UNDERSTANDING THE AUTISM ASSESSMENT EXPERIENCE FOR YOUNG PEOPLE

by

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Thesis Overview

This thesis consists of two volumes; volume one is a meta-analysis exploring the prevalence of autistic people in generic psychiatric inpatient settings; volume two is an empirical paper which explores the autism assessment experience for young people. The aim of the research papers was to identify areas of clinical practice that could be improved to better support the needs of autistic people and their families. Also, to explore whether assumptions that autistic people are over-represented in inpatient settings is accurate.

The meta-analysis found 13% of children in generic psychiatric inpatient units are autistic and 4% of adults are autistic. These estimates far surpass the estimated prevalence of autistic people in the general population (1%). The meta-analysis evaluated each included study in terms of their methodological quality and design features. High risk of reporting bias was significant in affecting the predicted prevalence rates of autistic people. Furthermore, the way in which autism was diagnosed and recorded varied considerably across the included studies. Suggestions for further research are discussed.

The empirical paper used a within-participants design to assess for change in young people's mental health symptoms during the autism assessment process. Descriptive statistics found young people and parents mostly rate mental health symptoms within clinical thresholds for anxiety diagnoses. Also, the repeated measures data appears to support the alternative hypothesis by demonstrating a decline in anxiety symptoms for young people. However, this finding was not mirrored in depressive symptoms or quality of life. Suggestions for future research are explored within the discussion.

For Loz,

for always believing in me

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A. Chapter and Sections

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Prevalence of Autism in Psychiatric Inpatient Settings: A Meta-Analysis

Abstract

Purpose

Government reports highlight global statistics of the number of autistic people admitted to psychiatric inpatient settings, however it is not clear the types of settings included in these reports, or the rate compared to non-autistic people. Literature reporting on autism demonstrates high rates of co-occurring mental health difficulties for autistic people, including more severe and life-threatening incidents often leading to inpatient admissions. National guidance suggests autistic people should be offered specialist care and treatment however, it is often reported this population are admitted to unsuitable, generic settings. This meta-analysis aims to synthesise the empirical literature reporting prevalence of autistic people in generic inpatient settings, with the aim to emphasise the over-representation.

Method

A systematic search of three databases (Ovid PsycInfo, Ovid Embase and Ovid Medline) was conducted on 25th July 2022. Specific search criteria were used to identify papers reporting on autistic people and psychiatric inpatient settings. Returned studies were reviewed using established inclusion and exclusion criteria. Data from the included studies were extracted and analysed. A quality assessment including risk of bias and design hierarchy were undertaken and subgroup analyses were performed.

Results

Fifteen studies were included in the review and rated in terms of methodological quality. The meta-analysis estimated the prevalence of autistic people in psychiatric inpatient settings to be 11%, with a 95% confidence interval of 6-16% (13% for child inpatient settings and 4% for adult inpatient settings). The prevalence rate found by the review is much higher

than the prevalence of autistic people in the general population. Significantly higher prevalence was estimated for studies of children vs. adults. High levels of heterogeneity were explored statistically.

Discussion

This review indicates that autistic people are over-represented in psychiatric inpatient settings. Differences in recruitment of autistic people, detection of autism, the settings themselves and referral pathways for autistic patients to inpatient settings may play a role in the prevalence rates found. Furthermore, the level of reporting bias was found to be significant where unclear reporting of prevalence figures suggested smaller event rates and may have missed the full autistic population in their calculations.

Introduction

Psychiatric inpatient care is acute hospital care for people in a mental health crisis, who may not be able to live safely at home/in the community (Horsfall et al., 2010). There are many different types of inpatient facilities, including: acute/generic psychiatric hospital wards, specialist units for people with neurodevelopmental or learning disability needs, forensic settings for those who have committed a crime and residential/rehabilitation settings for long-term mental health difficulties. Reasons for admission to psychiatric inpatient facilities can vary, however Bowers (2005) described some commonly reported themes: dangerousness (patients are primarily admitted to prevent harm to themselves and others), assessment and medical treatment, severe psychotic symptoms unmanageable in the community, severe self-neglect and respite purposes. In addition, Unick et al. (2011) reported overall psychosocial functioning as significantly associated with inpatient admission rates, with higher scores on the Global Assessment Scale (indicating better functioning) being associated with a lower probability of admission, while the presence of delusions were associated with higher probability of admission.

There has been a global shift in approach to psychiatric care, with the majority of countries prioritising community-based care (Thornicroft & Tansella, 2002). Mundt et al. (2021) reported a decrease in psychiatric beds in 29 out of 30 counties, with an average percentage change decrease of 34% over ~30 years. In the United Kingdom, inpatient care beds have gradually decreased from the year 2000 (54,117), to as few as 21,300 in 2021 (Michas, 2022). However, there continues to be a need for inpatient care for those experiencing a mental health crisis, and the evidence reports autistic people and people with cognitive impairments are over-represented in these inpatient settings (Tromans et al., 2018;

Wood et al., 2019). Understanding the particular profile of those who continue to access inpatient care is crucial to meet their needs.

Recent prevalence studies have reported that around 1% of the general population are autistic (Zeidan et al., 2022), with new estimates seeming to increase beyond this. Estimates of autistic children aged 8 years in the USA have increased from 6.7 per 1,000 in 2000 to 27.6 per 1,000 in 2020 (Maenner et al., 2023). Autism Spectrum Disorder (ASD) is a heterogeneous spectrum of neurodivergence, diagnosed on the basis of deficits in two domains: social communication and interaction, and repetitive, restrictive patterns of behaviour resulting in significant educational, social and health needs for the individual and/or family (Hyman et al., 2020). Comorbid neurodevelopmental and psychiatric conditions are common in autistic people, including mood disorders, conduct disorders and Attention Deficit Hyperactivity Disorder (ADHD) (Brookman-Frazee et al., 2018). Autism can be associated with poorer quality of life, increased disability and lower life expectancy. A review by Baxter et al. (2015) reported that, in children aged 5-14, autism was the fourth largest cause of disability and accounted for 7.7 million disability-adjusted life-years across the lifespan. A further review by Ruggieri et al. (2019) reported that autistic people were more vulnerable to premature health deterioration and mortality, given risk factors associated with the disorder such as neurological conditions, comorbid psychiatric illness, genetic conditions and prolonged drug therapy.

Compared to the general population, Mental Health (MH) difficulties are significantly more prevalent in autistic people, and co-occurring MH conditions are highly prevalent in the autistic population (Lai et al., 2019). This finding is consistent across genders, with autistic men, women and Non-Binary and Trans (NBT) groups displaying more anxiety and depression than non-autistic counterparts (Sedgewick et al., 2021). It is also consistent across ages, with 80% of an autistic adult sample accessing mental health services (Vogan et al.,

2017) and more autistic young adults being hospitalised for psychiatric reasons compared to non-autistic young adults. (Weiss et al., 2018). High prevalence of MH difficulties in autistic people is also found in older adults, with the largest between-group differences found in personality disorders, schizophrenia and psychotic disorders (Hand et al., 2020). Sedgewick et al. (2021) also found differences within the autistic population, with women and NBT groups displaying more anxiety than autistic men. Despite this high prevalence, a scoping review (Cleary et al., 2022) revealed significant barriers for autistic people in accessing mental health services including: under-resourcing, lack of understanding or training by health professionals, difficulties understanding how to access services and disrupted continuity of care, along with a void in the empirical literature on how autistic people access crisis helplines.

Autism diagnosis is also associated with higher risk of deliberate self-harm. In a recent systematic review, Blanchard et al. (2021) found 29 out of 36 included studies demonstrated significant associations between autism and self-harm, a finding that was mostly consistent across age and location. Rates of self-harm are also found to increase throughout adolescence for autistic young people, up to two times as much for girls and four times as much for boys aged 14-17 years, compared to lower incidence rates at 11 years (Widnall et al., 2022). Furthermore, there is a significantly increased risk of suicide (up to three times higher) in autistic young people and adults, compared to the general population, with women and girls and individuals with co-morbid MH difficulties being the most at risk (Kõlves et al., 2021). Researchers have urged funding agencies to dedicate more resources to understanding MH difficulties and suicidality in autistic youth and adults (South et al., 2021).

Given the increased risk of harmful behaviours and MH conditions, it is unsurprising that autistic young people present to Emergency Department (ED) services four times as often as non-autistic youth (Liu et al., 2017). Such ED visits are also more likely to lead to

inpatient admission. Compared to age-matched typical counterparts, Iannuzzi et al. (2022) reported autistic adolescents and young adults were 3.7 times more likely to be admitted to inpatient services following a visit to ED. Siegel and Gabriels (2014) reported the primary reasons for admitting autistic youth to inpatient services are due to externalizing behaviours, including self-harm, aggression and 'tantrums'. Similarly, in autistic adults, behavioural problems, including physical aggression, overactivity and "pestering staff" were found to be significant predictors of inpatient admissions, further involvement from psychiatric services and the use of psychotropic medications (Tsakanikos et al., 2007).

An increased awareness of autism has logically increased demand for assessments across the lifespan. A later diagnosis could be problematic, as children diagnosed with autism later in their adolescence (after 11 years old) have reported increased depressive symptoms and a stronger association to self-harm behaviours (Hosozawa et al., 2021). In addition, Russell et al. (2016) reported a significantly higher rate of anxiety and obsessive-compulsive disorders in adults meeting criteria for an autism diagnosis compared to those who did not meet the criteria. Furthermore, older people who are not diagnosed with autism as a child are at risk of having been mis-diagnosed with other conditions e.g. Learning Disability, ADHD, MH conditions, or could have been undiagnosed due to 'masking' difficulties for so long (Fusar-Poli et al., 2020). Reports have also found a significant overlap between autism and psychosis (Sullivan et al., 2013). However the 'psychotic' presentation may be better explained by being autistic, further demonstrating the system's difficulties in understanding the differences in presenting symptoms and possibly leading to over-prescribing medication and the person's true needs not being met (Van Schalkwyk et al., 2015).

Autistic people experiencing a mental health crisis could be admitted to either general psychiatric units or specialist units. Specialist units report a significantly lower average length of stay, a higher staff to patient ratio and a more diverse staff group (Siegel et al.,

2012), whereas it is likely that staff employed in general inpatient units have limited training in how to support this population and the unit is likely to offer a therapeutic approach that is not adapted to their needs (McGuire et al., 2015). Furthermore, a qualitative study by Maloret and Scott (2018) reported that autistic people who were admitted to generic psychiatric inpatient units experienced increased anxiety symptoms due to difficulties in relating to staff, difficulties accepting the changeability of the routine, anxiety around predictability of food, had limited access to their usual coping strategies and the physical environment playing a role in those with sensory difficulties. Whereas, in a prospective study of six specialist units, Pedersen et al. (2018) found a significant improvement in "problem behaviours" from autistic children at discharge and found this was maintained two months post discharge. Disappointingly, due to the limited number of specialist units world-wide, autistic young people are often admitted to general units for mental health care, with a call to changes to healthcare policy to be data-driven and include a long-term projection of cost savings when providing effective specialist units (McGuire & Siegel, 2018).

In England, government initiative 'Assuring Transformation' reports monthly figures of "people with autism and learning disabilities" in hospital, and reported 2030 people with autism and/or learning disability were in hospital at the end of December 2022 (NHS Digital., Jan 20, 2023). In addition, there is existing evidence that autistic children and adults are admitted to inpatient units more frequently than their neurotypical peers (Croen et al., 2006; Melvin et al., 2022). It is clear that this is not a problem unique to autistic individuals. Similar findings of over-representation have been reported for ADHD patients, highlighting higher prevalence of ADHD in acute inpatient settings compared to the general population (Lines & Sadek, 2018), patients with psychosis (Salazar de Pablo et al., 2021) and patients with conduct disorder (Patel et al., 2018).

Given the National Institute for Health and Care Excellence (NICE) guidance for supporting and managing autism suggests access to specialist care and intervention supported by staff with expert knowledge and competence (NICE, 2021), and given the increase in demand for autism assessments in the UK (NHS Digital., Sept 8, 2022), it was important to ascertain the extant estimate of the pooled prevalence of autism in generic psychiatric inpatient settings as reported in empirical studies. Though a level of over-representation in inpatient settings is expected given the higher rates of co-morbid mental health difficulties and high-risk behaviour, understanding the amount of over-representation of autistic people in these settings, understanding how autism diagnoses are counted/reported and knowledge of which inpatient settings are contributing to this data is clinically important for organisations planning healthcare spending and the development of services so that they are efficient and effective in treating autistic individuals.

Rationale

Literature exploring autism in psychiatric inpatient settings typically focuses on therapeutic interventions, psychotropic medications and length of stay compared to typically developed peers. Autistic people are over-represented in general psychiatric hospitals, which are not typically set-up to manage their needs. The creation of specialist units has been helpful in offering autistic people care and treatment more suited to their needs with appropriately trained staff, however places in these settings can be difficult to find and likely to be out-of-area for the individual/family.

Given the increased rate of severe and high-risk mental health difficulties found in autistic populations, it is unsurprising that evidence reports high rates of autistic people in inpatient settings compared to the general population. This meta-analysis will summarise peer-reviewed, empirical studies describing an autistic population within generic psychiatric

inpatient settings to establish a pooled event rate estimate. Establishing the pooled event rate estimate will help to highlight the extent to which autistic people are over-represented in generic inpatient settings. Various factors might affect the prevalence of autistic people in inpatient settings such as: age of sample, country of inpatient setting and variations in how autism diagnoses are made. As reported by Zaroff and Uhm (2012), a key reason for the variation in prevalence of autism worldwide is methodological variation in the diagnostic process. These factors will be considered in the meta-analysis as sub-group analyses. The review seeks to address the question: how many autistic people are in generic psychiatric inpatient settings?

Method

This meta-analysis follows the Preferred Reporting Items for Systematic Reviews and Meta-analyses (PRISMA) 2020 statement (Page et al., 2021), see completed checklist in Appendix 1. The review was accepted to the Prospero register on 12th July 2022 (registration number: CRD42022342000). An amendment was submitted on 1st August 2022, due to completing a new search.

Search Strategy

A systematic literature search was conducted on 25th July 2022, using Ovid PsycINFO (1967 – 2023), Ovid Medline (1946 – 2023) and Ovid Embase (1974 – 2023) databases. Forward and backward searching of references was not utilised. The search terms used to identify relevant papers are described in Table 1. The 11 search terms for Autism Spectrum Disorder were created using a recent review by Steenfeldt-Kristensen et al. (2020). Additionally, the reference lists of recent reviews on similar topics by Allely (2018) and

Tromans et al. (2018) were hand searched, to identify further papers not returned by the original search.

Table 1

Search Criteria

Construct	Free Text Search Terms	Method of Search
ASD	'Autis*' OR 'Autism*' OR 'Autistic*' OR 'ASD' OR 'Autism Spectrum Disorder exp' OR 'Asperger* Syndrom*' OR 'Asperger*' OR 'PDDNOS' OR 'Unspecified PDD' OR 'Pervasive developmental disorder' OR '"Pervasive developmental disorder not otherwise specified"' OR	Free search terms All search terms combined with *OR*
	AND	
Psychiatric Inpatient	'Psychiatric hospita*' OR 'Inpatient adj2 psychiatric' OR 'Inpatient adj2 mental health' OR 'Psychiatr*' OR '"psychiatric inpatient"' OR 'Partial hospita*' OR 'Psychiatric hospitalisation exp'	

Inclusion Criteria

The full inclusion/exclusion criteria are described in Table 2. Papers were included in the meta-analysis if they reported a population of autistic people within a generic psychiatric inpatient setting, were available in the English language and were empirical research enabling event rates to be calculated.

Table 2

Inclusion and Exclusion Criteria

Inclusion criteria	Justification
Language of research	
Papers published available in English language.	ASD is a well-known term in the English language. Ensuring papers are published in English language means that studies included are focused on ASD and not other conditions that could influence the results of the analysis.
Measurement of ASD	
An adequate ASD diagnosis/testing of autism process must be reported.	When reporting the prevalence of a condition it is important the diagnosis of ASD is reliable. Formal autistic testing using validated measures, multi-disciplinary discussion and observation of the person, use of staff/family completed measures or a diagnosis from an experienced consultant were accepted forms of diagnosis.
Participant focus	
Studies that included individuals of all ages, genders, ethnicities and mental health diagnoses were included.	There is no reason to exclude specific demographic/diagnostic information at this time.
Studies reporting pure LD populations were excluded.	Evidence suggests autism is more common in LD populations however there is confusion in the literature and within services as to whether a person requires hospital admission due to their LD or their mental health. It is assumed that people with LD will require specialist support within services and are less likely to be admitted to general psychiatric inpatient services.
Studies must include all those with autism in the sample.	Studies which only include a specific ASD diagnosis e.g. Asperger's or high functioning ASD will be excluded as other autistic people may have been excluded.
The population could be detained on a section under the mental health act.	Mental health act sections are used globally and should not confuse the data.
Forensic populations were excluded e.g. prison environments and those detained in secure forensic hospitals due to criminal activity were excluded.	The decision to exclude forensic populations was made due to reasons for access and admission to secure settings tend to be different to generic inpatient settings. No reason to believe these would produce reliable data combined in the prevalence rate.
Prevalence	
The studies are required to report the prevalence of autism within the inpatient psychiatric setting.	To ensure that the event rate can be calculated.
Setting	
The study must report data from a psychiatric hospital inpatient stay, either full time or part time (not based on length of stay), where the participants required treatment for a mental health difficulty, as opposed to a difficulty associated with a learning disability.	The sample will not meet intelligence quotient for a learning disability, suggesting their difficulty is not associated with their ability to understand information, to learn or complete everyday tasks.
The study must report data from a generic psychiatric inpatient setting.	The study aims to identify prevalence of autistic people within generic psychiatric inpatient settings, consequently specialist units will not be included.

Type of article	
Articles must be peer-reviewed.	To ensure studies have gone through a process of evaluation by journal editors and expert scholars to critically assess the quality and validity of the paper.
The following article types were excluded: meta-analysis/theoretical papers/ reviews/commentaries/clinical guidance/non-outcome focused studies i.e., validation of psychometric scales/qualitative papers.	These articles do not provide the outcome data needed for this meta-analysis.

Data Extraction

Prevalence figures of autistic people reported and total size of the inpatient population were extracted. Other demographic data of interest were extracted, including age, gender and ethnicity of the sample, the country the research was conducted in and which measures of autism were used. A second reviewer repeated the data extraction process and no differences were found, suggesting excellent consistency in extracting event rates.

Quality Review

A set of quality criteria were developed to assess any risk of bias within this literature. The quality criteria were adapted from existing risk of bias frameworks, including The Cochrane Collaboration Risk of Bias Tool (Higgins et al., 2011) and the Risk of Bias Assessment Tool for Nonrandomised Studies (Kim et al., 2013). Numerical quality weightings were used to evaluate the study design and consider other methodological flaws and biases to the data. Five areas of methodological quality were reviewed and rated in terms of risk of bias, these include: selection bias, detection bias, statistical bias, reporting bias and generalisation. Due to the present study evaluating prevalence rating, treatment fidelity was not included in the bias ratings. Similarly, performance bias was not relevant to prevalence rate data extraction (as this type of data is not influenced by social desirability bias) and most commonly participants were unaware of their involvement in the study (i.e. prospective or

retrospective data collection for individuals who gave consent at the time of their admission) and consequently their motivation was not assessed. Numerical weightings were given to low risk, unclear risk and high risk. In addition, study designs were split into a weighted hierarchy according to Ho et al. (2008). Important to note is, the studies were rated in terms of their quality in addressing the question relevant to this meta-analysis, i.e. the main outcome of interest which is the prevalence rating. It is acknowledged that these studies may score differently in terms of quality when addressing their own research question. A second reviewer also rated each included study in terms of the quality index to ensure consistency and reduce bias. This revealed excellent inter-rater consistency, as reported by Kappa = 0.887, with 95% confidence interval of 0.792 to 0.983.

The risk of bias in the five domains and the criteria for Low, Unclear or High risk is described in Table 3 and the design hierarchy in Table 4.

Table 3

Domains of Risk of Bias and the Criteria for Ratings of Low, Unclear or High Risk

Risk of Bias	High Risk	Unclear Risk	Low Risk
Selection Bias			
Selection bias in epidemiological studies occurs when there is a systematic difference between the characteristics of those selected for the study and those who are not. **Does the study design yield a sample of respondent's representative of the target population?** **Is the target population defined clearly?** **Was some form of random sampling used to select potential respondents?**	The characteristics of the study population are not reported. The characteristics of the study group are not representative of the target population. Selection criteria might be based on appropriateness for an intervention for another difficulty (e.g. challenging behaviour, isolation, restraint) and the event rate is secondary to the main outcome of the study. Other exclusion/inclusion criteria may contaminate estimate of events.	The characteristics of the study group are not clearly defined. It is not clear how the researchers sampled the study group. Sampling is adequate but is selected from a pre-existing (clinical) sample. Selection method is not ideal (e.g., quasi randomised), although characteristics of the study group are representative of the target population. Data is recruited from a single site and therefore at higher risk of confounding variables and less reflective of greater population. Not clear whether the selection of participants would contaminate estimate of event.	The characteristics of the study group are clearly described and without evidence of bias. Sampling method used is unbiased. The source population is well described, and the study reports the characteristics of the sample e.g., the study details subgroups. Data is recruited from multiple sites. The recruitment method is clearly reported and well defined. The article provides some reassurance that there is no selection bias.
Detection Bias			
Detection bias refers to whether the design of the study is optimised to detect the effect in question. Ratings of design bias therefore reflect the position of the study design within the hierarchy of possible designs, with less optimal designs receiving a penalty. **Systematic differences between participants in how outcomes are determined. Blinding (or masking) of outcome assessors may reduce the risk that knowledge of which intervention was received, rather than the intervention itself, affects outcome measurement. Blinding of outcome assessors can be especially important for assessment of subjective outcomes.** **Was the study instrument that measured the parameter of interest**	Outcome measures used are non-standardised and do not report psychometric properties, or global self-evaluation (e.g. yes/no) of ASD. Measure not fit for purpose. The outcome measures were implemented differently across participants. Only using one dimension/subscale of the scale or separating the subscales/dimensions in the analysis. No clearly reported description of how ASD diagnosis was made.	Assessment measure is not widely recognised, or peer reviewed and/or the psychometric properties are reported but poor. It is not clear if the measure was implemented consistently across all participants. Clearly defined diagnosis process but incomplete process e.g. uni-disciplinary or invalidated measures used. The research question is unclear.	The outcome measures are clearly defined, valid and reliable, and are implemented consistently across all participants. Standardised measures with good psychometric properties used to assess symptoms of/confirm diagnosis of ASD. MDT diagnosis inclusive of formal measures.

Risk of Bias	High Risk	Unclear Risk	Low Risk
shown to have reliability and validity?			
Statistical Bias			
Bias resulting from the statistical treatment of the data. Were prevalence rates appropriately reported (e.g. including descriptive statistics such as gender)?	Event rate is not provided. Event rates are adjusted for methodological confounds. No sample related data provided.	Event rate is inadequately calculated or unclear. Analysis of the samples varies across subgroups within the study.	Clear raw event rate or percentage provided or this can be calculated accurately using the statistics given. Sample statistics are provided for all subgroups.
Was there missing or incomplete data (e.g. the n in one section is different to the n in another section of the report) **Indicate if appropriate statistical methods used.**	Incorrect method of data analysis used to report sample statistics.		
Reporting Bias			
Reporting bias is due to selective or unclear reporting of the main outcome (prevalence) **Does the study provide reasons for attrition or exclusions where reported, and any re-inclusions in analyses for the review?**	Reports only a subsample of results/only significant results. Did not report the entire sample of inpatient unit or the sample of autism within it. Data does not appear to be accurately reported.	Not all/summary descriptive statistics are presented. Unclear report of size of inpatient unit and/or group of autistic people within it.	Size of inpatient unit and autistic group within it clearly reported.
Generalisation			
Generalisability describes the extent to which research findings can be applied to settings other than that in which they were originally tested. **Are there sufficient numbers of participants for the study to be statistically meaningful?**	Small sample with or without idiosyncratic feature.	Sufficient sample for generalisation but with some idiosyncratic features. Sample less than 200.	Sufficient sample for generalisation and representative of target population.

Table 4

Study Design Hierarchy

Study Design	Numerical Weighting	Description
Prospective case cohort study	40	Cohort Study (prospective) is a study of a group of individuals, some of whom are exposed to a variable of interest (e.g., drug or environmental exposure), in which participants are followed up over time to determine who develops the outcome of interest and whether the outcome is associated with the exposure.
Retrospective case cohort study	30	Cohort Study (retrospective) is when data is gathered for a cohort that was formed sometime in the past. Exposures and outcomes have already occurred at the start of the study. You are studying the risk factor and see if you can associate a disease to it. Individuals split by exposure.
Case control study	20	Case Control Study is a study in which patients who already have a specific condition or outcome are compared with people who do not. Researchers look back in time (retrospective) to identify possible exposures. They often rely on medical records and patient recall for data collection.
Cross-sectional studies	10	Cross-Sectional Study is the observation of a defined population at a single point in time or during a specific time interval to examine associations between the outcomes and exposure to interventions. Exposure and outcome are determined simultaneously. Often rely on data originally collected for other purposes.

Data Analysis

Data were analysed in R (R Core Team, 2022). A standard data analysis protocol and analysis script developed at the Centre of Applied Psychology at the University of Birmingham was used. The generic inverse variance method with the Restricted Estimator of Maximum Likelihood was used to calculate pooled prevalence methods. Quantile-Quantile (QQ) plots were examined to determine normality of Random and Fixed Effects Models.

Defining Problematic Variance

A study-level effect is considered heterogeneous if it presents with variation from the weighted average that cannot be attributed to true variation in the distribution of effect in the population. Heterogeneity can result from methodological variation in the studies, measurement error or uncontrolled individual difference factors within the body of literature. Higgins I^2 is a commonly used measure of heterogeneity, with greater values of I^2 indicating variation in effect that cannot be attributed to true variation in the distribution of effect in the population. As there is considerable variation in methodologies of the included studies that were used to calculate the meta-analytic synthesis, problematic heterogeneity was defined as a Higgins I^2 value greater than 75% (Higgins et al., 2003). Where unacceptable or

problematic heterogeneity was observed, the focus of the subsequent analyses was on the identification of the sources of heterogeneity between the estimates of prevalence in the included studies.

In the event of problematic variance, a 'leave one out' analysis was conducted using Baujat plots to identify studies that were substantially discrepant and influential. In the event that such studies were identified, papers were reviewed to ascertain whether there was a substantial risk of bias as determined by the overall score on the quality framework, and whether the paper was notably discrepant from the other papers in terms of their methodological choices such as measurement or recruitment. Influential and discrepant papers with high risk of bias were removed, and those discrepant and influential with low risk of bias were removed if clear methodological decisions were notably different from the field.

To identify and account for publication bias and small sample sizes, funnel plots were used. Where publication bias was evident, this was corrected using a trim and fill procedure and imputing further studies. A failsafe algorithm was used to identify the likelihood that unpublished studies would report different results (Orwin, 1983).

Results

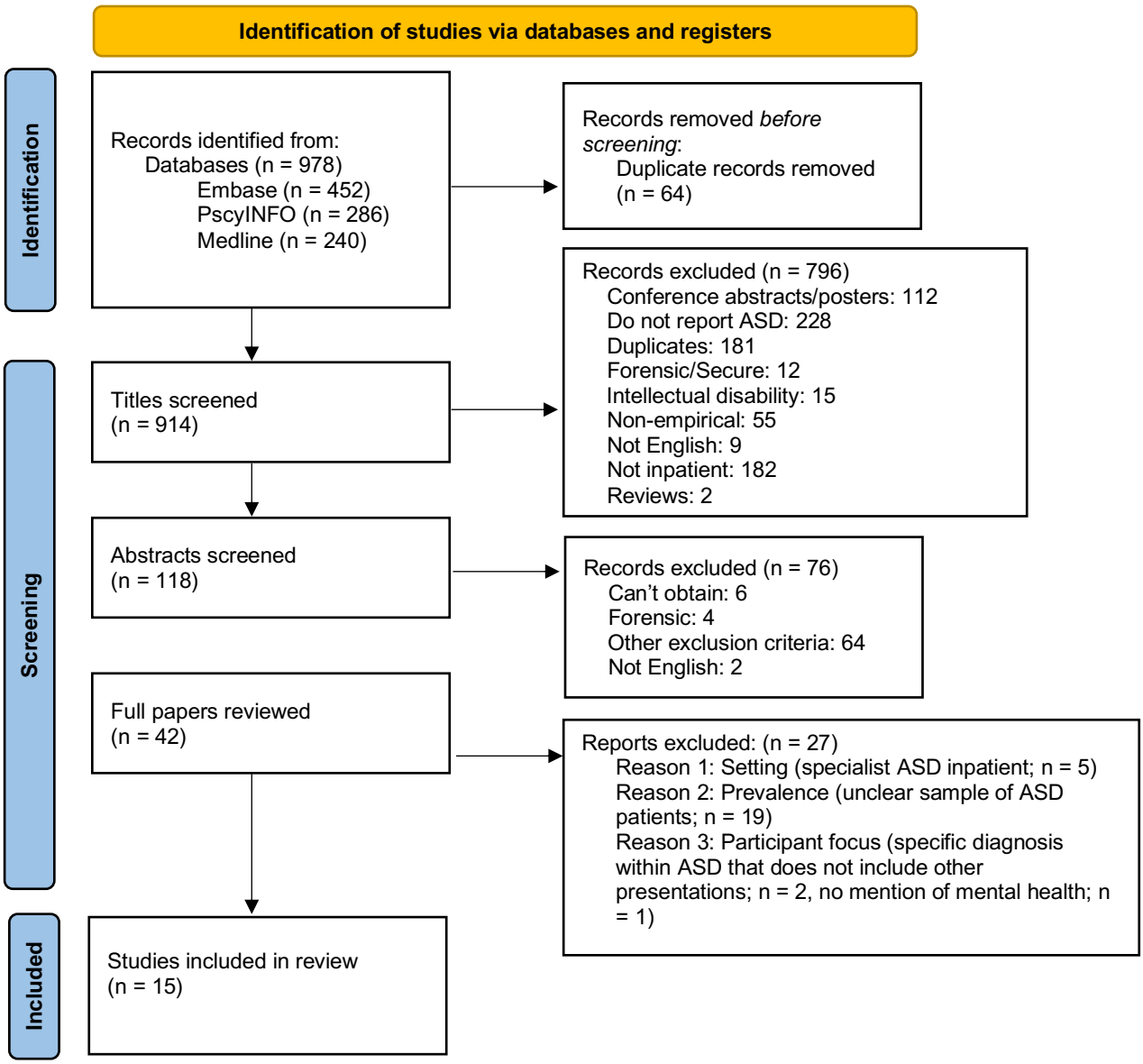
Search Results

The results of the systematic search are presented in Figure 1. The search yielded 978 articles and 914 once duplicates were removed. Studies were excluded if it could be clearly determined that they did not meet the inclusion criteria i.e. if the study title reported that it was a review study. All papers including adults or children with a reference to mental health and/or autism were included to abstract review. A second reviewer reviewed 10% of the initial 914 articles. This revealed discrepancies in how full texts were put forward for review. In further discussions, the screening approach was re-evaluated, and additional studies put

forward. Following this, 42 full papers were retrieved and reviewed. Five papers identified from recent reviews (Allely, 2018; Tromans et al., 2018) were all excluded at abstract screening. Fifteen articles met the full inclusion criteria for the meta-analysis. The second reviewer reviewed a further 10% of the articles, which did not find any additional papers to include.

Figure 1

PRISMA Diagram - Results of the Systematic Search and the Application of the Inclusion Criteria



Eligibility of Data

The inclusion/exclusion criteria were used to assess data eligibility for each study, with the added criterion that the study reported on a unique sample (or a potentially overlapping sample, but the proportion of overlap could not be readily determined). Furthermore, papers were not included in the synthesis if a clear figure for autistic people

requiring psychiatric inpatient admission was not reported. Several studies explored the clinical population in terms of treatment and outcomes but did not report total inpatient samples or used a pre-existing register of autistic people which was not specific to an inpatient setting. Papers were excluded where only one specific autism diagnosis was reported e.g. Asperger's or high functioning autism due to the authors excluding other individuals who likely met the criteria for an autism diagnosis, and so the reported admission rate is likely to be an underestimate of the actual population of autistic people.

Included Studies

The prevalence of autistic people described in the primary studies is reported in Table 5. There were 15 studies reporting a total of 5,394,828 participants, of which 40,225 were autistic. Also included in the table are demographic characteristics including mean age, gender and ethnicity statistics, information on the inpatient setting, the event rate and country in which the study was conducted.

Table 5

The Prevalence of Autistic People Described in the Studies

Study Name & Year	EXP cases	EXP N	Country	Setting	Mean Age	Gender	Ethnicity
Alikhani et al. (2019)	33	192	Iran	Academic psychiatric centre	15.2 years	56% male, 44% female	Not reported
Beer et al. (2005)	14	139	UK	20 low secure psychiatric units	39 years	77% male, 23% female	152 white, 44 black Caribbean & African, 17 other
Blazquez et al. (2019)	1	72	Spain	Inpatient unit for children & adolescents, Psychiatry & Psychology	15.3 years	74% female, 26% male	Not reported
Dean et al. (2008)	22	134	Australia	Child & Adolescent psychiatric inpatient	13.8 years	61.9% female	3% Aboriginal and Torres Straight Islanders
Etyemez et al. (2020)	72	14253	USA	Psychiatric Centre	23.4 years*	Not reported	Not reported
Galitzer et al. (2021)	113	211	UK	Child & Adolescent psychiatric inpatient	10.8 years	55% male	Not reported
Lunsky et al. (2009)	20	760	Canada	9 x psychiatric hospitals	35.43 years*	74% male, 26% female*	Not reported
O'Donoghue et al. (2020)	121	777	USA	Acute, inpatient psychiatric hospital	9.7 years	499 male, 278 female	Not reported
Ozbaran et al. (2022)	36	253	Turkey	Child & Adolescent psychiatric inpatient	11.85 years*	149 female, 104 male	Not reported
Pejovic-Milovancevic et al. (2011)	54	264	Serbia	Child & Adolescent psychiatric inpatient	11.4 years	61.4% male, 38.6% female	Not reported
Perisse et al. (2010)	41	420	France	Child & Adolescent psychiatric inpatient	14.8 years*	23 males, 6 females*	62% Immigrant families*
Potegal et al. (2009)	44	130	USA	Child psychiatry inpatient unit	9.6 years	78.5% male	78.5% White
Rast et al. (2022)	39,450	5,375,840	USA	National Inpatient Sample (NIS)	10.8 years*	75.8% male*	61.8% White*, 13.7% Black*, 16.4% Hispanic*, 8% Other*
Taylor et al. (2019)	85	1165	USA	Child & adolescent psychiatry units, academically affiliated	11.85 years*	92.5% male*	74% Caucasian* 96% non-Hispanic*
Zinna et al. (2021)	119	218	UK	Child & Adolescent psychiatric inpatient	10.7-10.8 years	45.9% female	Not reported

Note. *mean age of subsample (autistic sample) as authors did not report mean age of wider sample

Risk of Bias in Studies

The application of the risk of bias criteria to the included studies is shown in Table 6, which also reports an overall quality index. This index was calculated by first assigning a numerical weighting according to the methodological rigour of the study's overall design (see Table 4). A total risk of bias score was then calculated by summing the five risk of bias domains (low risk = 2 points, unclear risk 1 point, high risk = 0 points), such that the total risk of bias score could vary between 0 and 10 points, with 10 points indicating lowest possible risk of bias. The study design score and the total risk of bias score were then summed and the overall quality index for each study was expressed as a percentage of the theoretical maximum score (i.e., the highest quality design without risk of bias).

Therefore, the overall quality index provides a rating that combines the overall quality of the study design and the presence of the specific risks of bias. The overall quality index ranged in value between one study at 32% (Lunsky et al., 2009) to four studies at 94%. Each bias domain for each study included is presented in Table 6. Red indicates high risk of bias, amber marks an unclear risk of bias and green is a low risk of bias.

Table 6

Risk of Bias Ratings

Study Name & Year	Selection Bias	Detection Bias	Statistical Bias	Reporting Bias	Generalisability	Study Design Score	Risk of Bias Score	Overall Quality Index
Alikhani, 2019	Unclear risk	Unclear risk	Low risk	Low risk	Unclear risk	40	7	94%
Beer, 2005	Unclear risk	Unclear risk	Low risk	Low risk	Unclear risk	10	7	34%
Blazquez, 2019	Unclear risk	Unclear risk	Low risk	Low risk	Unclear risk	40	7	94%
Dean, 2008	Unclear risk	Unclear risk	Low risk	Low risk	Unclear risk	40	7	94%
Etyemez, 2020	Unclear risk	High risk	Low risk	Low risk	Low risk	30	7	74%
Galitzer, 2021	Unclear risk	High risk	Low risk	Low risk	Low risk	30	7	74%
Lunsky, 2009	Unclear risk	Unclear risk	Low risk	High risk	Low risk	10	6	32%
O'Donoghue, 2019	Unclear risk	Unclear risk	Low risk	Low risk	Low risk	30	8	76%
Ozbaran, 2022	Unclear risk	Low risk	Low risk	Low risk	Low risk	30	9	78%
Pejovic-Milovancevic, 2011	Unclear risk	High risk	Low risk	Low risk	Low risk	30	7	74%
Perisse, 2010	Unclear risk	Unclear risk	Low risk	High risk	Low risk	30	7	74%
Potegal, 2009	Unclear risk	High risk	Low risk	Low risk	Unclear risk	30	6	72%
Rast, 2022	Unclear risk	High risk	Low risk	High risk	Low risk	30	5	70%
Taylor, 2019	Unclear risk	Unclear risk	Low risk	Unclear risk	Low risk	40	7	94%
Zinna, 2021	Unclear risk	Low risk	Low risk	Low risk	Low risk	30	9	78%

Selection Bias

All fifteen studies were rated as unclear risk of bias. Thirteen studies recruited participants from a single site and two recruited from multiple sites. Single sites were deemed to be higher risk due to a greater risk of confounding variables. One study recruited from a national patient database. All studies recruited their sample from a pre-existing clinical population (i.e. psychiatric inpatient populations). This is unsurprising since the review is hoping to identify the prevalence of autistic people within these environments.

Detection Bias

Detection bias was mixed within the studies, with eight rated as unclear, five as high risk and two as low risk. Those rated high risk of bias either made no mention of how autism was diagnosed or used pre-existing diagnoses or a case note review to ascertain autism diagnoses. Those rated unclear risk of bias reported a clearly defined but incomplete diagnostic process e.g. uni-disciplinary clinician review or a used a generic medical screen. Those rated with a low risk of detection bias reported a multi-disciplinary diagnostic process inclusive of formal and validated measures.

Statistical Bias

Fifteen studies were rated as low risk for statistical bias in this review, as they reported clear event rates for the target population and/or appropriate descriptive statistics and analyses.

Reporting Bias

Reporting bias was generally rated low across the studies with three studies rated as high risk and one study rated as unclear risk. Those rated as high risk did not report the main outcome relevant to this meta-analysis, the prevalence of autistic people within an inpatient setting. The lead authors of the two studies rated as high risk, Lunsky et al. (2009) and Rast et al. (2022) were contacted to clarify the prevalence figures they reported. The authors

responded and provided this information. Furthermore, Perisse et al. (2010) reported an ambiguous total sample of the inpatient unit (high risk) stating “nearly 420” (p101) and Taylor et al. (2019) only reported the percentage of autistic people in the inpatient unit which required further calculations (unclear risk).

Generalisability

The majority of studies (eight) were rated as low risk of bias in terms of generalisability as their sample was deemed to be a good representation of the target population (psychiatric inpatients). Five studies were rated as unclear risk due to having a sample population size of less than 200, making it difficult to apply the results found to other psychiatric inpatient settings.

Summary

Overall, there was a mixed level of bias across the studies included in the meta-analysis. There was a notable unclear risk of bias across studies in the areas of selection, detection and reporting. Due to the low number of studies in this field, studies across all areas of risk of bias were included and the results should be interpreted with caution.

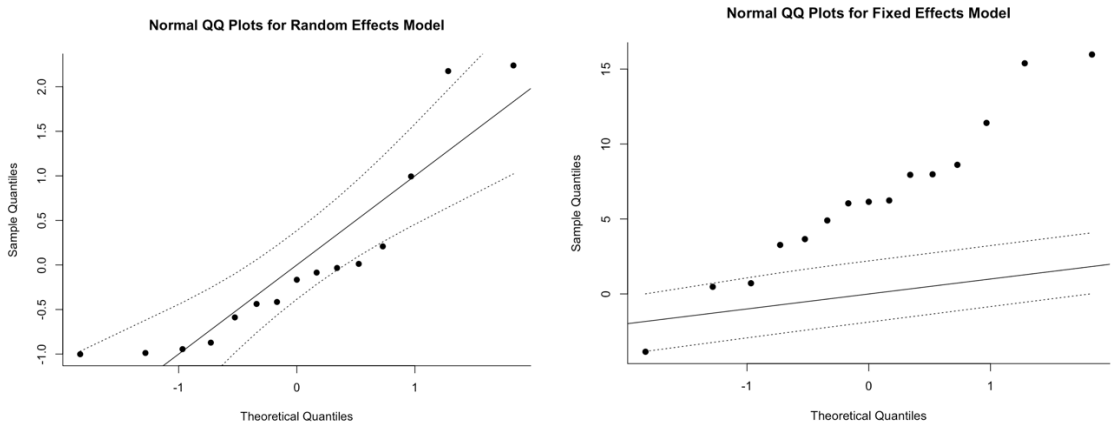
Meta-Analysis

Selection of the Meta-Analytic Model

The distribution of primary study effects is shown in Figure 2. The between studies variance (tau^2) was calculated using the restricted maximum likelihood estimator.

Figure 2

QQ Plot of the Distribution of Prevalence of Autistic People within the Primary Studies



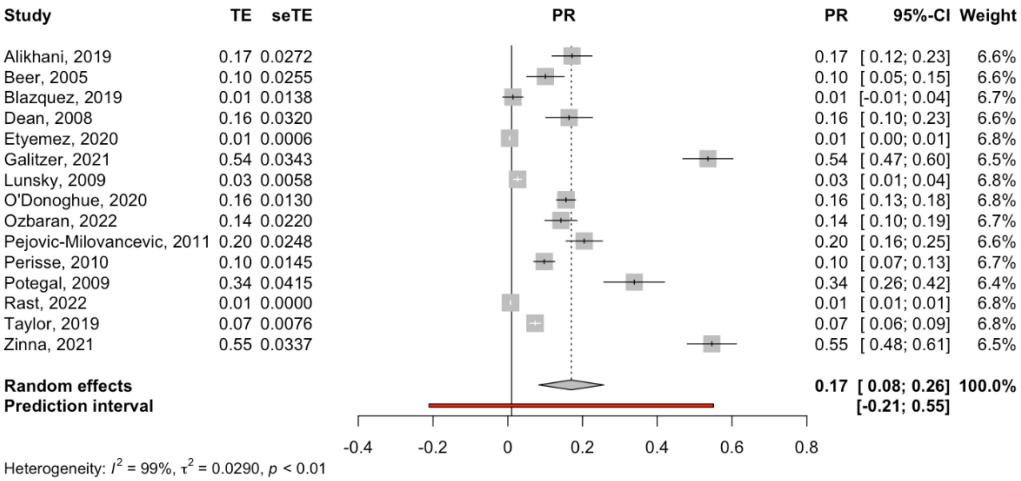
In the fixed effects model (see Figure 2), there is clear evidence of non-normality in the distribution of prevalence rates. However, in the random effect these data broadly conform to a normal distribution. Therefore, this indicates that the use of the random effects model and the restricted maximum likelihood estimator of between studies variation as the appropriate method for the calculation of weighted average prevalence rate (Banks, Mao, & Walters, 1985).

The Omnibus Test

A random effects model was calculated using the generic inverse variance method. The random effects model suggested a weighted average raw proportion of 0.17 ($z = 3.83$, $p = 0.001$) and a 95% confidence interval of between 0.08 and 0.26. The base rate of autism in the general population (global prevalence = 0.01 (Zeidan et al. (2022)) is significantly different from the weighted average prevalence estimate from the included studies.

Figure 3

Forest Plot of Prevalence of Autistic People in Inpatient Mental Health Settings



Note. The solid vertical line represents the base rate of autism in the general population.

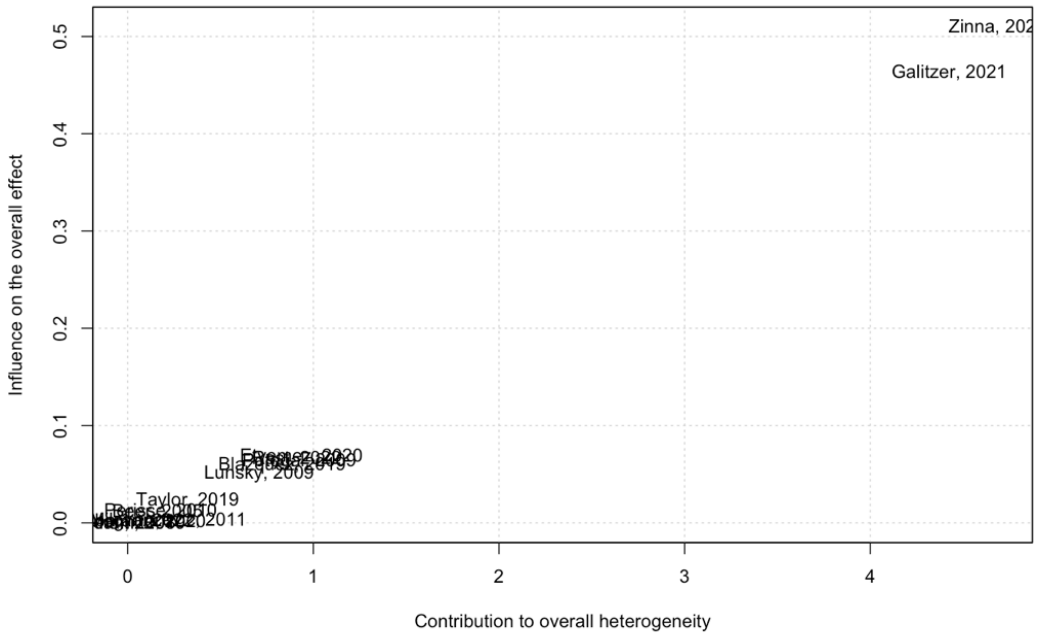
A high level of heterogeneity in the included studies was observed (tau^2 = 0.03, Higgins' I^2 = 99%; Q = 999.1, p < 0.01), suggesting that the estimates of prevalence of autistic people in the primary studies may be biased by the presence of uncontrolled or confounding factors. Therefore, the focus of the subsequent analyses was on identification of the sources of heterogeneity between the estimates of prevalence of autistic people in the primary studies.

The Impact of Influential Studies

The impact of disproportionately influential studies was assessed using a "leave-one-out" analysis, in which the random effects model was recalculated with each of the included studies removed in turn and change in weighted average effect size (i.e., influence) and the change in heterogeneity (i.e., discrepancy) were recorded. The result of this "leave-one-out" analysis is presented on the Baujat plot (Baujat et al., 2002) in Figure 4. The vertical axis reports the influence of the study on the overall effect and the horizontal axis reports the discrepancy of the study with the rest of the literature.

Figure 4

Baujat Diagnostic Plot of Sources of Heterogeneity



Galitzer et al. (2021) and Zinna et al. (2021) appeared to be discrepant from the other studies in the review and significantly influenced the overall estimate. The results of the 'leave one out' analysis for both studies are included in Table 7. If Galitzer et al. (2021) had been removed the new estimate of the effect would have been 0.14, likewise if Zinna et al. (2021) had been removed, 0.14 would have been the estimate. This reflects a 17.6% change in the prevalence estimate if either study were removed. The lower confidence interval when removing either study remains higher than the prevalence estimate of autism in the general population. Further review of these studies revealed they had both recruited their sample from Acorn Lodge, a small (10-bed) child inpatient psychiatric unit in the UK. Zinna et al. (2021) reports Acorn Lodge provides a service for children up to 13 years old with "severe and complex disorders" and Galitzer et al. (2021) reports Acorn Lodge provides the service for children aged 6-12 years with "severe and complex mental health and neurodevelopmental disorders". These include neuropsychiatric disorders including autism & ADHD, depression,

very early onset psychosis and bipolar affective disorder, obsessive-compulsive disorder, eating disorders, stress-related disorders, and complicated diagnostic conditions (Zinna et al., 2021). Given this, and the discrepancy from other estimates, it is reasonable to assume Acorn Lodge might be a "specialist" unit – so these studies were removed from further analysis.

The random effects model suggested a weighted average raw proportion of 0.11 (z = 4.38, $p < 0.01$) following removal of the two named studies, and a 95% confidence interval of between 0.06 and 0.16. Heterogeneity remained high, with $tau^2 = 0.008$, Higgins' $I^2 = 98\%$; $Q = 507.3$, $p < 0.0001$, suggesting removal of the two outliers has not completely resolved issues of heterogeneity.

Table 7

'Leave One Out' Analysis

	PR	Lower 95%-CI	Higher 95%-CI	p-value	tau^2	Tau	I^2
Omitting Galitzer, 2021	0.14	[0.07;	0.22]	0.0002	0.02	0.14	98.3%
Omitting Zinna, 2021	0.14	[0.07;	0.22]	0.0002	0.02	0.14	98.3%
Pooled estimate	0.17	[0.08;	0.26]	0.0001	0.03	0.17	98.6%

The Effect of Risk of Bias in the Included Studies

To assess the impact of study level risk of bias upon heterogeneity, a series of subgroup analyses were conducted on the prevalence for the risk of bias ratings of "low risk" and "any risk" (i.e., unclear risk and high risk of bias combined) for each of the five types of methodological bias. This was completed for the 13 studies remaining in the review following the 'leave one out' analysis.

Table 8

The Effect of Risk of Bias in the Included Studies

	Low Risk			Any Risk				
	EFFECT	95% CI	Studies	EFFECT	95% CI	Studies	X^2	*p*
Selection bias	-	-	-	0.11	0.06 – 0.16	13	-	-
Detection bias	0.14	0.1 - 0.19	1	0.11	0.06 - 0.16	12	0.91	0.34
Statistical bias	0.11	0.06 - 0.16	13	-	-	-	-	-
Reporting bias	0.14	0.08 – 0.2	9	0.05	0.01 - 0.09	4	5.59	0.02
Generalisability bias	0.09	0.04– 0.14	8	0.15	0.05 – 0.26	5	1.33	0.23

Estimated reporting bias evidenced a statistically significant differences estimates, with lower levels of bias being associated with higher estimates of prevalence. The Higgins I^2 value for the nine studies at low risk of reporting bias was I^2=98%. None of other 4 bias types evidenced a statistically significant difference in estimates of prevalence rate of autistic people in psychiatric inpatient units.

Impact of Study Design

A subgroup analysis was undertaken to assess the impact of study design in the estimation of autism prevalence. This revealed no significant difference in prevalence rates as a function of study design ($\chi^2 = 1.7$, $p = 0.43$).

Subgroup Analyses

To further explore the impact of study level covariates upon the prevalence of autistic people in psychiatric inpatient settings, a series of subgroup analysis were conducted. Firstly, age of participants was used, and the studies were split into ‘child’ and ‘adult’ subgroups. Secondly, autism identification was considered, with the variable ‘ASD Measure’ used to make subgroups. The three groups defined were: ‘case notes’ which refers to diagnoses on medical records or discharge paperwork, ‘clinician review’ which refers to a single, highly experienced, clinician rating of autism based on a review of the patient’s notes and possible behavioural observations, and ‘combined’ which refers to a combined approach of multi-

disciplinary rating and/or the use of formal, standardised measures to support a diagnosis of autism. Potegal et al. (2009) was removed from the 'ASD measure' subgroup analysis, due to not reporting how the autism diagnosis was made. Thirdly, studies were grouped into 'North America' which included all USA and Canadian studies, and 'Rest of World (RoW)' studies which included studies from the UK, Spain, Serbia, Australia, Iran, Turkey and France. The results of this analysis are presented in Table 9.

Table 9

Analysis of Subgroups

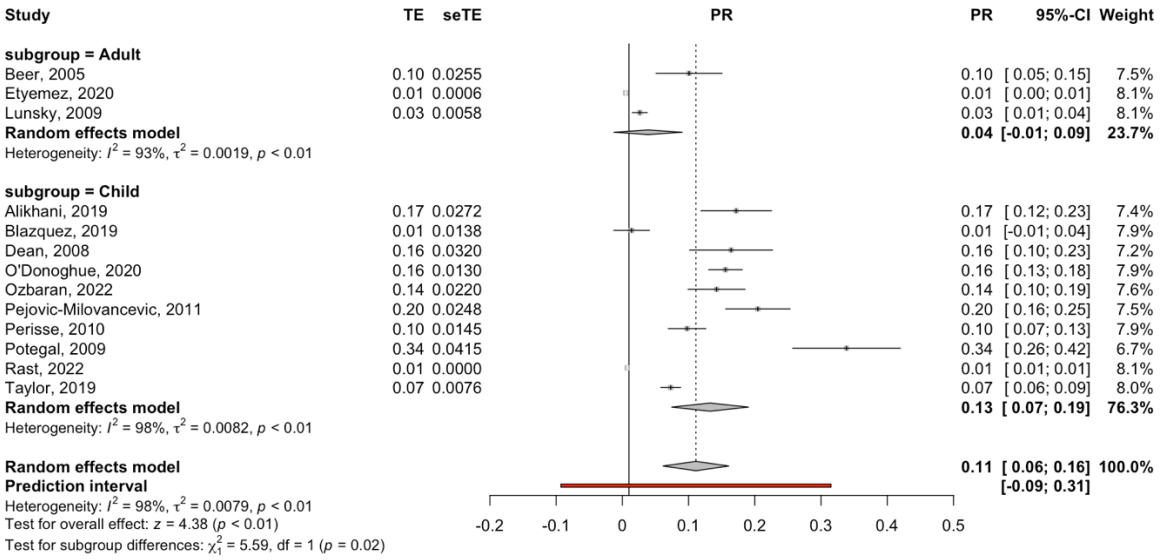
	Level	EFFECT	95% CI	k	X^2	p
Country	North America	0.1	-0.00-0.19	6	0.26	0.61
	Rest of the world	0.13	0.08-0.17	7		
ASD Measure*	Case notes	0.1	-0.09 – 0.3	2		
	Clinician Review	0.1	0.02 – 0.17	4	0.04	0.98
	Combined	0.09	0.04 – 0.14	6		
Age of participants	Child	0.13	0.07 – 0.19	10	5.59	0.02
	Adult	0.04	-0.01 – 0.09	3		

******Note.*** Potegal et al. (2009) was removed from the 'ASD measure' subgroup analysis due to not reporting how the autism diagnosis was made.

From the sub-group analyses, it was found that participant age had a significant impact on the effect. Figure 5 shows a forest plot of this analysis.

Figure 5

Sub-group Analysis to Assess Impact of Participant Age on the Estimation of Autism Prevalence in the Included Studies



Meta-Regression

The prevalence rate of autistic people within psychiatric inpatient units was also assessed using a continuous measure of the year published. Consequently, a meta regression was undertaken to test the significance of the association between the year published and prevalence rate. Results of the meta-regression are presented in Table 10.

Table 10

Meta-Regression of 'Year Published'

	Coefficient	SE	Z	p
Year published	-0.0053	0.0042	-1.2469	0.2124

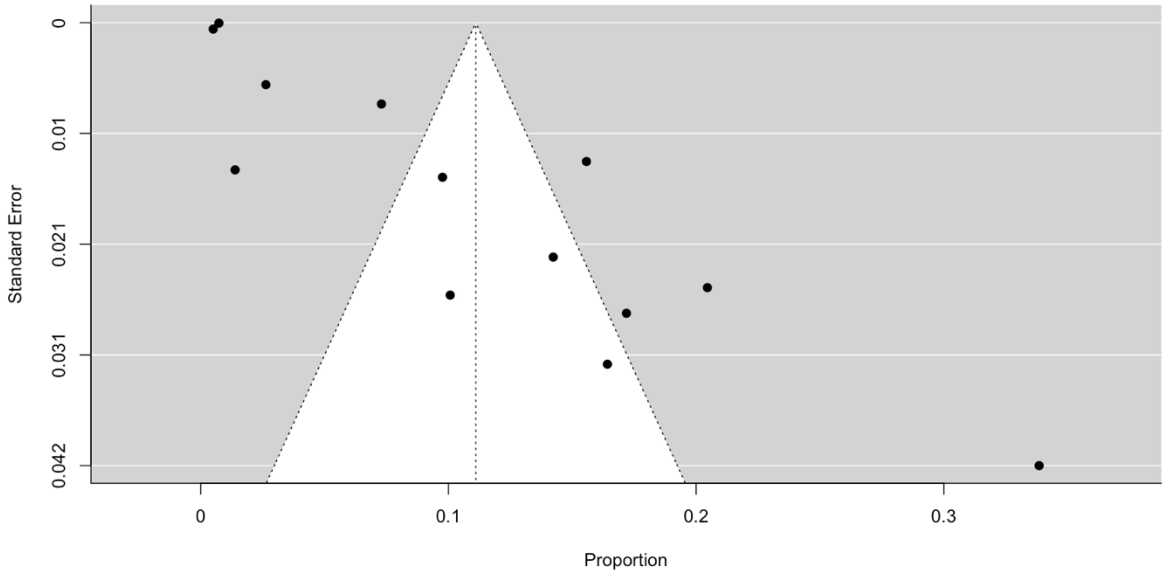
The association between year published and prevalence rate did not show a statistical significance.

The Impact of Publication and Small Study Biases

Publication bias is caused by the tendency for statistically significant results to be published and the reticence to publish papers with non-significant results. Small study bias is the tendency for studies with smaller sample sizes to show greater variability in their measurement of prevalence rate. These biases can be identified in a funnel plot, which plots the magnitude of the study's prevalence rate (i.e., the importance of the study in the synthesis) and estimates the study's deviation from the meta-analytic average (i.e., the discrepancy of the study within the literature). If there is an absence of publication bias, the effects from the studies with small sample sizes which show greater variability will scatter more widely at the bottom of the plot compared to studies with larger samples at the top which will lie closer to the overall meta-analytic effect, creating a symmetrical funnel shape. If there is an absence of studies in the area of the plot associated with small sample sizes and non-significant results, then it is likely there is some publication bias leading to an overestimation of the true effect. The funnel plot of prevalence is presented in Figure 6. The 95% confidence interval of the expected distribution of prevalence rate is shown as an inverted "funnel". White effect sizes are imputed using the Trim and fill procedure, described by (Duval & Tweedie, 2000).

Figure 6

Funnel Plot of the Prevalence Rate of Autistic People in Psychiatric Inpatient Settings



As can be seen from Figure 6, the heterogeneity previously described is clearly evident in this funnel plot. In addition, it would appear that small studies tended to be associated with larger effect sizes, and that there is an absence of small studies in the area of the forest plot that would be associated with publication bias. The effect of publication bias was simulated using a trim and fill procedure (Duval & Tweedie, 2000). The trim and fill procedure builds on the assumption that publication bias would lead to an asymmetrical funnel plot. Trim and fill procedure iteratively removes the most extreme small studies from the side of the funnel plot associated with positive effects, re-computing the effect size at each iteration until the funnel plot is symmetric about the (corrected) effect size. While this trimming yields the adjusted effect size, it also reduces the variance of the effects, resulting in biased and narrow confidence interval. Therefore, the original studies are returned into the analysis, and the procedure imputes a mirror image for each on the side of the funnel plot associated with negative effects. The trim and fill procedure did not impute any additional studies and therefore did not change the effect.

Orwin (1983) describes the calculation of a failsafe number which calculates the number of non-significant results which would need to be included in the meta-analysis for the overall effect to be reduced to a minimally interpretable value. The Orwin (1983) algorithm suggests that 1301 studies with an effect size averaging 0.01 would be required to change the observed average effect of 0.11 to a target effect size of 0.01 (i.e. the base rate estimate of autism in the general population as reported by Zeidan et al. (2022)). Accordingly, the reported effect size should be considered robust to publication bias.

Discussion

Summary of Findings

This meta-analysis reviewed 15, peer-reviewed, empirical studies reporting the prevalence of autistic people in generic inpatient psychiatric settings. While previous studies report autistic people are over-represented in these settings, which are not typically set up to manage their needs, much of the literature focuses on therapeutic interventions, use of psychotropic medication and length of stay. Current prevalence of autism in the general population is around 1% (Zeidan et al., 2022). The studies included in this review, on average, report a prevalence rate of autistic children at 13% and for autistic adults at 4% in generic inpatient settings, with a weighted average of 11% (95% confidence interval of 6% - 16%) across the final 13 studies included. After removing the two studies with the highest estimates, which were shown as discrepant from the other studies, we can be 95% confident that autism is at least six times more prevalent in generic inpatient services than in the general population. This estimated prevalence appears to be much higher for children and comes

from a greater number of studies. For adults, data are less clear currently, perhaps given the small number of studies.

This review revealed a large amount of heterogeneity amongst the studies (Higgins' I^2 = 98%, even after removing outliers) suggesting that the estimates of prevalence of autistic people may be biased by the presence of uncontrolled or confounding factors. Attempts were made to explain the large heterogeneity statistically. Fully explaining heterogeneity was not possible, given the relatively small number of studies and inconsistent reporting. It was predicted that various factors would affect the prevalence rate of autistic people including: age of sample, country of inpatient setting, year study was published and variations in how autism diagnoses are made. These factors were considered in the meta-analysis as sub-group analyses or meta-regressions. Of these sub-group analyses, only the participant's age found a significant result for explaining the effect. There were noticeably more studies conducted with children and young people compared to adults. Considering the literature tells us that most autistic people are diagnosed in childhood (van't Hof et al., 2021), and given the developmental nature of autism it is possible the topic is more of interest in child psychiatry compared to adult psychiatry, and hence unsurprising there are more studies conducted with children and young people compared to adults.

Why is Autism so Prevalent in Inpatient Settings?

High prevalence rates of autism in inpatient settings are consistent with the broader literature on this topic. As reported above, co-occurring MH conditions are highly prevalent in the autistic population (Lai et al., 2019) and an autism diagnosis is also associated with more 'crisis' behaviours including self-harm and suicide (Blanchard et al., 2021; Kõlves et al., 2021; Widnall et al., 2022). Consequently, autistic people present to ED services four

times as often as non-autistic people, and such ED visits are 3.7 times more likely to lead to an admission to inpatient services (Iannuzzi et al., 2022; Liu et al., 2017; Weiss et al., 2018).

What may be more problematic, however, is that these prevalence rates reflect rates in generic inpatient units. Especially as the evidence tells us that autistic people achieve the best outcomes in specialist units with reduced length of stay and maintained improvements in problem behaviours reported in data from specialist units (Pedersen et al., 2018; Siegel et al., 2012). Whereas generic inpatient units can actually increase anxiety symptoms for autistic people (Maloret & Scott, 2018).

Methodological Quality

The overall quality of the literature reported in this review is mixed. The majority of the studies use retrospective or prospective designs (as opposed to cross-sectional) which are mostly clear to follow and strengthen their replicability. Some studies have very small sample sizes making generalisability difficult, whereas others do not clearly report their methods of calculating the autistic sample or detecting autism clearly.

This review assessed each included study in terms of their methodological quality. The impact of study level risk of bias upon heterogeneity was analysed using sub-group analyses. The only risk of bias to be found to significantly impact the effect was ‘reporting bias’, with lower levels of bias being associated with higher estimates of prevalence. It is possible that those studies with high levels of reporting risk are missing lots of autistic people in their calculations. These studies were rated as high or unclear risk due to not reporting or disguising their full sample size. Therefore, it is possible that many autistic people were not accounted for in their sample, reducing their estimates.

Most of the included studies did a reasonable job of reporting the demographic information (age and gender) of the sample included. However, six of the studies only

reported this for the autistic sample. Consequently, it is unclear how gender and age information is comparable to the wider sample of mental health inpatients. Other demographic information including ethnicity, was not reported in nine of the fifteen studies.

Limitations of the Evidence

Most studies reviewed reported a higher prevalence rate of autistic people compared to the general population. However, this was not wholly consistent and there was large variance observed amongst the studies. There are several possible explanations for this variation. The first is the inconsistency in how autism is assessed and diagnosed worldwide. As reported by Zaroff and Uhm (2012), a key reason for the variation in prevalence of autism worldwide is methodological variation in the diagnostic process. This review attempted to analyse this statistically using sub-group analysis and three groups of the different methods. The first group was a case note review, which included studies using pre-existing diagnoses from medical files. The second was a clinician review, which included uni-disciplinary clinician review using diagnostic manuals (ICD-10 (2016) or DSM-V (2013)). The third methodology was a combined approach, which used clinician reviews (uni or multi-disciplinary), or this in addition to staff observations, routine clinical measures and/or validated, standardised measures used to support the assessment or formally assess autism and/or intelligence quotient. This subgroup analysis did not reveal significant difference in variance, however, a limitation of this literature is the vast amount of variation within the three groups of assessment methods, all of which claim to accurately diagnose autistic people.

In addition, studies were analysed by location. The subgroup ‘North America’ included all studies from USA and Canada (six) and the subgroup ‘Rest of World (RoW)’ included studies from the UK, Spain, Serbia, Australia, Iran, Turkey and France (seven, plus

two studies which were removed). While this analysis did not reveal a significant effect, it is interesting to note that half of the final included studies were from USA and Canada and there is a clear absence of studies from Asia, Africa and South America.

Furthermore, the variation in sample sizes and recruitment to the included studies in general was vast, varying from smaller inpatient units to larger databases of patient information collected from inpatient settings. It could be argued that the smaller studies provide more detailed information about their autistic sample and how this is diagnosed, compared to the larger studies which in general were rated 'high risk' for detection bias in this review.

Lastly, while much of the literature in this area reports therapeutic interventions, medication use, aggressive outbursts and length of stay for autistic people in inpatient settings, the majority of these studies do not clearly and accurately report the size of the inpatient setting or the groups of autistic individuals within it. In this review, forty-two studies progressed to full text review, however, nineteen of those were excluded due to not clearly reporting the event rate of an autistic population within the inpatient setting. Had this been reported in a proportion of those studies, this review would have a larger number of included studies and have more data to analyse and further conclusions could have been drawn.

Limitations of this Review

The data reported in this review suggest autistic people are over-represented in generic psychiatric inpatient settings. However, there are a number of limitations of the review which should be considered when interpreting the findings. Firstly, the small number of studies included (fifteen) leads to wider confidence intervals. Furthermore, this study was concerned with generic psychiatric inpatient settings, however there is a lot of research which

also explores autistic people within forensic or specialist neurodevelopmental settings. Restricting the search to generic settings will have reduced the number of studies included. In addition, the review did not consider other possible contributing factors to the prevalence of autistic people in inpatient settings including the presence of co-morbid diagnoses, physical health conditions or learning disabilities, gender, ethnicity and socio-economic status.

While all included studies were subjected to a quality review, there were discrepancies in how the studies detected autism in their sample and how they reported the sample size, which should be considered when interpreting these findings. The review attempted to differentiate between methods of detecting autism in the subgroup analysis, however there was variation within the subgroups which may affect the conclusions that can be drawn.

Clinical Implications of this Review

The implications of the high prevalence estimates of autistic people in generic inpatient settings found in this review are important for services to improve identification of autistic people. To meet this need, specialist services need to expand, offer more inpatient beds and where possible, share knowledge and insight into how to support autistic people effectively in inpatient settings. The data from the sub-group analyses in the meta-analysis highlights significant variation in how different services diagnose and monitor autistic people in psychiatric inpatient settings. Services could improve their transparency in the process to offer consistency to families and support with tolerating uncertainty.

Similarly, the various referral pathways for autistic people with mental health conditions into inpatient settings are not clear or consistent across and within countries. It is unclear why some inpatient units have more autistic people than others and there is not a well-defined or consistent way to estimate the prevalence which could be anywhere between

6% and 16% based on this review. The implications of the lack of specificity in this area of research makes understanding the variation clinically very difficult. Clear referral pathways would support a practitioner and patient/family understanding of the mental health support available to autistic people and those suspected of autism prior to inpatient admission.

Research on autistic inpatients needs more attention. Further research may want to explore data in autistic adults given the limited number of empirical studies for adults returned by this review. Future research may also which to explore the suspected issues of later diagnosed autistic people in terms of rate of inpatient admission. It would also be beneficial if future research could encourage use of clear reporting of autism and use of standardised autism assessments and the reporting of these assessments.

Conclusion

This meta-analysis reports the estimate of autistic people in inpatient settings is higher than estimates of autistic people in the general population; high levels of heterogeneity means we cannot be exact but estimate the prevalence rate as between 6% and 16%; there is a notable difference between autistic children and autistic adult prevalence estimates. Whilst the estimates of autistic children in inpatient settings is higher than autistic adults, this is based on limited published studies on adults.

As adults outweigh children in inpatient settings, future research is urged to report on these populations as a priority. It is hoped that in the future, services are better equipped to measure and report the characteristics and co-morbidities of all individuals within the service. Lastly, it is hoped that future research will demonstrate clearer reporting of referral routes for autistic people into inpatient settings so that the process can be kept consistent.

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Understanding the Autism Assessment Experience for Young People

Abstract

Purpose

The autism assessment process can be long and arduous for young people and their families. Autistic people are more likely to have co-occurring mental health difficulties and often, autistic young people are misdiagnosed with other difficulties. Familial quality of life is reported to be low during the autism assessment process, however, evidence on how young people's mental health symptoms may change during the assessment process has not been explored.

Method

Young people referred for an autism assessment and with reports of additional mental health presentations completed mental health questionnaires, along with their carers, at varying timepoints during the autism assessment process. Mental health and quality of life symptoms were examined at four timepoints. Correlations and comparisons across timepoints were analysed.

Results

The findings mostly align with previous literature, reporting severe and sustained mental health difficulties in autistic people. Significant differences between parent-reported and young person-reported mental health symptoms were found and possible explanations considered. Whilst inconclusive, the results of changes in symptomatology from the waiting list to the time of the assessment do not indicate that mental health gets worse during this time.

Discussion

Young people referred for assessment experience severe and chronic mental health difficulties that do not seem to improve while they await assessment for autism. Limitations of the dataset are provided with suggestions for further research. The lack of a control group limits the conclusions that can be drawn, and the small sample size limits the generalisability of this data. Challenges associated with clinical research recruitment within NHS services are discussed. Further research is encouraged to recruit a more diverse population.

Introduction

Recent prevalence studies have reported that around 1% of the general population are autistic[1] (Chapter 1; Zeidan et al., 2022). Receiving an autism diagnosis can be a stressful process (Eggleston et al., 2019) and the assumption that familial Quality of Life (QoL) might improve following an autism diagnosis (McKechanie et al., 2017) has vital clinical implications for services. Understanding and alleviating mental health symptoms are a particular priority for the autism community (James Lind Alliance., 2016), thus knowing how these change through the autism assessment process is important.

The Autism Assessment Process

The autism assessment process is often lengthy, systemic and should involve one of a number of 'gold standard' diagnostic tools (Pennington et al., 2019). Best practice suggests a variety of stages to the assessment process (National Institute for Health and Care Excellence, 2011). Clinicians should complete a thorough developmental history with parents/carers. Questionnaires assessing the child's global presentation, relevant to the autism diagnostic criteria, are typically completed by parents/carers and schoolteachers. The young person completes a comprehensive play/activity-based assessment (Ozonoff et al., 2005). Following completion of the questionnaires, developmental history and play-based assessment, clinicians should write-up the findings of their assessment into a report and meet with the family to discuss these and make recommendations for further interventions at home and school. NICE guidance (2011) suggest the diagnostic assessment for children aged 0-19 years

[1] While many terms are used to describe a person diagnosed with autism, Kenny et al. (2016) explored how this population prefers to be known by and the results suggest most adults (61%) were happy to be called 'autistic'. Consequently, this language will be used in this chapter.

should start within three months of the referral to the autism team. Due to increased level of demand, some services have much longer waiting times, with some parents in the UK reporting a delay of 3.5 years from first approaching a professional to their child receiving an autism diagnosis (Crane et al., 2016). Whilst most autistic children are diagnosed early in life, a significant number of autistic people are diagnosed in adolescence or early adulthood (Brett et al., 2016). Early recognition of autism is preferable, as a diagnosis may increase access to early intervention, leading to possible improvements in language and cognition compared to those children diagnosed later (Clark et al., 2018). Later diagnosis may also be problematic in relation to autistic people's experience of mental health difficulties (Hosozawa et al., 2021) in addition to physical co-morbidities and challenging behaviour (Leader et al., 2022).

Mental Health in Autistic Young People

Co-occurring mental health conditions are highly prevalent in the autistic population (Chapter 1; Lai et al., 2019), and mental health difficulties are significantly more prevalent in autistic people than their peers across the lifespan (Lever & Geurts, 2016). The clinical implications of this are such that autistic people require specialist care to manage both core differences associated with autism and mental health difficulties (NICE, 2021). Due to the increased prevalence of emotional and behavioural difficulties in autistic people, these symptoms may overshadow core diagnostic differences in autism, which may lead to a mood disorder diagnosis and delay subsequent exploration of autism (Grosso, 2022). Avlund et al. (2021) reported the risk factors contributing significantly to delayed autism diagnoses included a prior diagnosis of Attention Deficit Hyperactivity Disorder (ADHD) and prior diagnoses of emotional disorders, highlighting the importance of identifying and managing co-occurring disorders.

Mental health difficulties can often be associated with a late diagnosis of autism (Bargiela et al., 2016; Cage & Troxell-Whitman, 2019). Mandy et al. (2022) examined the frequency and severity of emotional, behavioural and social problems in later-diagnosed children (aged 8-14 years), showing a steeper growth of these problems as they aged compared to the earlier-diagnosed children. In addition, autistic children diagnosed later in their adolescence (after 11 years old) may also have increased depression symptoms and a stronger association to self-harm behaviours (Hosozawa et al., 2021). Older autistic people, who were not diagnosed as a child could have been undiagnosed due to 'masking' difficulties for so long (Fusar-Poli et al., 2020). Autistic adults diagnosed in adulthood who reported masking their difficulties also reported having more mental health challenges compared to non-autistic adults (Atherton et al., 2022) and were significantly more likely to endorse co-occurring mental health difficulties compared to child-diagnosed autistic adults (Jadav & Bal, 2022). Age of diagnosis has also been found to relate to QoL, where those diagnosed later in life report lower QoL and more severe autistic traits (Atherton et al., 2022). Less is known about the impact of the autism assessment process on later diagnosed autistic people, with retrospective qualitative evidence suggesting potential substantial benefits, but also pitfalls (Livingston et al., 2019).

Possible Impacts of the Autism Diagnostic Process on Mental Health

There is a reasonable amount of retrospective, qualitative research with autistic people on their experience of being diagnosed with autism (Finch et al., 2022; Jones et al., 2014; Prentice, 2020). Studies using Interpretative Phenomenological Analysis with autistic young people revealed the disclosure of having autism for some can offer clarity and legitimise certain behaviour, however for others, the label can be perceived as stigmatising (Huws & Jones, 2008). A meta-synthesis of this research by Wilson et al. (2023) reported autistic

adults described their feelings towards their diagnosis changed over time and their experience of the emotional impact of the assessment process was associated with feeling analysed and examined and feeling unsupported by professionals. Autistic adults report mixed views about their diagnosis varying from feeling 'relieved' and helping to understand difficulties better to feeling 'disappointed' and that life pre-diagnosis was 'wasted' due to not understanding themselves (de Broize et al., 2022). For some young people, receiving a diagnosis of autism may provide answers and reassurance; for others, the experience may negatively affect their sense of identity (Samra, 2016).

Data on the experience and impact of the broader process of waiting for and engaging with the autism assessment is sparse – and prospective recruitment to understand this is almost non-existent. There are, however, good reasons to believe the process will present challenges for people referred. Intolerance of uncertainty is linked to anxiety in autistic people (Boulter et al., 2014; Wigham et al., 2015). Intolerance of uncertainty can be characterised by the aversive response triggered by feeling overwhelmed by the unexpected/unknown or an absence of information (Carleton, 2016). A meta-analysis on this association for autistic people (Jenkinson et al., 2020) reported significant correlations between intolerance of uncertainty and anxiety in 90% of the included studies, all of which demonstrated between large and moderate effects in the positive direction (i.e. higher anxiety was found in those more intolerant of uncertainty). Consequently for the autistic population, or those suspected of being autistic, the diagnostic process itself which can involve a lot of waiting and tolerating uncertainty may be more problematic for them compared to non-autistic people, adding to the distress experienced by the whole family (Maisel et al., 2016). The diagnostic period can also entail higher prevalence of parental mental health difficulties, huge challenges to typical family functioning, adjustment difficulties and lower QoL (Boshoff et al., 2019). Emotional well-being and family functioning were reported to be rated

lowest in terms of QoL for families during the diagnostic process, highlighting the importance of offering support to families during this critical time (Rivard et al., 2022). In addition, Jones et al. (2017) found families with an autistic child reported the wait-list period for further therapeutic input was challenging and contributed to their low rated familial QoL.

Rationale

At present it is unclear whether waiting for an autism assessment influences young people's mental health, and if the assessment ultimately leads to a change in mental health symptoms. If service providers had a clear understanding of mental health symptom change and/or familial QoL change during a waiting list period, they may be able to offer effective support to young people and families during this time. Similarly, if the study finds mental health worsens whilst on the waiting list, this adds motivation for the cause of attempting to shorten waiting times for young people and their families. Conveniently, the waiting list provides services with a readily collected sample of families potentially needing more support managing mental health symptoms.

This study will be the first to capture and analyse the autism assessment process, including changes in young people's mental health symptomatology while waiting for an autism assessment. The study will offer a starting point upon which other studies can build on. Without further investigation it will not be clear whether mental health change is unique to autism assessment waiting lists or waiting lists in general.

Firstly, mental health and QoL data will be analysed at timepoint 1 (waiting list), which aims to provide an overview of the topography of mental health presentations in young people with mental health symptoms who have been referred for an autism assessment. Next, we will compare young people's mental health symptoms, as reported by the young person and their parents, from the waiting list period (3-6 months before their scheduled assessment) to the assessment itself. Lastly, we will analyse individual participant level data of those

young people who progressed to the final data collection timepoints (at the time of the feedback appointment when a diagnosis may or may not be given and mental health symptoms three months later). The data will offer insight into whether the autism diagnostic process may influence young people's mental health symptoms. It is hypothesised that mental health symptoms will worsen for young people from the waiting list to the time of the assessment. The null hypothesis expects to find no change in mental health symptomatology.

Method

The method for the study was revised following consultation with an advisory group made up of members of the autism community.

Design

The study recruited a purposive sample of young people with mental health symptoms and their parents/carers who had been referred for an autism assessment. The study used a within-subjects design and participants were invited to complete four data collection timepoints. The four timepoints were: whilst on the waiting list, at the time of the autism assessment, at the time of the feedback and three months after the feedback. Mental health symptoms were measured using widely used and validated psychometric assessments completed by the young person and their parent/carer. The study aimed to collect a sample of 30 young people. No formal power analysis was conducted; sample size was determined based on similar research studies in the area which used a pre and post-design and gained a statistically significant findings (Hepburn et al., 2016; Juliano et al., 2020; Lecciso et al., 2021) and how much data could be feasibly collected given the time restraints of the project.

Participants

Participation in the project required both young person and parent/carer reported data. Participant recruitment took place between March 2022 and May 2023. Participants were recruited from one of two National Health Services (NHS) offering autism assessments in the West Midlands. One service offered autism assessments and accepted referrals from General Practitioners and/or Paediatricians, from here will be referred to as the 'Paediatric' service. While the other service sat within a broader mental health service and accepted referrals from mental health professionals who were care co-ordinators for the young person and suspected autism as an additional difficulty, from here will be referred to as the 'Mental Health' service. The services differed in their waiting list times (however this was controlled for in this study as only referrals of young people with estimated assessment dates 3-6 months in the future were screened for inclusion) and assessment process. The Paediatric service had a waiting list time of around 2 years, and once they had their first appointment the assessment and feedback were completed within two weeks, whereas the Mental Health service had a waiting list time of around 6 months, and typically took 3 months to deliver the report and feedback from the assessment. The content of both services' ASD assessments consisted of the same NICE recommended methods. Within both services, access to further support during the waiting period was referred to the appropriate service in the same way as other young people needing support who are not waiting for an ASD assessment.

Clinicians screened referrals for young people who had a pre-existing/co-morbid mental health difficulty (e.g. depression, anxiety, eating disorder). Full inclusion and exclusion criteria are presented in Table 1. Participants were aged between 8 and 25 years old. When the young person was younger than 18, their parents/carers also completed data collection. Young person demographic information including gender and ethnicity along with parental education level and household income was also captured at timepoint 1 and is

presented in Table 2. Other parental demographic information was not collected. All parents/carers were mothers or grandmothers. Only one young person above 18 years of age was recruited. Due to this very small group, the data are not reported here.

Of all the young people recruited to the study, 60% have now received a diagnosis of autism, 3% were not diagnosed and 37% are still waiting for the outcome of their assessment.

Table 1

Inclusion and Exclusion Criteria

Inclusion criteria	Exclusion criteria
Experimental participants must:	Experimental participants will be excluded if:
Be under a mental health service or have a mental health difficulty described on the referral information	Under 8 years or over 25 years
Have been referred for an autism assessment	Both the young person and their parents are unable to complete the questionnaires.
Have the ability to provide informed consent (themselves, or through a parent/carer if under 16)	Young people that have not been referred for an autism assessment
Be aged 8-25 years old.	Individuals for whom care coordinators advise against their participation.
Have sufficient command of English, written and spoken to be able to complete the questionnaires.	Individuals under the age of 16 and who are unable to have consent given by a parent/carer will be excluded.

Table 2

Participant Information (Timepoint 1)

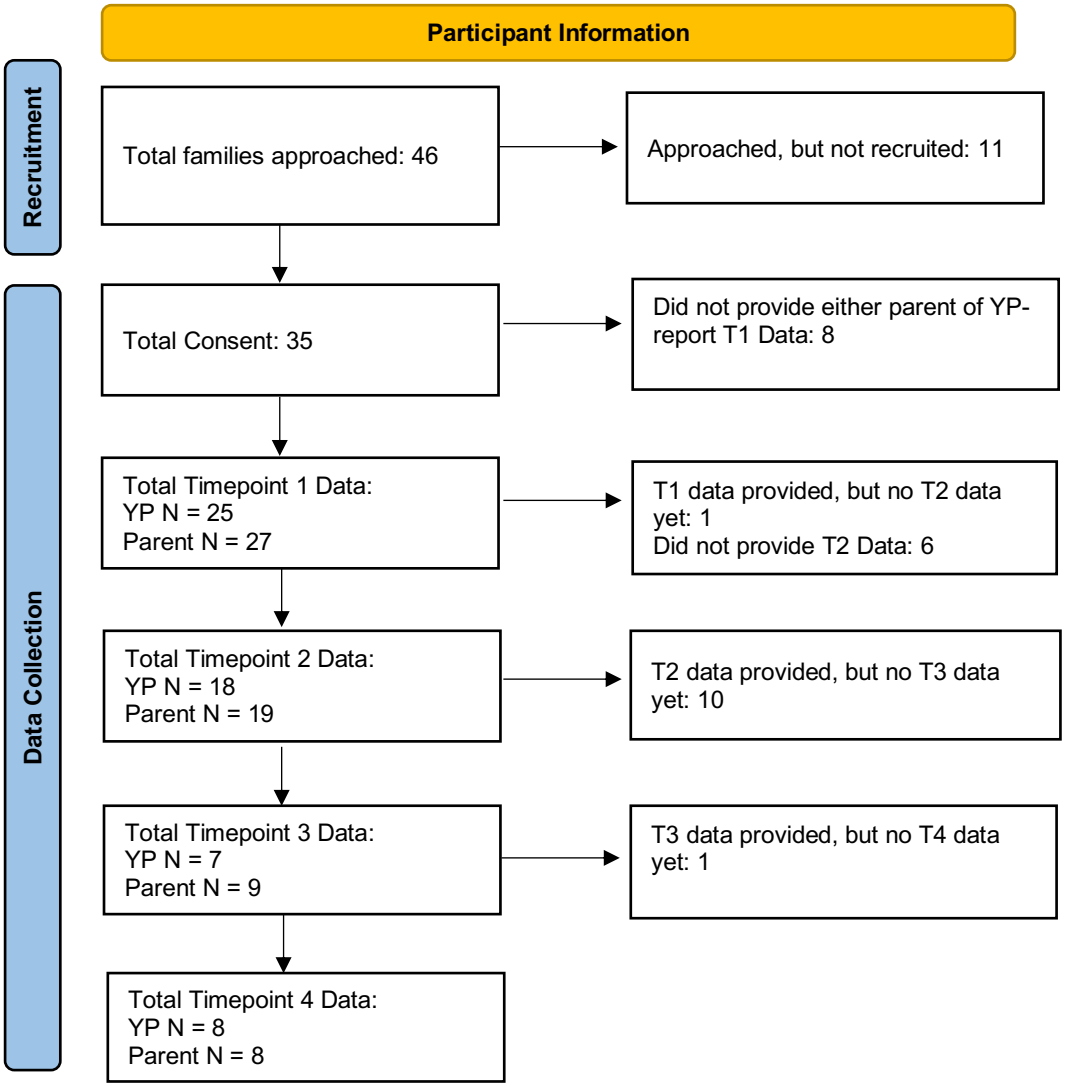
Demographic	Young People (N=25)
Age 8 – 12 years	9
Age 13 – 15 years	8
Age 16 – 18 years	8
Gender	Male 8 Female 16 Non-binary 1
Ethnicity	White British 21 White (other) 1 British 1 Polish 1 Black Caribbean 1
Parental Education (*N=27)	No formal education qualifications 5 Prefer not to say 1 Fewer than 5 GCSE's or equivalent 3 5 or more GCSE's or equivalent 4 3 or more 'A' Levels or equivalent 2 Polytechnic/University degree or equivalent 9 Masters/Doctoral degree or equivalent 3
Household income (*N=27)	Prefer not to say 7 Less than £15,000 2 £15,000 - £25,000 2 £25,000 - £35,000 4 £35,000 - £45,000 6 £45,000 - £55,000 1 £55,000 - £65,000 1 £65,000+ 4

Partial Datasets

There were a number of families who consented to the research study but did not complete questionnaires. There are also a number of families who completed timepoint 1 questionnaires but did not complete any further data collection timepoints. Some families have not yet arrived at these timepoints in their assessment journey. This data is presented in Figure 1.

Figure 1

Participant Flow Diagram



Note: YP = Young Person

Materials

Young people and their parents completed psychometric assessments which asked questions about mental health symptoms. The chosen questionnaires are widely used and validated for use with young people. Given that participants did not have a diagnosis of autism when they were recruited to the study, it was appropriate to use the measures used as standard practice within child mental health services. However, these measures have also been found to be valid for use with autistic populations (Findon et al., 2016; Sterling et al.,

2015; Viecili & Weiss, 2015). The Strengths and Difficulties Questionnaire was used to help describe the sample and were not repeated beyond timepoint 1. The one young person recruited aged over 18 years completed age-appropriate and validated mental health measures (not presented hereon).

The Revised Child Anxiety and Depression Scale (RCADS)

The RCADS uses self-report and parent/carer-report methods to identify anxiety and depression symptomatology in children and teenagers (Chorpita et al., 2000). The RCADS is a reliable and valid measure for assessing depression and anxiety in both clinical and general populations of children in different cultural settings (Piqueras et al., 2017), and with autistic youth (Sterling et al., 2015). Consequently, the RCADS is used routinely in child mental health services in the UK. On the RCADS, a higher score indicates poorer mental health. The highest possible total score as rated by both young person and parent is 141; this is a combined total anxiety and depression score. A T-score above 70 is considered the clinical threshold, i.e., the score is in the top 2% of scores of un-referred young people of the same age, and T scores between 65-70 are considered to be borderline clinical, i.e., the score is in the top 7%. The RCADS includes subscales of social phobia (possible total = 27), panic disorder (possible total = 27), depression (possible total = 30), separation anxiety (possible total = 21), generalised anxiety (possible total = 18) and obsessive-compulsive disorder (possible total = 18). A total anxiety score combines all subscales except depression.

The Strengths and Difficulties Questionnaire (SDQ)

The SDQ is a 25-item questionnaire, widely used questionnaire completed by parents/carers and teachers, which assesses for behavioural, emotional, hyperactivity-inattention and peer problems as well as assessing for strengths (Goodman, 1997). The SDQ has been widely validated for assessing psychosocial dysfunction in children (Mieloo et al., 2013; Vogels et al., 2009) and is routinely used in children's services. The SDQ also shows

promise in detecting co-morbid emotional disorders and hyperactivity in autistic adults and youth (Findon et al., 2016). The SDQ is completed by parents for young people aged 8-18 years and by the young person themselves aged 11-18 years. For the SDQ a higher total score equates to more significant problems inclusive of domains of emotional problems, conduct problems, hyperactivity and peer problems. The total score ranges from 0-40. The SDQ uses a 4-band categorisation for each subdomain. For the parent reported total score, the ranges are "close to average" = 0-13, "slightly raised" = 14-16, "high" = 17-19 and "very high" = 20-40. For the subdomains, a "very high" score rated by parents is between 7-10 for emotional problems, 6-10 for conduct problems, 9-10 for hyperactivity and 5-10 for peer problems.

The Pediatric QoL (PedsQL)

The PedsQL is a self-report and parent-report assessment of children and young people's health related QoL (Varni et al., 1999). The PedsQL has been found to be reliable, valid and reviewed in many studies with data for over 25,000 healthy children and those with chronic health conditions (Varni et al., 2005) and found to reliably distinguish between autistic and non-autistic youth (Viecili & Weiss, 2015). The PedsQL includes four subscales: physical functioning, emotional functioning, social functioning and school functioning. On the PedsQL, a higher total score equates to better quality of life. The highest possible total score is 100, similarly the highest possible total score for each subscale is also 100.

Procedure

Ethical approval for the study was confirmed on 28th September 2021 (see Appendix 2). All age-appropriate information sheets and consent forms were approved and included information about withdrawal and confidentiality. All participant information and data were password protected and stored on the University of Birmingham server. It was not anticipated that the participants would be subjected to any harm based on their participation in the study,

however, it was acknowledged that completing the questionnaires would take some additional time (15-20 minutes at timepoint 1 and 10 minutes at each timepoint thereafter), and young people were reminded that if they found the content of the questionnaires to be too distressing that they could ask for support or they did not have to complete them. Participants were not paid to participate in this study.

Referrals of young people with estimated assessment dates 3-6 months in the future were screened by the Principal Investigators (PIs) in the relevant trusts. Those fulfilling the inclusion criteria were contacted to ask for consent to be contacted by the researcher. The pre-existing mental health difficulty was defined by formal diagnoses or current difficulties causing distress e.g. anxiety, low mood/depression, obsessive-compulsive disorder, school refusal, challenging behaviour, eating disorder etc. The researcher recruited the participants and remained in regular contact with them. The approved consent forms were transferred to Qualtrics, an online survey platform, and sent to families to access via a link. Following the initial phone call with the family, approved information sheets and links to the consent forms were emailed. The family were contacted again if consent was not received within one week. During the second contact, the researcher answered any questions and offered further detail if needed. Parents gave informed consent for their child to take part if they were less than 16 years old. For young people aged 14 and 15, they provided assent in addition to parental consent. Young people aged 16+ gave informed consent. Once consent was received, the links to the questionnaires, also on Qualtrics, were emailed for the young person and/or parent/carer to complete.

Data Collection

The study aimed to capture data at four timepoints during the autism assessment. The first was whilst the young person was on the waiting list for an assessment. The time between the waiting list and timepoint 2 was considered the “Wait period”. The following timepoints

were: timepoint 2, at the time of the assessment (as close to the assessment date as manageable), timepoint 3, at the time of the feedback appointment (when a diagnosis may or may not be given) and timepoint 4, around three months after the feedback was given. Parents completed questionnaires for their child up to 18 years old. The PI at each trust kept the researcher up to date with upcoming assessment and feedback appointment dates so that the questionnaires could be sent to the family in good time. Further information on the data collected at each timepoint is presented in Table 3. Fewer questionnaires were given at timepoints 2, 3 and 4 (the SDQ was not repeated) as a way to reduce the time spent for participants and to ensure the key mental health and QoL questions were repeated at each timepoint.

Table 3

Questionnaires and Timepoints

Age	Timepoint 1 (T1)	Timepoints 2, 3 & 4 (T2, T3, T4)
8 – 11 years	RCADS, child and parent SDQ, parent PedsQL, child and parent	RCADS, child and parent PedsQL, child and parent
11 – 18 years	RCADS, child and parent SDQ, child and parent PedsQL, child and parent	RCADS, child and parent PedsQL, child and parent

Analysis

Three main stages of data analysis/presentation were undertaken.

1. Descriptive statistics for all T1 data were calculated and paired sample t-tests assessed for differences between parent reported and young person reported symptoms. Frequency data were analysed highlighting the proportion of mental health scores falling within the clinical threshold for anxiety diagnoses. Summary measures of Mental Health and Strengths and Difficulties were correlated with Quality of Life and age of young person to understand relations between these factors. Similarly, independent t-tests assessed for differences between gender and these factors.

2. Bayes Factor (BF_{01}) related sample t-tests were employed to compare T1 and T2 data. T-test statistics and related p-values were used to provide statistical evidence for rejection of the null hypothesis – i.e. as firm evidence for a change in mental health symptoms between T1 and T2. Given relatively small sample sizes for this comparison, Bayes Factors (BF_{01}) were used to identify how closely the data supported the alternative vs. null hypothesis in terms of symptom change between T1 and T2. A $BF_{01} = 1$ suggests that the null and alternative hypotheses are equally consistent with the data. $BF_{01} > 1$ provides more support for the null hypothesis. Jeffreys (1998) suggests the following for Bayesian statistics:
    - $BF_{01} = 1–3$ as "anecdotal evidence" in favour of the null hypothesis
    - $BF_{01} = 3–10$ as "moderate evidence" in favour of the null hypothesis
    - $BF_{01} = 10–30$ as "strong evidence" in favour of the null hypothesis
    - $BF_{01} = 30–100$ as "very strong evidence" in favour of the null hypothesis
    - $BF_{01} > 100$ as "extreme evidence" in favour of the null hypothesis

Reciprocally, $BF_{01} < 1$ provides more support for the alternative hypothesis, such that:

- $BF_{01} = 1–1/3$ as "anecdotal evidence" in favour of the alternative hypothesis
- $BF_{01} = 1/10–1/3$ as "moderate evidence" in favour of the alternative hypothesis
- $BF_{01} = 1/30–1/10$ as "strong evidence" in favour of the alternative hypothesis
- $BF_{01} = 1/100–1/30$ as "very strong evidence" in favour of the alternative hypothesis
- $BF_{01} < 1/100$ as "extreme evidence" in favour of the alternative hypothesis

3. Longer-term descriptive data for a small group of participants were analysed on an individual trajectory basis.

Given several families of tests included multiple statistical comparisons, differing approaches to correct for this were considered. Bonferoni correction would allow for stringent protection against type-1 error, but with a limited sample size would increase the chances of type-2 error. No correction would present the opposite problem. As a compromise, adjusting significance to the more stringent $p < 0.01$ was chosen (following Surtees et al., 2019).

Results

Data were analysed to address each aim of the study. There were unequal datasets at each timepoint due to some young people not yet reaching the timepoint, some young people may have missed a timepoint and some young people chose not to complete the questionnaires (see Figure 1).

Timepoint 1 Data Analysis

Distributions of data were checked for consistency with normality. Across the 44 variables measured, three were shown to differ significantly from a normal distribution, using the Shappiro Wilkes test – Young person ratings of Generalized Anxiety and Social Phobia on the RCADs, and parent rating of Emotional Problems on the SDQ. In each of these cases, the non-parametric Wilcoxen Signed-Rank test was run subsequent to the paired t-test. In each case, conclusions of significance were consistent across parametric and non-parametric tests. T-test data are therefore maintained in the main text to allow for comparison across variables, with Wilcoxen data included in Appendix 3.

Timepoint 1 Descriptive Statistics

Descriptive statistics of timepoint 1 data were analysed in SPSS to include the means and standard deviations for both young person and parent data. The young person reported data were N = 25, with only 19 completing the SDQ based on their age and the parent reported data were N = 27. For the RCADS, a higher score equates to worse mental health symptom, for the SDQ a higher total score equates to more significant emotional problems, conduct problems, hyperactivity and peer problems, and for the PedsQL a higher score equates to a *better* QoL. Parents rated the young person's anxiety and depression as less severe than the young people themselves on a number of subscales; paired sample t-tests revealed significant differences in young person and parent reported generalised anxiety ($t(24) = 3.1$, $p = 0.005$), panic ($t(24) = 4.5$, $p < 0.001$), obsessions ($t(24) = 2.9$, $p = 0.008$), depression ($t(24) = 4.4$, $p < 0.001$), total anxiety ($t(24) = 3.4$, $p = 0.003$), with a trend for total anxiety and depression ($t(24) = 2.4$, $p = 0.022$).

Young person and parent scores on the SDQ were very similar across the sample, with only one item showing significance on the paired sample t-tests, SDQ impact score ($t(18) = -3.5$, $p = 0.002$) – with parents reporting a greater impact of the difficulties than the young person themselves. On the QoL scale, no significant differences were identified. Descriptive data are presented in Table 4.

Table 4

Timepoint 1 Descriptive Statistics. For young person reports, N = 25 for RCADS and PedsQL and N = 19 for SDQ. For parent report, N = 27.

	YP Mean (SD)	YP Range	Parent Mean (SD)	Parent Range	YP-Parent Comparison paired t-test
RCADS Separation Anxiety	11.96 (5.1)	3-21	11.3 (4.4)	2-21	$t(24) = 1.3$, $p = 0.197$
RCADS Generalised Anxiety	13.2 (4.9)	2-18	10.8 (3.5)	2-18	$t(24) = 3.1$, $p = 0.005$*
RCADS Panic	15.3 (6.6)	5-26	11.2 (6)	1-22	$t(24) = 4.5$, $p < 0.001$*
RCADS Social Phobia	20.1 (6.9)	5-27	18.3 (6.8)	1-27	$t(24) = 1.3$, $p = 0.195$
RCADS Obsessions	10.8 (5.3)	1-18	8.1 (4.5)	0-17	$t(24) = 2.9$, $p = 0.008$*
RCADS Depression	19.2 (6.1)	9-30	15.3 (4.1)	9-25	$t(24) = 4.4$, $p < 0.001$*
RCADS Total Anxiety	71.4 (23.5)	30-105	60.1 (19.8)	6-101	$t(24) = 3.4$, $p = 0.003$*
RCADS Total Anxiety and Depression	87.8 (30.4)	24-135	75.4 (21.9)	24-126	$t(24) = 2.4$, $p = 0.022$
SDQ Emotional Problems	7.9 (1.8)	4-10	7.7 (2)	3-10	$t(18) = 0.16$, $p = 0.875$
SDQ Conduct Problems	3.4 (2.6)	0-9	3.4 (2.8)	0-10	$t(18) = 1.2$, $p = 0.23$
SDQ Hyperactivity	7.5 (1.9)	2-10	7.1 (2.7)	1-10	$t(18) = 1.6$, $p = 0.132$
SDQ Peer Problems	4.6 (2.8)	1-10	4.6 (2.5)	0-9	$t(18) = -0.57$, $p = 0.578$
SDQ Prosocial Score	6.9 (2.6)	0-10	6.1 (2.5)	2-10	$t(18) = 0$, $p = 1$
SDQ Impact Score	7.2 (2.9)	1-12	9.2 (3.6)	1-14	$t(18) = -3.5$, $p = 0.002$*
SDQ Overall Difficulty	23.5 (6.3)	12-38	22.9 (6.8)	10-37	$t(18) = 0.96$, $p = 0.348$
PedsQL Physical Function	50 (23.5)	6.25-100	55.3 (21.3)	6.25-100	$t(24) = -1.42$, $p = 0.169$
PedsQL Emotional Function	25.4 (18.6)	0-60	27.8 (19)	0-65	$t(24) = -1.11$, $p = 0.276$
PedsQL Social Function	51 (24.5)	0-100	49.2 (24.1)	0-85	$t(24) = 0.21$, $p = 0.836$
PedsQL School Function	36 (19.4)	0-70	42 (25.5)	0-95	$t(24) = -1.75$, $p = 0.092$
PedsQL Psychosocial Health	37.5 (16.8)	10-70	40.1 (17.5)	1.7-71.7	$t(24) = -1.15$, $p = 0.261$
PedsQL Physical Health	50 (23.5)	6.25-100	55.3 (21.3)	6.25-100	$t(24) = -1.42$, $p = 0.169$
PedsQL Total QoL	42.4 (17.9)	10.9-71.7	45.4 (17.4)	3.3-77.2	$t(24) = -1.28$, $p = 0.215$

Note: * = $p < 0.01$

Note: *RCADS: Higher score indicates poorer mental health, highest possible total anxiety & depression score = 141, highest possible social phobia = 27, panic = 27, depression = 30, separation anxiety = 21, generalised anxiety = 18, obsessive compulsive = 18*
SDQ: Total score ranges 0-40, 4-band categorisation for each subdomain (emotional problems, conduct problems, peer problems and hyperactivity) – "very high" = 20-40 (total) and between 5-10 (subdomains)
PedsQL: Higher score indicates better quality of life, highest possible total score = 100, 4 subscales include physical, emotional, social and school functioning – highest score = 100.

Timepoint 1 Frequency Data

The analysis also considered the frequency at which mental health symptoms were rated as within the clinical threshold of anxiety disorders, according to the RCADS, as rated by both young people and parents/carers. A T-score above 70 is considered the clinical threshold, i.e., the score is in the top 2% of scores of un-referred young people of the same age, and T scores between 65-70 are considered to be borderline clinical, i.e., the score is in the top 7%. The data demonstrate parents rated their children's mental health to be above the clinical threshold more often than young people rated this. Frequency data are presented in Figures 2 and 3.

Figure 2

Young Person Frequency Data

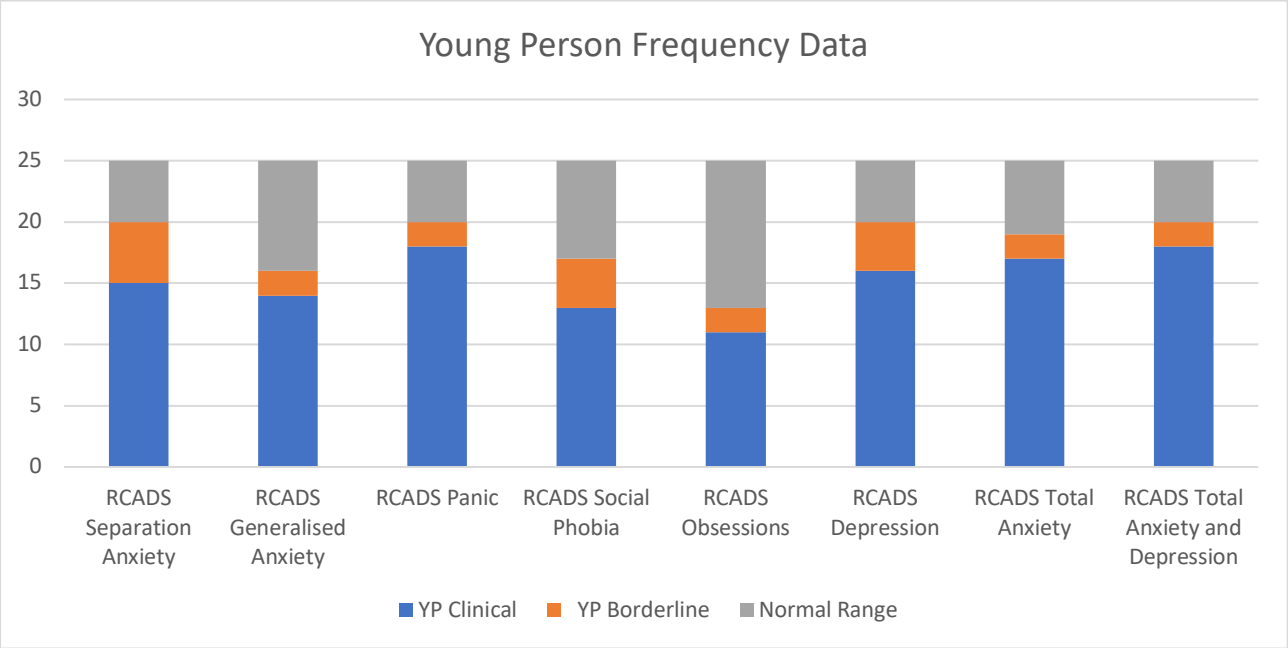
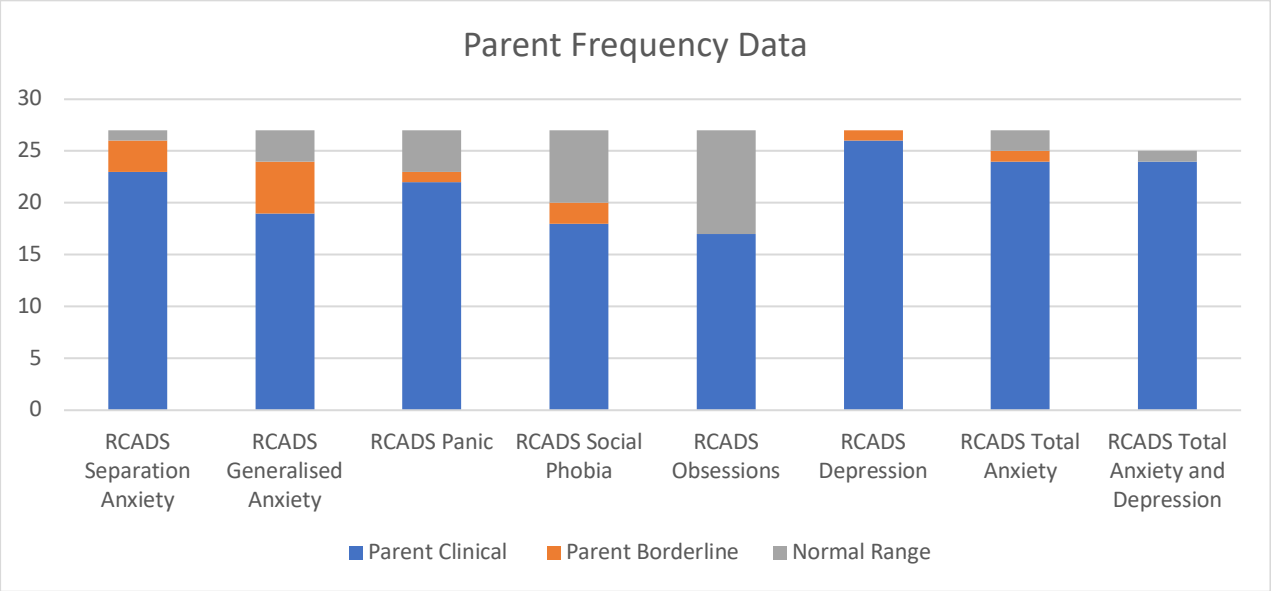


Figure 3

Parent Frequency Data



Correlations with Mental Health

Pearson's correlations were calculated to explore possible relationships between age of young person and total depression, total anxiety, overall SDQ and total QoL scores. This did not reveal any significant relationships for young person or parent reported data. Correlations were also included between total QoL and total depression, total anxiety and overall SDQ. This revealed significant relationships with all mental health symptoms, suggesting poorer QoL is associated with poorer mental health. See correlation matrix in Table 5.

Table 5

Correlation Matrix for YP and Parent Reported Relationships Between Mental Health with Age and QoL with Mental Health

	YP				Parent			
Measure	**Correlation with Depression** *ρ (p)*	**Correlation with Total Anxiety** *ρ (p)*	**Correlation with SDQ Overall** *ρ (p)*	**Correlation with PedsQL Total** *ρ (p)*	**Correlation with Depression** *ρ (p)*	**Correlation with Total Anxiety** *ρ (p)*	**Correlation with SDQ Overall** *ρ (p)*	**Correlation with PedsQL Total** *ρ (p)*
Age	.28 (.175)	.249 (.23)	-.311 (.194)	.013 (.95)	.281 (.156)	.135 (.502)	-.206 (.303)	.078 (.698)
PedsQL	-.651 (<.001)*	-.660 (<.001)*	-.758 (<.001)*	-	-.651 (<.001)*	-.485 (.01)*	-.697 (<.001)*	-

Note: * = $p < 0.01$

Gender and Mental Health

Independent samples T tests were calculated to explore possible relationships between gender of young person and total depression, total anxiety, overall SDQ and total QoL scores, as reported by both young people and parents. The data for young people showed a trend for higher ratings of anxiety for female participants ($t(22) = -2.16$, $p = 0.042$), that did not meet our threshold for significance following correction, see Table 6. The data for parent reported symptoms revealed no differences between gender and mental health, see Table 7.

Table 6

Independent Samples T Test, Gender & YP Reported Mental Health

	Male Mean (SD)	**Female Mean (SD)**	***t***	***df***	***p***
Depression	16 (6.6)	20.7 (5.6)	-1.819	22	.083
Total Anxiety	57 (27)	77.7 (19.5)	-2.16	22	.042
SDQ Overall	40 (3.5)	37.1 (9.4)	.522	16	.609
PedsQL	48.4 (20.8)	40 (16.8)	1.064	22	.299

Table 7

Independent Samples T Test, Gender & Parent Reported Mental Health

	Male Mean (SD)	Female Mean (SD)	*t*	*df*	*p*
Depression	14 (3.4)	15.9 (4.4)	-1.087	25	.287
Total Anxiety	55.4 (17.5)	62 (20.8)	-.796	25	.434
SDQ Overall	38.4 (10.1)	38.1 (8.1)	.702	25	.942
PedsQL	48.1 (10.7)	44.2 (19.7)	1.04	25	.605

Change in Symptoms from Waitlist to Assessment

Data were checked for normality and were consistent with normal distribution, meeting assumptions for parametric testing, see output in Appendix 3. To analyse the change in mental health symptoms for young people from the waiting list period to the time of the assessment (T1 – T2), a related sample Bayes factor t-test was used. The Bayes factor t-tests demonstrated trends for reduction in young person and parent reported anxiety scores and for an improvement in parent-reported quality of life score (Figures 4 and 5). None of these findings reached our stringent significance threshold. Regarding Bayes Factors, data provided moderate evidence that parent-rated quality of life had improved, whilst all other tests provided only “anecdotal” evidence in favour of the alternative hypothesis (that young person and parent-reported anxiety had improved) or the null hypothesis (that there was no change in either parent or young person reported depression, or in young person reported quality of life). These data are presented in Tables 8 and 9.

Table 8

Bayes Factor Data for Young People

	Mean Difference	Std Dev	Std Error Mean	Cohen's d (95%CI)	Bayes Factor	Sig. (2-tailed)
T1 RCADS Depression – T2 RCADS Depression	2	5.9	1.4	0.36 (-0.17 – 0.9)	2.2	.186
T1 RCADS Anxiety – T2 RCADS Anxiety	9.1	13.9	3.9	0.39 (0.03 – 0.75)	0.6	.033
T1 PedsQL Total – T2 PedsQL Total	-3.7	9.7	2.4	-0.21 (-0.49– 0.06)	1.8	.134

Table 9

Bayes Factor Data for Parents

	Mean Difference	Std Dev	Std Error Mean	Cohen's d (95%CI)	Bayes Factor	Sig. (2-tailed)
T1 RCADS Depression – T2 RCADS Depression	1.2	4.1	0.97	0.28 (-0.20 – 0.76)	2.9	.248
T1 RCADS Anxiety – T2 RCADS Anxiety	7.2	14.8	3.5	0.40 (-0.01 – 0.81)	0.89	.054
T1 PedsQL Total – T2 PedsQL Total	-6.6	10.2	2.4	-0.40 (-0.72 – -0.08)	0.27	.014

Figure 4

Young Person Reported Change in Symptoms from T1-T2

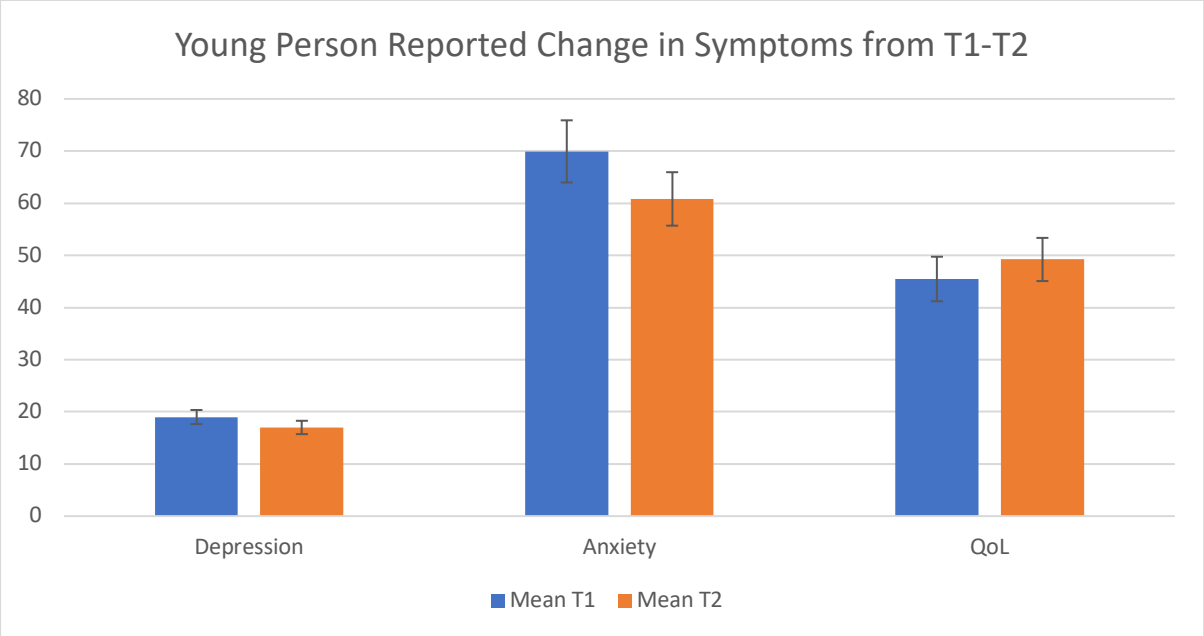
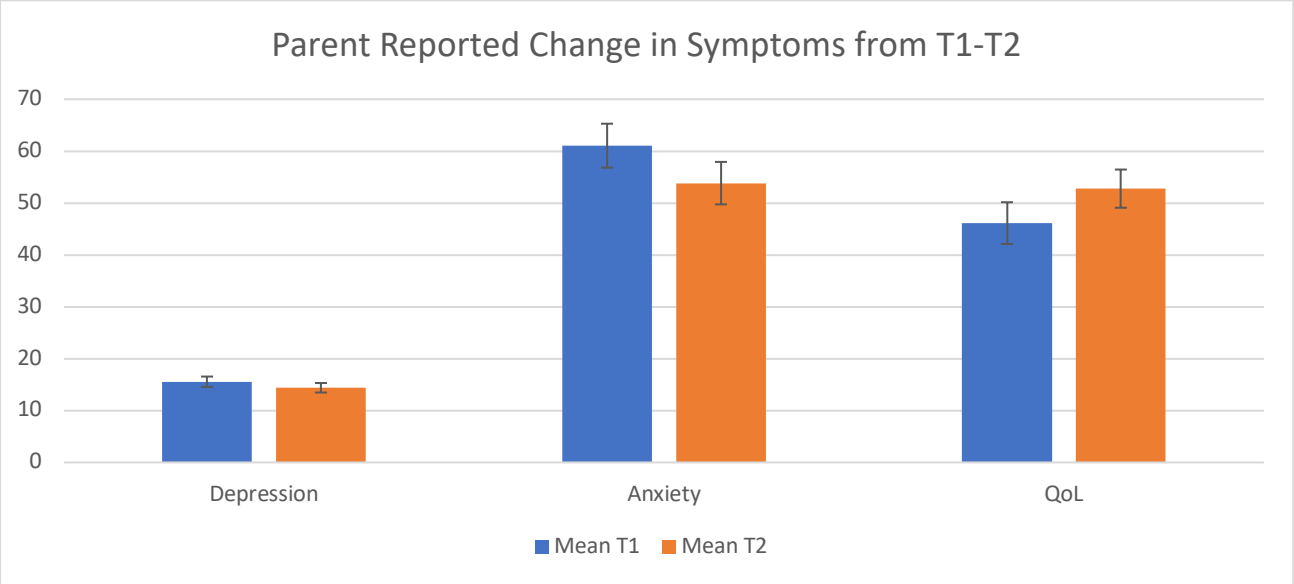


Figure 5

Parent Reported Change in Symptoms from T1-T2



Individual Trajectories from Waitlist to 3-months Post-Diagnosis

At the start of the study, we hoped to look at longitudinal differences at a group level. However, at this stage, only a small number of participants have completed data collection around the time of the feedback appointment (T3) and 3 months after this (T4), contributing to the longer-term data in the study. There were also differences between the two recruiting sites in terms of the structure of the assessment. The Paediatric service typically has a longer waiting list period, but the assessment to feedback period is very quick and it was impractical to complete two data collection points in the time. The Mental Health service typically has a shorter waiting list period, but the assessment to feedback period is often longer creating two distinct data collection points at timepoint 2 and timepoint 3 (the waiting period in the current study was around 3 months for both sites). Consequently, there are differences between the sites in whether data was collected at timepoint 3 or timepoint 4 for the follow up data collection. The data show a large amount of variability, with no clear singular pattern of change, see Figures 6 and 7.

Figure 6

Mental Health Service Participant Level Trajcetory Data

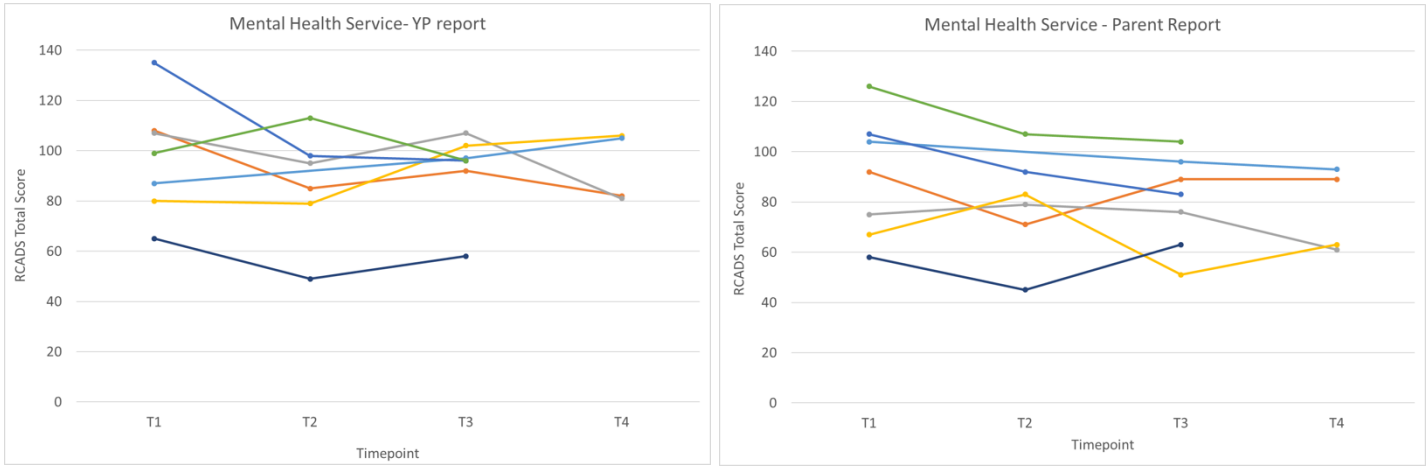
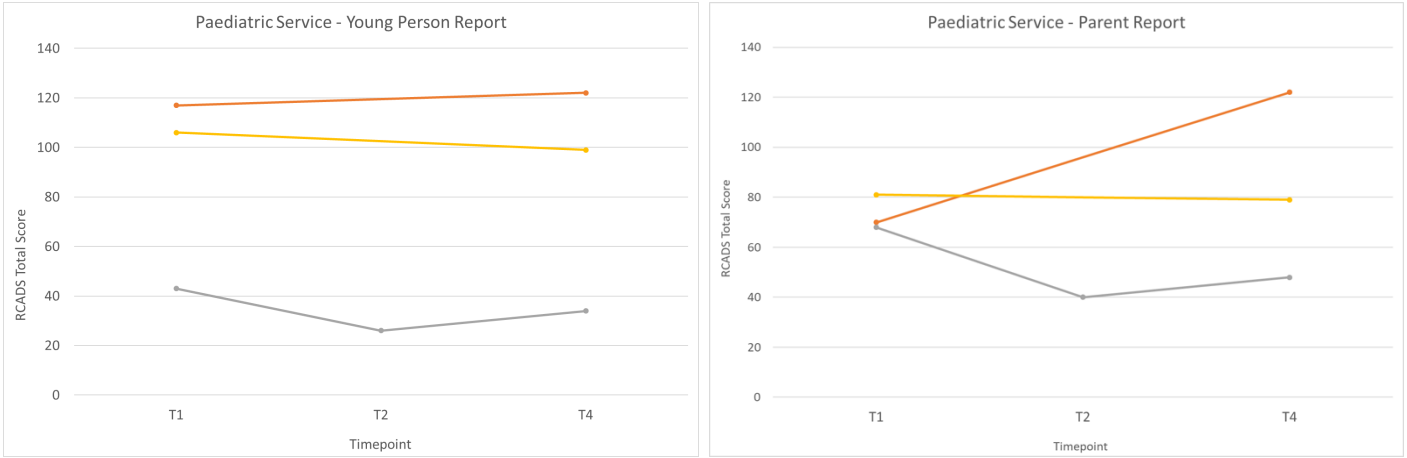


Figure 7

Paediatric Service Participant Level Trajectory Data



Discussion

This study offers early insights into how the autism assessment experience may impact young people's mental health. While a larger sample, with data across all timepoints, would have been beneficial, the study proposes initial evidence about how young people's mental health and QoL varies through the experience of the autism assessment. The majority of those recruited to the study have subsequently been diagnosed with autism and

consequently, the mental health data described can be aligned to previous literature of autistic young people. Levels of mental health difficulty were high, with young people reporting these as higher than their parents. Change while awaiting assessment suggested relatively little change, with no evidence for worsening of mental health or quality of life.

Mental Health of Young People waiting for Autism Assessment

Timepoint 1 data reflected the mental health and well-being of young people awaiting an autism assessment. Both young person and parent reports showed young people to be experiencing significant levels of mental health difficulties, challenging behavioural attributes and low quality of life. Parent-reports, for instance suggested 89% of young people met the clinical threshold for anxiety/depression, with a further 7% in the borderline range. Though the sample was recruited through services and procedures with reference to an experience or history of mental health difficulty, the levels identified here remain notable. The findings support previous literature reporting significant rates of mental health difficulties in autistic people (Lai et al., 2019; Lever & Geurts, 2016). Similarly, as the sample recruited young people aged 8+ years old, the findings align with Mandy et al.'s (2022) work which demonstrated a steeper growth of frequency and severity of emotional, behavioural and social problems in later-diagnosed children (over 8 years old) compared to the earlier-diagnosed children.

Reasons for high rates of anxiety and depression in "late-diagnosed" autistic young people are likely multi-factorial. Rates of anxiety in autistic people more generally are high (Lai et al., 2019), with reasons suggested including autistic people finding tolerating uncertainty difficult (Jenkinson et al., 2020) and having difficulties with describing and identifying emotions (alexithymia), which subsequently leads to difficulties with emotional regulation (Cai et al., 2018; Morie et al., 2019). Rates of depression in autistic people are also

high (DeFilippis, 2018) with reasons suggested including having a higher intelligence quotient coupled with limited social skills (Chandrasekhar & Sikich, 2015), increased levels of loneliness and poor quality friendships (Whitehouse et al., 2009) and a lack of social support (Hedley et al., 2018). Late diagnosed autistic people may experience particularly elevated rates of mental health difficulties (Bargiela et al., 2016; Cage & Troxell-Whitman, 2019) because of 'masking' of difficulties associated with autism leading to being undiagnosed (Fusar-Poli et al., 2020) also contributing to mental health difficulties. Similarly, a later age of diagnosis has also been found to relate to a lower QoL for autistic people (Atherton et al., 2022).

Descriptive statistics of the T1 data collected revealed differences in how parents rate their child's mental health symptoms compared to how young people rate their mental health symptoms, with significant differences found for generalised anxiety, panic, obsessions, depression, total anxiety and with a trend for total anxiety and depression. Data also suggest that parents rate their child's symptoms as less severe than the young people themselves. Previous studies with non-autistic children have reported similar findings, whereby adolescents report worse health across social and emotional domains, including their experience of poor mental health (Waters et al., 2003). With anxiety specifically, Lagattuta et al. (2012) reported that parents significantly under-estimated their child's worry and under-estimated the frequency of this worry compared to child self-report. Klassen et al. (2006) also reported discrepancies between parent and child report of QoL symptoms in a sample of children with ADHD, highlighting the need for both parent and child reported data. However, in a study with high-functioning autistic adolescents, Blakeley-Smith et al. (2012) reported fair to strong agreement between parent and young person reported anxiety symptoms. The mixed findings highlight the need for more understanding in this area of clinical research.

In the current study, the young person and parent scores on the SDQ were similar across the sample, with only the impact score showing as significant on the paired sample t-tests, with parents reporting a higher impact of difficulties. Similarly, with the QoL scale, parent rated and young person rated scores were similar, with parents generally rating the QoL domains as better than the young people, but no significant differences found.

Comparison of parent-child frequency data analysis showed the opposite pattern, parents rated their children's total anxiety and depression as above clinical threshold for anxiety diagnoses in 89% of cases, compared to 72% of young person rated total anxiety and depression. This is interesting when considered in relation to the descriptive statistics of parent and young person reported raw scores for mental health symptoms, reported above. The clinical threshold is calculated using T scores rather than raw scores and then used to inform a category. One consequence of this is that raw scores are a more sensitive measure of individual differences – as all scores above threshold are effectively equivalent for frequency data. The frequency data also take into account distributions of scores in a normative sample, so equivalent scores on parent and child responses may be scaled differently. Taken together, these results suggest a flexible and cautious approach may be needed to assessing changing mental health in autistic young people – use of individual raw scores vs. t-scores reaching threshold makes a meaningful difference to severity as rated by young people vs. their parents.

This data identified significant correlations between poor quality of life and poor mental health symptoms. In line with previous literature, mental health, particularly depression, is reported to relate significantly to poor quality of life in autistic youth (Lawson et al., 2020). Similarly with autistic adults, having a mental health difficulty and more severe autism symptoms have been found to be negative predictors of quality of life (Mason et al., 2018). The correlations between age and mental health symptoms were not found to be

significant. We may have expected to find older young people with poorer mental health since studies report that depression is positively associated with chronological age in autistic youth (Greenlee et al., 2016; Rai et al., 2018). Similarly, with differences between genders, t-tests were non-significant but we may have expected to find poorer mental health symptoms in girls as highlighted in previous reports of autistic youth (Gotham et al., 2015; Schwartzman et al., 2022).

Mental Health between Waiting List and Assessment

Change in symptoms from T1 to T2 were not substantial enough to demonstrate significant differences on any of our measures. Bayes Factor estimates were consistent with moderate evidence for improvement in parent-reported quality of life. As previous findings suggest emotional well-being and family functioning are reported to be low during the diagnostic process (Rivard et al., 2022), it is encouraging to notice parents report this element of QoL might start to improve once reaching the time of the autism assessment. It is possible the older young people in this sample may continue to report low QoL due to the delay in their diagnosis (Atherton et al., 2022). That all other findings were in the "anecdotal" range is suggestive that changes in mental health measures may be relatively modest during this period. There was some evidence for improvement in anxiety, but estimated effect sizes were low-moderate. Depression scores were more consistent with the null hypothesis.

Although this data is not conclusive, and larger data sets would be preferred, it is mostly considered that the findings do not show evidence suggesting young people's mental health is getting worse from the waiting list to the time of the autism assessment. The caveat to this being the current study used a waiting list period of around 3 months given the time restraints of the project, when in practice, some young people are waiting for two years for their assessment. This could mean that the waiting list offers some containment for young

people and families whereby they know they will be assessed in due course, or it could be that the young person has accessed mental health support whilst on the waiting list which has been beneficial.

Individual Trajectories to 3-months Post-Diagnosis

The individual trajectories of longer-term data show a large amount of variability, with no clear singular pattern of change. Larger groups of this data would be beneficial in determining the long-term impact of the autism assessment experience on young people's mental health symptoms. While retrospective, qualitative data on the autism assessment experience for young people is reasonably well documented (Finch et al., 2022; Jones et al., 2014; Prentice, 2020), the quantitative understanding of long-term advantages or disadvantages of receiving an autism diagnosis is lacking.

Clinical Implications

The data from the current study confirms previous findings as to the severity and chronicity of mental health difficulties for autistic young people (or 'suspected' autistic young people), in conjunction with poorly rated familial QoL. Consequently, it is clinically important service providers have an understanding of how to support and treat poor mental health in autistic young people to ensure appropriate risk assessments and other crisis supports are in place.

The headlines from the data reporting change in symptomatology are that young person anxiety appears to reduce during the waiting list period and parent reported QoL appears to improve. The implications of these findings are such that practitioners may feel reassured that the waiting list may be offering some containment to families, and relaying this whilst offering a channel of communication between the service and family may emphasise a feeling of validation. It is possible, that feeling heard and understanding more about the

autism assessment process is helpful for families. Services could capitalise on this possible improvement in mental health and QoL by providing active listening, offering further support on managing challenging behaviour and offering mental health interventions including psychoeducation, basic self-care and psychological safety. The implications of which could lead to more significant improvements for young people and families and reduce time spent on other waiting lists.

Limitations & Future Directions

Other Contributions to Mental Health

The current study offers a snapshot of a young person's mental health symptoms at varying timepoints during the autism assessment. The study was unable to control for extraneous variables also playing a role in how the young person's mental health symptoms fluctuated over the period of the study. It is expected that most of the sample were also experiencing difficult life events such as challenges at school and home which are likely to contribute to their mental health difficulties. Consequently, the change in mental health symptomatology cannot be attributed solely to the autism assessment experience and more data are needed to explore this.

Control Group and Baseline Data

The current study would benefit from the presence of a control group. This group could include young people referred to mental health services for support but who have not been referred to the neurodevelopmental team for an autism assessment and are not considered to display autistic traits. This group could offer insight into the differences in mental health symptomatology between suspected autistic young people and non-suspected autistic young people. Furthermore, the study would benefit from a controlled waiting list

period to add weight to the findings reported here on the impact of the waiting list on young people's mental health symptoms.

Sample

The final figures at each data collection timepoints are unequal. Of 35 people who consented to the study, eight did not complete timepoint 1 questionnaires and at timepoint 2, six people did not complete questionnaires. A large proportion of the sample are still active within the study and have not yet arrived at the final timepoints in their assessment journey. However, it is hypothesised that the families that consented to the study and did not complete data collection are possibly the families experiencing the most significant challenges in family life. It could also be that those young people found accessing the online questionnaire platform too difficult considering their possible rigidity and sensory needs associated with autism. Future research would benefit from larger samples and even groups of data collection at each timepoint to offer more detail and clarity to the findings.

Also worthy of noting is that most of the sample were white British, and the parent reported data mostly came from mothers. Future studies are encouraged to explore the autism assessment experience with more diverse populations and with father-reported data.

Electronic Questionnaire Platform

The electronic questionnaire platform used in the current study offers a quick and easy method for families to complete consent forms and questionnaires. These can be completed on a mobile phone or tablet/laptop. However, as with all electronic systems, there is a level of user error. This includes missed questions with no response, participants not including their identification code and failing to submit completed questionnaires. This happened in around 10% of cases in the current study. In these instances, data quality was not impacted, but young people were required to redo some questionnaires impacting their experience of the study.

Recruitment of families within NHS services

Empirical research with families in the NHS can be challenging. Naturally, young people and their families have their own busy lives and other priorities. Consequently, collecting data at set timepoints may not be possible. The current study required flexibility in data collection and for the clinicians involved to offer support where needed. Future studies could explore how to support families at the recruitment stage of research studies. In the current study, it was hypothesised that those families who consented to the study but did not complete data collection may be meaningfully different. Exploring this finding qualitatively would be helpful in understanding how to encourage families to take part in vital clinical research in the future.

Furthermore, the differences in how the two NHS trusts assess children and young people for neurodevelopmental conditions offered variability to the data collection process. Consequently, for some families, the time difference between assessment and feedback was very short (within two weeks) – making T3 inconsequential for one trust. Whereas other families had a longer waiting period between the two appointments and collecting data at each timepoint seemed to be meaningful. Future studies should consider ways to control the time between appointments for continuity and to eliminate potential extraneous variables.

Conclusion

The current study offers initial quantitative data which attempts to understand the impact of the autism assessment experience on young people's mental health. The data presented highlight the need for larger samples. Mostly, the findings are consistent with previous literature reporting high rates of mental health difficulties in autistic populations. However, the findings do not indicate that mental health was substantially declining during

the autism assessment experience. Further efforts to recruit larger and more diverse samples are needed.

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Autistic People are 11 Times More Likely to be in Psychiatric Inpatient Care

Recent data tells us that around 1% of the population are autistic. A new review reports that on average, 11% of people in psychiatric inpatient settings are autistic.

Psychiatric inpatient care is acute hospital care for those experiencing a mental health crisis. There has been a global shift away from traditional inpatient institutions with a focus on community-based care, however, there continues to be a need to inpatient mental health care for those in crisis.

Autism is a spectrum of neurodivergence and is diagnosed based on difficulties in two domains: social communication and interaction, and repetitive, restrictive patterns of behaviour. These difficulties can result in significant educational, social and health needs for the individual and/or family.

Research reports autistic people have more mental health difficulties compared to non-autistic people and a higher risk of self-harm and suicide. Considering this, it is unsurprising that autistic people present to emergency services four times as often as non-autistic people. These emergency visits are 3.7 times more likely to lead to an inpatient admission for autistic people compared to non-autistic people.

Using previously published, peer-reviewed studies, data was analysed to find the rate of autistic people in generic psychiatric inpatient settings. Fifteen studies were reviewed and data found a much higher rate of autistic people in inpatient settings compared to in the general population. An average of 11% of people in generic inpatient units are autistic, with 13% of children in inpatient units being autistic and 4% of adults.

The data revealed a big range of prevalence rates, with some studies reporting rates of autistic people around the general population estimates (1%) and some studies reporting much higher rates (up to 55%). It is apparent that different services and countries diagnose

autism in inpatient settings in different ways. Some use pre-existing diagnoses, some take a single clinician review approach and some take a more thorough, in-depth approach including autism-specific diagnostic tools and multi-disciplinary discussions and observations. This variation in diagnostic approach highlights that some of the data describing 'autistic populations' may not be completely accurate.

The included studies were rated by the quality of their methods. Those which did not report clear numerical rates of autistic people were rated as 'high risk' and also reported smaller rates of autistic people, suggesting they might have missed the full population in their calculations.

This new report found high rates of autistic people in generic psychiatric inpatient settings. However, the big variation in rates is difficult to understand. In the future, services need to be better equipped to measure and report the individualities of all people within the service. In addition, future research should focus on unifying the referral routes for autistic people into mental health inpatient facilities, and unifying the diagnostic process of autistic populations.

Do Mental Health and Quality of Life Change while Young People Wait for an Autism Assessment?

New evidence reports the severe mental health difficulties experienced by young people as they wait for an autism assessment. Promisingly, it also suggests that things do not get worse while they wait. While evidence tells us that mental health difficulties are more common in autistic people, symptoms associated with autism can often be overshadowed, leading to misdiagnoses. With an increase in awareness of autism and the associated challenges, there has been an increase in demand for autism assessments. However, a new report highlights associated benefits and challenges with the autism assessment experience.

Most autistic people are diagnosed as young children, however more teenagers and adults are now being assessed and diagnosed. If a diagnosis is given late, due to the significant increase of mental health difficulties in autistic people, it is likely they will come into contact with mental health services first. Evidence tells us there is value in timely autistic diagnosis for improvements in mental health difficulties and quality of life.

Autistic adults diagnosed in adulthood may have been mis-diagnosed with other conditions or undiagnosed due to 'masking' difficulties. This group also report having more mental health challenges compared to child-diagnosed autistic adults. Similarly, women and girls are often diagnosed later than boys and men due to camouflaging core autistic traits with better social interaction and language skills and fewer peculiar interests. As a result, autistic women revealed they had been diagnosed with other mental health difficulties which did not 'fit' with their experience. Age of diagnosis is found to significantly relate to quality of life for the individual and family, with a later diagnosis contributing to lower quality of life and more severe autistic traits.

The autism assessment process can be lengthy, stressful, emotionally charged. This period can entail an increase in parental mental health difficulties and challenges to typical family functioning. Previously there was an assumption that having an assessment and receiving a diagnosis would bring closure and relief for families.

This small study recruited 35 young people and their parents and followed them through their autism assessment experience. Participants completed mental health questionnaires at four timepoints. The data were analysed and showed young people and parents rated their mental health symptoms as within the clinical threshold for the majority of cases. There was some evidence that parents thought their children's quality of life improved while they waited for assessment and no evidence that mental health got worse. More data are needed that track young people's well-being over a longer period.

These new findings highlight the importance of supporting young people and families during the autism assessment process and beyond.

Appendix 1: PRISMA 2020 Checklist

Section and Topic	Item #	Checklist item	Location where item is reported
TITLE			
Title	1	Identify the report as a systematic review.	Page 1
ABSTRACT			
Abstract	2	See the PRISMA 2020 for Abstracts checklist.	Reviewed
INTRODUCTION			
Rationale	3	Describe the rationale for the review in the context of existing knowledge.	Page 8
Objectives	4	Provide an explicit statement of the objective(s) or question(s) the review addresses.	Page 8
METHODS			
Eligibility criteria	5	Specify the inclusion and exclusion criteria for the review and how studies were grouped for the syntheses.	Pages 9 - 11
Information sources	6	Specify all databases, registers, websites, organisations, reference lists and other sources searched or consulted to identify studies. Specify the date when each source was last searched or consulted.	Page 9
Search strategy	7	Present the full search strategies for all databases, registers and websites, including any filters and limits used.	Page 9
Selection process	8	Specify the methods used to decide whether a study met the inclusion criteria of the review, including how many reviewers screened each record and each report retrieved, whether they worked independently, and if applicable, details of automation tools used in the process.	Page 9
Data collection process	9	Specify the methods used to collect data from reports, including how many reviewers collected data from each report, whether they worked independently, any processes for obtaining or confirming data from study investigators, and if applicable, details of automation tools used in the process.	Page 11
Data items	10a	List and define all outcomes for which data were sought. Specify whether all results that were compatible with each outcome domain in each study were sought (e.g. for all measures, time points, analyses), and if not, the methods used to decide which results to collect.	Page 11
	10b	List and define all other variables for which data were sought (e.g. participant and intervention characteristics, funding sources). Describe any assumptions made about any missing or unclear information.	N/A
Study risk of bias assessment	11	Specify the methods used to assess risk of bias in the included studies, including details of the tool(s) used, how many reviewers assessed each study and whether they worked independently, and if applicable, details of automation tools used in the process.	Pages 11 - 14
Effect measures	12	Specify for each outcome the effect measure(s) (e.g. risk ratio, mean difference) used in the synthesis or presentation of results.	Page 11
Synthesis methods	13a	Describe the processes used to decide which studies were eligible for each synthesis (e.g. tabulating the study intervention characteristics and comparing against the planned groups for each synthesis (item #5)).	Page 18
	13b	Describe any methods required to prepare the data for presentation or synthesis, such as handling of missing summary statistics, or data	Page 11

Section and Topic	Item #	Checklist item	Location where item is reported
		conversions.	
	13c	Describe any methods used to tabulate or visually display results of individual studies and syntheses.	Pages 25, 26, 31 & 33
	13d	Describe any methods used to synthesize results and provide a rationale for the choice(s). If meta-analysis was performed, describe the model(s), method(s) to identify the presence and extent of statistical heterogeneity, and software package(s) used.	Page 15
	13e	Describe any methods used to explore possible causes of heterogeneity among study results (e.g. subgroup analysis, meta-regression).	Pages 29 - 34
	13f	Describe any sensitivity analyses conducted to assess robustness of the synthesized results.	Pages 27 - 28
Reporting bias assessment	14	Describe any methods used to assess risk of bias due to missing results in a synthesis (arising from reporting biases).	Pages 13 - 14
Certainty assessment	15	Describe any methods used to assess certainty (or confidence) in the body of evidence for an outcome.	Page 15
RESULTS			
Study selection	16a	Describe the results of the search and selection process, from the number of records identified in the search to the number of studies included in the review, ideally using a flow diagram.	Pages 16 - 18
	16b	Cite studies that might appear to meet the inclusion criteria, but which were excluded, and explain why they were excluded.	Pages 18-19
Study characteristics	17	Cite each included study and present its characteristics.	Page 20
Risk of bias in studies	18	Present assessments of risk of bias for each included study.	Pages 21 - 24
Results of individual studies	19	For all outcomes, present, for each study: (a) summary statistics for each group (where appropriate) and (b) an effect estimate and its precision (e.g. confidence/credible interval), ideally using structured tables or plots.	Page 26
Results of syntheses	20a	For each synthesis, briefly summarise the characteristics and risk of bias among contributing studies.	Pages 21-24
	20b	Present results of all statistical syntheses conducted. If meta-analysis was done, present for each the summary estimate and its precision (e.g. confidence/credible interval) and measures of statistical heterogeneity. If comparing groups, describe the direction of the effect.	Pages 24 - 27
	20c	Present results of all investigations of possible causes of heterogeneity among study results.	Pages 26 – 34
	20d	Present results of all sensitivity analyses conducted to assess the robustness of the synthesized results.	Pages 27 - 28

Section and Topic	Item #	Checklist item	Location where item is reported
Reporting biases	21	Present assessments of risk of bias due to missing results (arising from reporting biases) for each synthesis assessed.	Pages 28 - 29
Certainty of evidence	22	Present assessments of certainty (or confidence) in the body of evidence for each outcome assessed.	Page 26 & 31
DISCUSSION			
Discussion	23a	Provide a general interpretation of the results in the context of other evidence.	Pages 34 - 35
	23b	Discuss any limitations of the evidence included in the review.	Pages 37 – 38
	23c	Discuss any limitations of the review processes used.	Pages 38 - 39
	23d	Discuss implications of the results for practice, policy, and future research.	Pages 39 – 40
OTHER INFORMATION			
Registration and protocol	24a	Provide registration information for the review, including register name and registration number, or state that the review was not registered.	Page 8
	24b	Indicate where the review protocol can be accessed, or state that a protocol was not prepared.	N/A
	24c	Describe and explain any amendments to information provided at registration or in the protocol.	Page 8
Support	25	Describe sources of financial or non-financial support for the review, and the role of the funders or sponsors in the review.	N/A
Competing interests	26	Declare any competing interests of review authors.	N/A
Availability of data, code and other materials	27	Report which of the following are publicly available and where they can be found: template data collection forms; data extracted from included studies; data used for all analyses; analytic code; any other materials used in the review.	N/A

Appendix 2: HRA Ethical Approval

Health Research Authority

East of England - Cambridge South Research Ethics Committee
Equinox House
City Link
Nottingham
NG2 4LA

Please note: This is the favourable opinion of the REC only and does not allow you to start your study at NHS sites in England until you receive HRA Approval

28 September 2021

Dr Andrew Surtees
School of Psychology, University of Birmingham
Edgbaston
Birmingham
B15 2TT

Dear Dr Surtees,

Study title:	**Understanding young peoples' experience of autism assessment and its impact on their mental health.**
REC reference:	**21/EE/0176**
Protocol number:	**RG_20-185**
IRAS project ID:	**285174**

Thank you for your letter of 07 September 2021, responding to the Research Ethics Committee's (REC) request for further information on the above research and submitting revised documentation.

The further information has been considered on behalf of the Committee by the Chair.

Confirmation of ethical opinion

On behalf of the Committee, I am pleased to confirm a favourable ethical opinion for the above research on the basis described in the application form, protocol and supporting documentation as revised, subject to the conditions specified below.

Appendix 3: Considerations of Normality

Normality tests for comparing T1 data between young people and parents

Young person

Tests of Normality

	Kolmogorov-Smirnov[a]			Shapiro-Wilk		
	Statistic	df	Sig.	Statistic	df	Sig.
T1_RCADS_SA_Raw	.090	25	.200*	.973	25	.715
T1_RCADS_GA_Raw	.208	25	.007	.853	25	.002
T1_RCADS_Panic_Raw	.099	25	.200*	.950	25	.251
T1_RCADS_SP_Raw	.231	25	.001	.843	25	.001
T1_RCADS_Ob_Raw	.124	25	.200*	.941	25	.159
T1_RCADS_Dep_Raw	.176	25	.045	.946	25	.199
T1_RCADS_TA_Raw	.218	25	.004	.888	25	.010
T1_RCADS_TAD_Raw	.219	25	.003	.928	25	.076
T1_PedsQL_PF	.115	25	.200*	.979	25	.855
T1_PedsQL_EF	.152	25	.139	.939	25	.139
T1_PedsQL_SF	.124	25	.200*	.963	25	.476
T1_PedsQL_SchF	.138	25	.200*	.960	25	.408
T1_PedsQL_PSH	.070	25	.200*	.973	25	.719
T1_PedsQL_PH	.115	25	.200*	.979	25	.855
T1_PedsQL_Total	.110	25	.200*	.952	25	.274

*. This is a lower bound of the true significance.

a. Lilliefors Significance Correction

Tests of Normality

	Kolmogorov-Smirnov[a]			Shapiro-Wilk		
	Statistic	df	Sig.	Statistic	df	Sig.
T1_SDQ_EP	.248	19	.003	.883	19	.024
T1_SDQ_CP	.143	19	.200*	.938	19	.245
T1_SDQ_Hyp	.227	19	.011	.889	19	.031
T1_SDQ_PP	.169	19	.157	.908	19	.068
T1_SDQ_ProSo	.154	19	.200*	.898	19	.044
T1_SDQ_Impact	.163	19	.200*	.959	19	.559
T1_SDQ_Overall	.100	19	.200*	.973	19	.839

*. This is a lower bound of the true significance.

a. Lilliefors Significance Correction

Parents

Tests of Normality

	Kolmogorov-Smirnov[a]			Shapiro-Wilk		
	Statistic	df	Sig.	Statistic	df	Sig.
T1_Parent_RCADS_SA	.110	25	.200*	.959	25	.394
T1_Parent_RCADS_GA	.138	25	.200*	.962	25	.456
T1_Parent_RCADS_Panic	.112	25	.200*	.956	25	.339
T1_Parent_RCADS_SP	.181	25	.035	.894	25	.014
T1_Parent_RCADS_Ob	.135	25	.200*	.964	25	.494
T1_Parent_RCADS_Dep	.148	25	.165	.923	25	.059
T1_Parent_RCADS_TA	.138	25	.200*	.974	25	.739
T1_Parent_RCADS_TAD	.109	25	.200*	.988	25	.987
T1_Parent_SDQ_EP	.187	25	.024	.883	25	.008
T1_Parent_SDQ_CP	.152	25	.138	.906	25	.025
T1_Parent_SDQ_Hyp	.158	25	.111	.888	25	.010
T1_Parent_SDQ_PP	.158	25	.109	.950	25	.255
T1_Parent_SDQ_ProSo	.155	25	.122	.914	25	.038
T1_Parent_SDQ_Impact	.149	25	.154	.934	25	.107
T1_Parent_SDQ_Overall	.148	25	.164	.967	25	.563
T1_Parent_PedsQL_PF	.114	25	.200*	.977	25	.817
T1_Parent_PedsQL_EF	.092	25	.200*	.961	25	.433
T1_Parent_PedsQL_SF	.138	25	.200*	.951	25	.264
T1_Parent_PedsQL_SchF	.123	25	.200*	.965	25	.532
T1_Parent_PedsQL_PSH	.108	25	.200*	.973	25	.720
T1_Parent_PedsQL_PH	.114	25	.200*	.977	25	.817
T1_Parent_PedsQL_Total	.106	25	.200*	.972	25	.709

*. This is a lower bound of the true significance.

a. Lilliefors Significance Correction

Non-Parametric tests for comparisons including non-normally distributed data

Test Statistics

	T1_Parent_RCADS_GA - T1_RCADS_GA_Raw	T1_Parent_RCADS_SP - T1_RCADS_SP_Raw	T1_Parent_SDQ_EP - T1_SDQ_EP
Z	-2.669[b]	-1.324[b]	-.193[b]
Asymp. Sig. (2-tailed)	.008	.186	.847

a. Wilcoxon Signed Ranks Test
b. Based on positive ranks.

Normality tests for comparing T1 and T2

Young person

Tests of Normality

	Kolmogorov-Smirnov[a]			Shapiro-Wilk		
	Statistic	df	Sig.	Statistic	df	Sig.
T1_RCADS_TA_Raw	.186	17	.122	.922	17	.161
T1_RCADS_Dep_Raw	.176	17	.172	.943	17	.360
T1_PedsQL_Total	.166	17	.200*	.931	17	.227

*. This is a lower bound of the true significance.
a. Lilliefors Significance Correction

Tests of Normality

	Kolmogorov-Smirnov[a]			Shapiro-Wilk		
	Statistic	df	Sig.	Statistic	df	Sig.
T2_RCADS_Dep	.127	17	.200*	.966	17	.746
T2_RCADS_TA	.108	17	.200*	.976	17	.906
T2_PedsQL_Total	.167	17	.200*	.966	17	.751

*. This is a lower bound of the true significance.
a. Lilliefors Significance Correction

Parents

Tests of Normality

	Kolmogorov-Smirnov[a]			Shapiro-Wilk		
	Statistic	df	Sig.	Statistic	df	Sig.
T1_Parent_RCADS_Dep	.199	18	.058	.941	18	.300
T1_Parent_RCADS_TA	.168	18	.194	.961	18	.630
T1_Parent_PedsQL_Total	.108	18	.200*	.949	18	.412

*. This is a lower bound of the true significance.

a. Lilliefors Significance Correction

Tests of Normality

	Kolmogorov-Smirnov[a]			Shapiro-Wilk		
	Statistic	df	Sig.	Statistic	df	Sig.
T2_Parent_RCADS_Dep	.148	18	.200*	.942	18	.309
T2_Parent_RCADS_TA	.192	18	.077	.904	18	.068
T2_Parent_PedsQL_Total	.174	18	.159	.914	18	.102

*. This is a lower bound of the true significance.

a. Lilliefors Significance Correction