (RRBs) in ASC, particularly when trying to differentiate ASC and schizotypal PD. There were some individuals who showed examples of quite strongly fixated interests, but which on closer examination appeared to have more

of a psychotic than autistic nature. Being aware of the distinction between ASC and schizotypal PD was useful in these types of cases, and meant that they were not screened as positive for ASC traits.

Increasing the Impact of the Research and Working With Other Organisations

The initial impetus for this work was a homelessness commissioner making contact with our secondary supervisor to ask if a study could be carried out into ASC and homelessness. Given this it seemed likely that our findings would be of interest beyond the academic field, so a major part of this research has been making contact with other interested parties. We have held meetings with the charities the National Autistic Society and Homeless Link, and also with the Rough Sleeping and Single Homelessness lead in the Department for Communities and Local Government. Arranging meetings with these other organisations was straightforward, and there has been a high level of interest in the research. In addition we have presented the findings of our research at the Homelessness, Social Exclusion and Health Inequalities 2017 conference.

As someone without any previous experience of policy work it has been interesting to see the process of how research might convert into actual changes in policy. It seems to me that researchers often hope that their studies may effect change through influencing policy-makers, but in meetings with policy-makers I have realised that they also rely on influencing others and trying to create a general context in which changes may be implemented. It has gradually become clear that in the interface between research and policy a useful role for clinical psychologists can be to provide the information which allows policy specialists (both in charities and government) to create that general context in which change can happen. An example of this in practice might be research by Wardle, Griffiths, Orford, Moody, and Volberg (2012) into gambling in Britain, which has contributed to national policy change.

Given that I have realised how there is a great deal of work that needs to be put into building networks and making contacts, but also that the way information is communicated has to be adapted to a policy context. The people we have met have been interested in how the study was designed, but they have also wanted to know what the 'headline' message is and brief summaries of what we have found. Presenting information in this way seems to me to be a real skill, as it requires the simplification of information while at the same time not altering or exaggerating the findings. This was emphasised by a recent graduate from UCL who specialises in policy work and gave a lecture on this topic (Browne, 2017).

When making contact with these other organisations we have worked closely with the homelessness commissioner who first approached our external supervisor about the potential of carrying out research in this area. It has been very helpful to work together on increasing the impact of our research, as we have been able to provide the academic background while the commissioner has been more focussed on practical implications.

The outcome of these meetings is that we plan to create a briefing document for organisations around the country about the potential importance of being aware of ASC in a homelessness context. This would be partly based on the documents already created by organisations such as Homeless Link which provide some suggestions about how to work with homeless adults with ASC (Homeless Link, 2015).

Final Reflections

The empirical paper seems to show that it is possible to begin to create an evidence base in an area as complex as ASC and homelessness, and I hope that this may be the start of a broader programme of research. If the findings are validated and rates of ASC are shown to be raised among homeless people I also hope that there will be practical changes

to how support is provided, as it is clear that additional support is required for this client group.

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Appendices

Appendix 1: Confirmation of ethical approval

UCL RESEARCH ETHICS COMMITTEE
ACADEMIC SERVICES



18 March 2016

Dr Will Mandy
Research Department of Clinical, Educational and Health Psychology
UCL

Dear Dr Mandy

Notification of Ethical Approval
Project ID: 8359/001: Estimating the prevalence and associated needs of autistic traits in a homeless population

I am pleased to confirm in my capacity as Chair of the UCL Research Ethics Committee (REC) that your study has been approved by the UCL REC for the duration of the project i.e. until 15th April 2017.

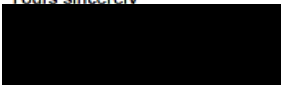
Approval is subject to the following conditions:

1. You must seek Chair's approval for proposed amendments to the research for which this approval has been given. Ethical approval is specific to this project and must not be treated as applicable to research of a similar nature. Each research project is reviewed separately and if there are significant changes to the research protocol you should seek confirmation of continued ethical approval by completing the 'Amendment Approval Request Form': <http://ethics.grad.ucl.ac.uk/responsibilities.php>
2. It is your responsibility to report to the Committee any unanticipated problems or adverse events involving risks to participants or others. The Ethics Committee should be notified of all serious adverse events via the Ethics Committee Administrator (ethics@ucl.ac.uk) immediately the incident occurs. Where the adverse incident is unexpected and serious, the Chair or Vice-Chair will decide whether the study should be terminated pending the opinion of an independent expert. The adverse event will be considered at the next Committee meeting and a decision will be made on the need to change the information leaflet and/or study protocol.

For non-serious adverse events the Chair or Vice-Chair of the Ethics Committee should again be notified via the Ethics Committee Administrator (ethics@ucl.ac.uk) within ten days of an adverse incident occurring and provide a full written report that should include any amendments to the participant information sheet and study protocol. The Chair or Vice-Chair will confirm that the incident is non-serious and report to the Committee at the next meeting. The final view of the Committee will be communicated to you.

On completion of the research you must submit a brief report of your findings/concluding comments to the Committee, which includes in particular issues relating to the ethical implications of the research.

Yours sincerely



Professor John Foreman
Chair of the UCL Research Ethics Committee

Academic Services, 1-19 Torrington Place (2nd Floor),
University College London
Tel: +44 (0)20 3108 8216
Email: ethics@ucl.ac.uk
<http://ethics.grad.ucl.ac.uk/>

Appendix 2: Keyworker information sheet and consent form

RESEARCH DEPARTMENT OF CLINICAL, EDUCATIONAL
AND HEALTH PSYCHOLOGY



Estimating the prevalence and associated needs of autistic traits in a homeless population

Information sheet for Keyworkers

We would like to invite you to take part in this research project. You should only take part if you would like to, and before you decide whether you want to take part it is important for you to read the following information and discuss it with others if you wish. Please ask us if there is anything that is not clear, or if you would like more information.

What is this study about?

This research aims to estimate the percentage of service users [redacted] works with who have autistic traits, and to find out more about the particular needs of a homeless person with autistic traits. Autistic Spectrum Disorder is a condition which can lead to a person having many problems coping in everyday life, and we think that there may be clients on your caseload who have this condition but have not received a diagnosis.

We will not seek to make full diagnoses, but will rather identify whether or not clients show evidence of autistic traits. If we do find evidence that this is the case it may serve as the basis for better support to be offered to this particular group of clients, and could also lead to further services being developed to meet their needs.

Who is being invited to take part?

We are inviting all keyworkers at [redacted] to take part in the research.

Do I have to take part?

It is up to you to decide whether to take part or not; choosing not to take part will not disadvantage you in any way. If you decide to take part you will be given this information sheet to keep and be asked to sign a consent form. If you do decide to take part you are still free to withdraw at any time and without giving a reason.

What will taking part involve?

If you agree to take part, we will be asking you to take part in interviews with us where we will ask you questions about all the clients you work with. We will ask you how your clients act, how they communicate with you, and about their strengths, needs, and history of homelessness. We will also ask you to complete questionnaires asking similar questions. We will not at any point ask you for any personally identifiable details of the client, to ensure that we protect their confidentiality. This data will be stored securely and will only be seen by the research team.

We will record a random selection of our interviews to allow us to test how reliable our measures are. This is to test the quality of the research we are doing and the recordings will only be used for this purpose. They will only be listened to by members of the research team, and they will be anonymised and stored on an encrypted drive.

What will happen to the information that is collected?

Your responses on the questionnaires will be anonymous and will be analysed together with other keyworker's responses.

All written information will be stored securely and will be destroyed five years after the study has ended. All data will be collected and stored in accordance with the Data Protection Act 1998. If for any reason you decide to withdraw from the study, all information you provided can be deleted at your request.

Everything that you tell us will be kept confidential; only the research team will have access to what has been said.

The recordings will only be listened to by members of the research team, and they will be anonymised and stored on an encrypted drive. They will be deleted once all reliability checks have been completed.

Once the project is over, the results will be written up as part of a postgraduate thesis and may be submitted for publication in an academic journal. Reports will not reveal the identity of anyone who took part. An anonymised summary of the findings will be sent to [REDACTED] and shared with all keyworkers in the service, and will also be sent to the homelessness commissioners at [REDACTED] Council.

Are there any risks of taking part?

We do not expect your taking part in this study to carry any risk to you. If we identify a client with suspected autistic traits who you feel would benefit from further support around this there is a care pathway through [REDACTED]. We would also be happy to discuss this further with you if required.

What are the possible benefits of taking part?

The benefits of this study are that it may help increase and improve service provision for homeless adults in [REDACTED] with autism, as this is a potentially very vulnerable client group with a large unmet need. We will share the results with you and the rest of the team at [REDACTED], and we hope that you may find this research has some practical benefit in terms of your day-to-day work with clients.

Incentive for participation:

As a thank you for taking part we will be offering £30 in food vouchers to [REDACTED] for use with clients, for each keyworker who participates.

Further information and contact details, and what if something goes wrong?

If you have any questions about this study please contact the researchers. If this study has harmed you in any way or if you wish to make a complaint about the conduct of the study you can contact the principal researcher Will Mandy using the details below:

[REDACTED]

Will Mandy, Senior Lecturer <w.mandy@ucl.ac.uk>

Research Department of Clinical, Educational and Health Psychology
University College London
Gower St
London WC1E 6BT
Telephone: 020 7679 5962

Thank you for considering taking part in this study.

This study has been approved by the UCL Research Ethics Committee (Project ID Number): 8359/001

You will be given a copy of this information sheet to keep.

Informed Consent Form for Keyworkers

Please complete this form after you have read the Information Sheet and/or listened to an explanation about the research.

Title of Project: Estimating the prevalence and associated needs of autistic traits in a homeless population

This study has been approved by the UCL Research Ethics Committee (Project ID Number): 8359/001

Thank you for agreeing to take part in this research. Before you agree to take part, the person organising the research must explain the project to you.

If you have any questions arising from the Information Sheet or explanation already given to you, please ask the researcher before you to decide whether to join in. You will be given a copy of this Consent Form to keep and refer to at any time.

Participant's Statement

I

- have read the notes written above and the Information Sheet, and understand what the study involves.
- understand that if I decide at any time that I no longer wish to take part in this project, I can notify the researchers involved and withdraw immediately.
- understand that as a result of my assistance with the project, the service will be given a donation of £30 worth of food vouchers, I understand that this donation will be assured irrespective of whether I decide that I no longer wish to take part in the project.
- understand that my participation may be tape recorded and I consent to the use of this material as part of the project.
- understand that such information will be treated as strictly confidential and handled in accordance with the provisions of the Data Protection Act 1998.
- understand that the information I have submitted will be published as a report and I will be sent a copy. Confidentiality and anonymity will be maintained and it will not be possible to identify any service users from any publications.
- agree that the research project named above has been explained to me to my satisfaction and I agree to take part in this study.

Signed:

Date:

Appendix 3: DSM-5 based ASC traits in homeless individuals semi-structured interview (DATHI)

Rubric

Autistic Spectrum Disorder (ASD) is a condition which manifests in a wide variety of ways, and two people with ASD may have completely different presentations. This questionnaire does not therefore provide a checklist of particular behaviours, as the presence of a behaviour is not in itself diagnostic of ASD. It rather lists a number of behaviours, and asks that the researcher consider with keyworkers whether the ways these behaviours manifest is consistent with a presentation of ASD. Throughout researchers should proceed according to the following process:

1. Is the behaviour manifested by the client?
2. If yes, what form does the behaviour take?
3. Is the behaviour consistent across different settings/contexts?
4. Why does the keyworker think the behaviour is being manifested? Are there any obvious reasons why the client acts in this way?

Guidelines for individual items:

Classification	Criteria
Present	<ul style="list-style-type: none"> • Behaviour(s) associated with trait clearly observed with examples given. • Each behaviour is seen across multiple contexts <u>OR</u> Behaviour seen in one context very clearly meets ASD criteria. • The behaviour is not attributable to other causes. • Not every behaviour has to be present for this to be met, and a single behaviour may be sufficient to give this classification if it very clearly matches DSM-5 criteria (ie. One clearly evident fixated interest would be sufficient to meet criterion B3).
Possibly present	<ul style="list-style-type: none"> • Meeting any of the following criteria is sufficient reason to give this overall classification: <ul style="list-style-type: none"> ○ Behaviour(s) associated with trait observed, but it is unclear whether they fully match up with DSM-5 criteria. ○ A single behaviour likely to be consistent with ASD is observed, but no other ASD-related behaviours are observed. ○ Behaviour(s) associated with trait observed, but they do not reliably appear across multiple contexts. ○ Aspects of trait observed and may be better explained by other cause, but this is unclear (ie. Is it anxiety or ASD?).
Not present	<ul style="list-style-type: none"> • Trait not observed, or only bears superficial resemblance to DSM-5 criteria (ie. Unfriendly when drunk).
Present but attributable to	<ul style="list-style-type: none"> • Trait only appears when another factor is clearly influencing the individual's behaviour / mental state (ie. Alcohol). The variability in

cause other than ASD	presentation of the trait can be closely matched up with this additional factor (ie. Poor eye contact and social rapport when drinking, but otherwise eye contact and social rapport are fine).
Insufficient information to classify	<ul style="list-style-type: none"> Client is so poorly known to services that any attempt to match their behaviour to criterion would be a guess.

Additional guidelines for decision making on each item

Where the scorer thinks a score on an item falls between classifications (i.e. between 'Not present' and 'Possibly present', or between 'Possibly present' and 'Present') the following guidelines should be followed:

- For Section A (items A1-A3) the scorer should score down
 - E.g. If the scorer thinks the score falls between 'Present' and 'Possibly present' the scorer should rate the item as 'Possibly present'. Similarly if the scorer thinks the item falls between 'Not present' and 'Possibly present' they should rate the item as 'Not present'.
- For Section B (items B1-B4) the scorer should score up
 - E.g. if the score falls between 'Present' and 'Possibly present' the scorer should rate the item as 'Present'. If the scorer thinks the item falls between 'Not present' and 'Possibly present' they should rate the item as 'Possibly present'.
 - The only exception to this is B2 – prompt around difficulty coping with change. It is evident that the general homeless population for different reasons struggle with change. There should be clear examples here of previous difficulties coping with change (e.g. change in the way benefits are given) rather than general fear of change (e.g. refusing accommodation due to avoidance of change)

Guidelines for 'Overall classification'

The following guidelines should be followed to give an overall classification of the presence of autistic traits:

Classification	Criteria
Present	<p>Section A:</p> <ul style="list-style-type: none"> • 3 items = present OR • At least 2 items = present AND 1 item = possibly present <p>AND</p> <p>Section B:</p> <ul style="list-style-type: none"> • At least 2 items = present OR • 1 item = present AND at least 2 items = possibly present
Possibly present	<p>Section A:</p> <ul style="list-style-type: none"> • At least 3 items = possibly present <p>AND</p> <p>Section B:</p> <ul style="list-style-type: none"> • At least 2 items = possibly present
Not present	<ul style="list-style-type: none"> • Does not meet criteria for 'Possibly present'
Insufficient information to classify	<ul style="list-style-type: none"> • Client is so poorly known to services that any attempt to match their behaviour to criteria would be a guess (this same classification will be seen on individual items).

The above guidelines should normally be followed to make the overall classification. However, in some cases the general clinical presentation and/or contextual information may raise doubts about the accuracy of the overall classification. In the case the overall classification may be changed, but this should only happen rarely and after careful consideration. Examples of when this might occur include:

- An individual whose overall presentation appears markedly autistic, but who has not quite met criteria for 'Present' and has instead been put in the 'Possibly present' category. In this case it would be appropriate to re-categorise them into 'Present'.
- An individual who has met criteria for 'Present', but it is very unclear what the nature and cause of their autistic traits is. This might be seen in a very chaotic clinical presentation with other confounding factors such as a high level of substance misuse. In this case it would therefore be more appropriate to put them in the 'Possibly present' category.

Criterion	Prompt questions	Answers	Trait present?
A1: Deficits in social-emotional reciprocity	<p>Is the client able to initiate social contact?</p> <ul style="list-style-type: none"> • Specific prompts: <ul style="list-style-type: none"> ○ Appears completely absent ○ Absence of greetings ○ Does so in a strange manner <p>Does the client respond to social interactions in an odd fashion?</p> <ul style="list-style-type: none"> • Specific prompts: <ul style="list-style-type: none"> ○ Awkward ○ Overly blunt ○ Hostile ○ Response to smile ○ Overfriendliness ○ Gives too much information <p>Can the client engage in back-and-forth conversation?</p> <ul style="list-style-type: none"> • Specific prompts: <ul style="list-style-type: none"> ○ Monosyllabic replies / only limited responses ○ Responds only to questions ○ Tangential responses ○ Monopolises conversation ○ Overly repetitive in same conversation <p>Can the client talk about their feelings, and if so how do they talk about them?</p> <ul style="list-style-type: none"> • Specific prompts: <ul style="list-style-type: none"> ○ Completely immersed ○ Only superficial or stereotyped descriptions ○ Possible to explore further? 		<ul style="list-style-type: none"> ○ Present ○ Possibly present ○ Not present ○ Present but attributable to cause other than ASD ○ Insufficient information to classify

Criterion	Prompt questions	Answers	Trait present?
<p>A2: Deficits in nonverbal communicative behaviors used for social interaction</p>	<p>What is the client's eye contact like?</p> <ul style="list-style-type: none"> • Specific prompts: <ul style="list-style-type: none"> ○ Absent ○ Fixed gaze <p>What are the client's facial expressions like?</p> <ul style="list-style-type: none"> • Specific prompts: <ul style="list-style-type: none"> ○ Absent ○ Limited range ○ Smile but nothing else ○ Could you guess how the client was feeling from their facial expression? <p>Does the client use and understand body language and gestures?</p> <ul style="list-style-type: none"> • Specific prompts: <ul style="list-style-type: none"> ○ Pointing ○ Nodding ○ Shaking the head ○ Inexpressive posture: stiff / rigid upper body ○ Absence of demonstrative gestures ○ Exaggerated / odd gestures <p>Does the client recognise unspoken cues when you are interacting with them?</p> <ul style="list-style-type: none"> • Specific prompts: <ul style="list-style-type: none"> ○ eg. Standing up at the end of a meeting to indicate the conversation is at an end ○ Responding to non-verbal instructions. Eg. shake of the head when you don't want someone to do something <p>When talking to others people typically coordinate their tone of voice, facial expressions, eye contact, gestures and body language with what they're saying. Does the client do this?</p>		<ul style="list-style-type: none"> ○ Present ○ Possibly present ○ Not present ○ Present but attributable to cause other than ASD ○ Insufficient information to classify

Criterion	Prompt questions	Answers	Trait present?
<p>A3: Deficits in developing, maintaining, and understanding relationships</p>	<p>Does the client adjust their behaviour depending on who they are around?</p> <p>Does the client notice and understand the impact their behaviour has on others?</p> <ul style="list-style-type: none"> • Specific prompts: <ul style="list-style-type: none"> ○ Rudeness ○ Losing temper ○ Being friendly / giving compliments ○ Oversharing <p>Does the client show an intuitive understanding of social situations?</p> <p>How successful has the client been at forming and maintaining friendships?</p> <p>Has the client been able to forms relationships with other individuals they come into contact with, such as hostel workers and staff?</p> <ul style="list-style-type: none"> • Specific prompts: <ul style="list-style-type: none"> ○ One sided friendships? <p>Is the client interested in making friends?</p> <p>Does the client show any interest in other people?</p> <ul style="list-style-type: none"> • Specific prompts: <ul style="list-style-type: none"> ○ Enjoys small talk / socialising for its own sake (beyond meeting wants/needs) ○ Asking people how they are ○ Asking people what they are up to ○ Remember what people have told them in previous conversations? 		<ul style="list-style-type: none"> ○ Present ○ Possibly present ○ Not present ○ Present but attributable to cause other than ASD ○ Insufficient information to classify

Criterion	Prompt questions	Answers	Trait present?
<p>B1: Stereotyped or repetitive motor movements, use of objects, or speech</p>	<p>Does the client show any repetitive movements?</p> <p>Does the client show any unusual hand mannerisms?</p> <p>Does the client repeat the same phrases many times?</p> <p>With regards to the sound of the client's voice, is their intonation unchanging / monotonous?</p> <p>Is the way the client speaks especially formal or stilted?</p> <p>Does the client use words they have made up themselves in conversation?</p> <p>Does the client repeat words you or someone else has said in a socially inappropriate manner?</p>		<ul style="list-style-type: none"> <input type="radio"/> Present <input type="radio"/> Possibly present <input type="radio"/> Not present <input type="radio"/> Present but attributable to cause other than ASD <input type="radio"/> Insufficient information to classify

Criterion	Prompt questions	Answers	Trait present?
<p>B2: Insistence on sameness, inflexible adherence to routines, or ritualized patterns of verbal or non-verbal behaviour</p>	<p>Does the client have any unusual routines?</p> <ul style="list-style-type: none"> • Specific prompt: <ul style="list-style-type: none"> ○ Very bound to this routine? ○ How do they cope if routine breaks down? (ie. Changing appointment time) <p>Does the client find it unusually difficult to cope with change and new activities?</p> <ul style="list-style-type: none"> • Specific prompt: <ul style="list-style-type: none"> ○ Even small change ○ Even if change / new activity is something others see as positive ○ Consider many types of behaviour ie. Food, greeting rituals <p>Does the client show any ritualized or compulsive behaviour, either verbal or non-verbal?</p> <ul style="list-style-type: none"> • Specific prompt: <ul style="list-style-type: none"> ○ Organisation of belongings ○ Routes taken ○ Sleep sites ○ Patterns of touching ○ Mentioning dates / pieces of information ○ Strong need to get to end of what they're saying 		<ul style="list-style-type: none"> ○ Present ○ Possibly present ○ Not present ○ Present but attributable to cause other than ASD ○ Insufficient information to classify

Criterion	Prompt questions	Answers	Trait present?
<p>B3: Highly restricted, fixated interests that are abnormal in intensity or focus</p>	<p>Does the client show an excessive interest in particular topics or objects?</p> <ul style="list-style-type: none"> • Specific prompt: <ul style="list-style-type: none"> ○ Keeps on wanting to talk about a particular topic? ○ Fixation on an issue, not just a hobby? <p>Does the client have any very focussed interests?</p> <ul style="list-style-type: none"> • Specific prompt: <ul style="list-style-type: none"> ○ Collecting an entire set of a particular item 		<ul style="list-style-type: none"> ○ Present ○ Possibly present ○ Not present ○ Present but attributable to cause other than ASD ○ Insufficient information to classify

Criterion	Prompt questions	Answers	Trait present?
<p>B4: Hyper- or hyporeactivity to sensory input or unusual interests in sensory aspects of the environment</p>	<p>Does the client show an odd response or seem unduly sensitive to any sensations? Ie. Sight, sound, taste, touch, smell</p> <ul style="list-style-type: none"> • Specific prompts <ul style="list-style-type: none"> ○ Loud noises / wears ear protectors? ○ Bright lights ○ General levels of stimulation (eg. daycentre, canteen) ○ Refusing to wear certain clothes because of the feel of the material ○ Clothes need to be a certain level of tightness / looseness, have a favourite bit of clothing ○ Commenting on smells that most people would not notice ○ Eating <p>Does the client have a particularly strong interest in any sensory stimuli? Ie. Sight, sound, taste, touch, smell</p> <p>Does the client appear to find any everyday sensory stimuli painful or distressing?</p> <p>Does the client appear under-reactive to certain sensations?</p> <ul style="list-style-type: none"> • Specific prompts <ul style="list-style-type: none"> ○ Pain ie. injuries going untreated ○ Cold / heat 		<ul style="list-style-type: none"> ○ Present ○ Possibly present ○ Not present ○ Present but attributable to cause other than ASD ○ Insufficient information to classify

Do any of the symptoms talked about above cause significant impairment in the client's current functioning? If so, which ones?

Is there anything else you have noticed about the client which you think might be relevant to what we have been discussing today?

Appendix 4: Autism Spectrum Disorder in Adults Screening Questionnaire

Date:

Participant ID:

Name of researcher:

	Yes	No	Don't know
1. Does the patient have any problems regarding contacts with others? (e.g. cannot get or keep friends of the same age, or cannot get reciprocally satisfying contacts with sex partners).	<input type="checkbox"/>	<input type="checkbox"/>	
2. Is the patient odd, eccentric, 'one of a kind'?	<input type="checkbox"/>	<input type="checkbox"/>	
3. Do you find the patient compulsive or rigid, occupied by rituals, routines or rules?	<input type="checkbox"/>	<input type="checkbox"/>	
4. Has the patient trouble with clothing, grooming and personal care? (e.g. conspicuously old-fashioned or ill-fitting clothing).	<input type="checkbox"/>	<input type="checkbox"/>	
5. Has the patient or has he/she earlier had, special interests, i.e. an intense interest that keeps the patient from engaging in other activities, or an interest that the patient wants to talk about all the time? The subject of the special interest is not important, but the intense engagement or repetitive talking about it.	<input type="checkbox"/>	<input type="checkbox"/>	
6. Has the patient a bizarre language or a strange/unusual voice? Does he/she speak in a very grammatical or old-fashioned way, or use standard phrases or clichés, or talk in an unnecessarily loud or low voice? Does he/she talk in a monotonous, or shrill or whining voice?	<input type="checkbox"/>	<input type="checkbox"/>	
7. Has the patient an unusual non-verbal communication, e.g. abnormalities in gaze, gestures or facial, expression, unusual posture, stiff gait, etc.?	<input type="checkbox"/>	<input type="checkbox"/>	
8. Does the patient seem to have a lack of common sense, or lack the ability to understand and foresee the consequences of his/her doings or sayings? This might cause the patient to repeatedly getting into difficult or embarrassing situations, or get others into these situations.	<input type="checkbox"/>	<input type="checkbox"/>	
9. Is the patient uneven in his/her abilities, i.e. very skilful in some areas while lacking elementary knowledge or skills in others?	<input type="checkbox"/>	<input type="checkbox"/>	
10. Has the patient had any contacts with child and adolescent psychiatry?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Appendix 6: Details of joint project

This project was run jointly with Morag Ryder, trainee clinical psychologist at UCL. All study planning was completed together, including deciding on study methodology, writing the ethics application, and liaising with the homeless outreach team and other interested parties.

I created the DATHI, Morag created the two measures in appendix 5.

Both trainees did all parts of the screening interview including the DATHI, ASDASQ, and the additional measures detailed immediately above. The workload was split so each trainee screened approximately half of all cases on the caseload.

We assisted each other with the reliability checking process. Morag helped me with sending scans of the DATHI and other documents to the supervisors, and I was the second rater for her reliability check. All analyses were conducted separately.

We collaborated on all aspects of increasing the 'impact' of the study.