



The  
University  
Of  
Sheffield.

## **Loneliness, social identity and mental health in autistic individuals**

**By:**

Rebecca Hymas

A thesis submitted in partial fulfilment of the requirements for the award of Doctor of  
Clinical Psychology at the University of Sheffield

The University of Sheffield

Faculty of Science

Clinical Psychology Unit, Department of Psychology

Submission Date: June 2021

### **Declaration Page**

I declare that this thesis is submitted for the Doctorate in Clinical Psychology at the University of Sheffield. This work has not been submitted to any other academic institution or for any other degree. The work presented is original and all other sources have been referenced accordingly.

## **Structure and Word Counts**

### **Literature Review**

Excluding References and Tables: 7,998

Including References and Tables: 18,213

### **Empirical Study**

Excluding References and Tables: 7,987

Including References and Tables: 12,305

### **Total**

Excluding References and Tables: 15,985

Including References and Tables: 30,518

### **Abstracts (not included in the word count)**

Lay Summary: 485

Literature Review Abstract: 250

Empirical Study Abstract: 250

## **Lay Summary**

### **(Targeted Toward Research Participants)**

There has been a lack of research into the social and emotional experiences of autistic individuals, despite this being seen as a research priority by the UK autistic community. Understanding more about the social experiences of autistic individuals, and how this relates to their mental health may lead to better targeted interventions being developed.

The first part of this thesis aimed to review previous research on loneliness in autistic individuals (specifically literature comparing the levels of loneliness in autistic and neurotypical groups, as well as literature investigating the association between loneliness and anxiety/depression in autistic individuals). Thirty-four studies were identified following a systematic literature search. Of these, 20 studies looked at differences between loneliness rates in autistic and neurotypical individuals. Significant differences were found between groups, with autistic individuals consistently reporting higher loneliness levels compared with neurotypical individuals. The results of this review also found a significant association between loneliness and both anxiety (in 11 studies) and depression (in nine studies), with those reporting higher loneliness also reporting elevated anxiety and/or depressive symptoms. There were several limitations with this part of the thesis, which are described in more detail below, along with the clinical implications and recommendations for further research regarding loneliness and mental health in autism.

The second part of this thesis investigated social identity in autistic and neurotypical adults. Social identity can be defined as your perceived belongingness to groups that you are a member of. Research among neurotypical people suggests there is an association between social identity (as measured by the number of groups one feels are important and the number of groups one feels positive about belonging to) and mental health. However, this has never been explored in autistic people. An online survey was created to explore social identification with groups and mental health in autistic adults, and whether this is

different or similar to neurotypical adults. The survey included questions on demographics, group memberships, social identification and mental health (anxiety, depression and stress). In total, 199 autistic adults and 174 neurotypical adults completed the survey and were included in analyses.

The results showed that autistic individuals reported belonging to fewer overall groups, fewer important groups and fewer positive groups, compared with neurotypical individuals. In neurotypical individuals, having fewer numbers of positive groups was associated with having more anxiety (although not depression or stress). This association remained even after controlling for the impact that self-esteem, loneliness and Covid-19 had on participants' mental health. No significant associations were found between social identification with groups and anxiety, depression or stress in the autistic sample. These findings suggest that social identification with groups may not contribute to the wellbeing of autistic adults. However, these findings are preliminary and should be interpreted with caution due to several limitations. The implications of these findings and recommendations for future research into social identity in autism are described below in further detail.

## **Acknowledgements**

I would firstly like to express my gratitude to all the people who helped to shape this research, from the development of the initial ideas to the final product. I especially thank those who took the time to provide feedback on their experiences of the initial stages of the survey, as well as those completing the full survey. I am also grateful to all the individuals and organisations who helped to advertise the study, who proved that even in the midst of a pandemic, the power of collective action can prevail!

My sincerest thanks go to my supervisor, Professor Elizabeth Milne. Your passion and dedication to ASD research inspired me during the more overwhelming aspects of the work. I am so very grateful for your guidance, encouragement and timely feedback.

Thank you, also, to all of my friends who have always encouraged me to put work into perspective and allowed me to stay connected to fun and laughter.

Lastly, I would not be where I am without my family. Thank you for always believing in me and being there for me in those moments when I did not believe in myself. And to Tim, words cannot describe how grateful I am for the invaluable support you have given me over these last three years (and throughout all my academic endeavours). Thank you!

## List of Contents

Access to Thesis Form.....	ii
Declaration Page .....	iv
Structure and Word Counts.....	v
Lay Summary.....	vi
Acknowledgements.....	viii
List of Contents.....	ix

### Section 1: Literature Review with Meta-Analyses

Abstract .....	2
Practitioner Points.....	3
Introduction.....	4
Method.....	9
Results.....	16
Discussion .....	50
Conclusions .....	56
References .....	58
Appendices.....	80

### Section 2: Empirical Study

Abstract .....	95
Practitioner Points.....	96
Introduction.....	97
Method.....	102
Results.....	110
Discussion .....	125
Conclusions .....	131
References .....	133
Appendices.....	145

## **Section 1: Literature Review**

**Loneliness and its association with anxiety and depression in autistic individuals: A systematic review with meta-analyses**



## Abstract

**Objectives:** Loneliness is an important construct in the socio-emotional experiences of autistic individuals, yet there has been a paucity of research in this area. This review aimed to quantify the differences in loneliness rates between autistic and neurotypical samples and investigate the association between loneliness and anxiety/depression in autistic individuals.

**Methods:** Studies were identified through searching four databases (Scopus, PsycINFO, MEDLINE and ProQuest Dissertations and Theses) using a combination of search terms related to 'autism', 'loneliness', 'anxiety' and 'depression'. Three meta-analyses were conducted to address the research aims. Included studies were methodologically appraised using established tools.

**Results:** Overall, 34 studies were included in the reviews, the majority of these were appraised as weak-moderate in methodological quality. The primary meta-analysis (N=20) found autistic samples reported higher loneliness scores compared with neurotypical samples, with a large pooled effect size (Hedges'  $g=.87$ ). Significant between-study heterogeneity was partially explained by the use of gold standard diagnostic procedures for confirming autism diagnosis (suggesting studies with more accurate characterisation of autistic participants had a larger effect size of mean differences in loneliness scores). The meta-analyses on the associations between loneliness and anxiety (N=11) and between loneliness and depression (N=9) both found significant pooled correlations of medium effect ( $r=.30$  and  $r=.48$ , respectively), indicating those with higher loneliness scores also reported elevated anxiety and depressive symptoms.

**Conclusions:** These findings have important clinical and research implications. However, several methodological limitations of the included studies lessen the overall credibility of the conclusions that can be drawn from these findings.

### **Practitioner Points**

- Autistic individuals report higher levels of loneliness compared to neurotypical individuals.
- Significant positive correlations exist between loneliness and both anxiety and depressive symptoms in autistic individuals.
- Assessment of loneliness presence, duration and severity in autistic individuals should be incorporated in relevant settings (e.g., mental health settings or school) and interventions to alleviate loneliness should be considered and implemented if this is warranted.
- Further research is required to validate loneliness measures in autistic populations and assess whether interventions that decrease loneliness and improve wellbeing in the neurotypical population are also beneficial for autistic individuals, to enable more appropriately tailored interventions.

*Key Words:* Autism, Loneliness, Anxiety, Depression

## **Introduction**

There is debate regarding the conceptualisation of loneliness, which is studied as both a unidimensional and multidimensional construct (Heinrich & Gullone, 2006). Nevertheless, it can broadly be defined as the subjective discrepancy between one's desired and actual social relationships in terms of number and/or quality (Peplau & Perlman, 1982). Within a multidimensional approach, 'social loneliness' indicates the recognised shortage of desired social relationships with accompanying feelings of exclusion and boredom, whereas 'emotional loneliness' indicates the absence of emotional connection/attachment and a sense of sadness and emptiness (DiTommaso & Spinner, 1997; Weiss, 1973). Importantly, loneliness is distinct from- although may be related to- objective social isolation i.e., those who have objectively small social networks may not feel lonely, and likewise, loneliness can be felt by those with seemingly large social networks (Hawkley & Cacioppo, 2010). The experience of loneliness is thought to drive the formation and maintenance of relationships necessary for the survival of humans, therefore acting as a motivator of social connection (Cacioppo et al., 2006).

Occasional feelings of loneliness are commonplace, with reports of between 10-80% of people in the general population experiencing loneliness at least sometimes (Beutel et al., 2017). Loneliness prevalence has been found to vary across the lifespan (i.e., being more prevalent with increasing age), and also within age-groups (i.e., being more prevalent among adolescents compared to younger children) (Beutel et al., 2017; Hawkley & Cacioppo, 2010). Loneliness prevalence may also be moderated by gender, for example some research has shown a higher prevalence in women (Thurston & Kubzansky, 2009), however this finding has been inconsistent in the literature (e.g., Barreto et al., 2021; Maes et al., 2019).

### **Loneliness and Mental Health**

Loneliness is not considered to be a mental health condition, therefore estimating the prevalence of—and threshold for—clinically relevant loneliness has been challenging in both research and clinical practice. Some research has delineated normative loneliness

experiences from 'chronic loneliness' (i.e., feeling lonely for at least two years; Martín-María et al., 2020; Peplau & Perlman, 1982) and 'pathological loneliness' (i.e., increased distress resulting from loneliness; Tiwari, 2013). Research demonstrates between 2-38% of the general UK population may feel lonely 'most' or 'all of the time' and may feel moderately to severely distressed by loneliness (Victor & Yang, 2012).

Persistent and/or intense feelings of loneliness can negatively impact on one's quality of life. Research has shown that loneliness can predict increased morbidity and earlier mortality (Shiovitz-Ezra & Ayalon, 2010). A recent overview of 40 systematic reviews pertaining to the public health consequences of loneliness and social isolation found a consistent association with worse mental health outcomes, including depression and anxiety (Leigh-Hunt et al., 2017). Feelings of loneliness have been found to be more prevalent among those with mental illnesses than in the general population (Achterbergh et al., 2020; Wang et al., 2018). The association between loneliness and depressive symptoms has been shown to be moderate-large across the lifespan ( $r = .50-.63$ ; Erzen & Çikrikci, 2018; Matthews et al., 2016; Richardson et al., 2017). Similarly, the association between loneliness and anxiety has been found to be moderate-large in children and adult samples ( $r = 0.41-.67$ ; Beutel et al., 2017; Danneel et al., 2019; Richardson et al., 2017).

### **Loneliness in ASD**

Individuals with Autism Spectrum Disorder (ASD) may be at an increased risk of having fewer social relationships (Milton & Sims, 2016). This lifelong neurodevelopmental condition affects approximately 1-2% of the population (National Academy of Sciences, 2015), and is characterised by difficulties in social communication and interaction, and engagement in restricted, repetitive behaviours or interests (American Psychiatric Association; APA, 2013).

The characterisations of autism itself, as well as comparisons between autistic<sup>1</sup> and neurotypical (non-autistic) samples may have maintained a narrative that autistic individuals are content in being alone; indeed, autistic individuals were historically considered to have “a powerful desire for aloneness” (Kanner, 1943, p.249). Autism diagnostic criteria emphasise individuals’ deficits in social skills and interaction, including the lack of social-emotional reciprocity and a failure to develop developmentally appropriate peer relationships (APA, 1994; 2013). In line with the social motivation theory of autism, some researchers have posited that autistic individuals have less desire for- and may derive less pleasure from- social interactions, which subsequently decreases the likelihood of successful relationship development and maintenance (Chevallier et al., 2012). Research suggests autistic people have fewer, or no friendships in comparison to neurotypical peers (Orsmond et al., 2004; Shattuck et al., 2011) and in both child and adult samples, friendships have been reported to be of lower quality, result in less enjoyment, and be defined in terms of social proximity rather than emotional connectedness (Baron-Cohen et al., 2002; Bauminger et al., 2004; Whitehouse et al., 2009).

Nevertheless, there is research demonstrating that autistic individuals not only desire social interaction but may experience loneliness to a greater degree without it, compared to neurotypical individuals. For example, Bauminger et al. (2003) found autistic adolescents reported increased feelings of both social and emotional loneliness compared to neurotypical peers. Much of the research on loneliness in autism pertains to children and adolescents, in line with broader autism research (Evans, 2013). However, studies within adult samples have also suggested the occurrence of loneliness among autistic adults (Hickey et al., 2018; Mazurek, 2014) and suggest that this is higher than neurotypical adults (Sundberg, 2018). However, evidence for increased loneliness in autistic compared to neurotypical samples is not ubiquitous in the literature e.g., Chamberlain et al. (2007) and Bottema-Beutel et al. (2019) did not find any significant differences in loneliness levels between autistic and

---

<sup>1</sup> The term ‘autistic’ has been found to be preferred by the UK autistic community (Kenny et al., 2016).

neurotypical children. It is notable that these studies had small sample sizes (17-21 participants per group) which may have compromised statistical power (Cohen, 1992).

Loneliness may be understood, experienced, and expressed differently in autistic individuals compared with neurotypical individuals (Bauminger & Kasari, 2001). Moreover, the current methods used for measuring loneliness may be unsuitable for autistic individuals. In a study of 7–12-year-olds, an experimental approach-avoidance task demonstrated autistic children showed an implicit desire for social interaction which was not captured in explicit questionnaire responses (Deckers et al., 2014). In their study of loneliness in high-functioning autistic children, Bauminger and Kasari (2000) found neurotypical children defined and understood loneliness as being alone with accompanying feelings of sadness, whereas most autistic children defined loneliness as being alone without attributing an affective component.

There are several important factors which may influence loneliness experiences in autistic individuals. Co-occurring intellectual disability (ID) is highly prevalent in those diagnosed with autism, with reported rates between 30-70% (Thurm et al., 2019). Those with higher intellectual functioning may have greater self-awareness of their social impairments and social isolation (Volkmar et al., 2005), increasing susceptibility to loneliness (Bauminger & Kasari, 2001). Additionally, gender and age may influence loneliness experiences in autistic samples. For example, research has suggested autistic adolescent males have lower social motivation and friendship quality compared to autistic females (as well as in comparison to neurotypical adolescent females and males) (Sedgewick et al., 2016). There is also evidence of changes in the number and quality of friendships in autistic samples across the lifespan, with fewer friends in adolescence and adulthood compared to childhood (Howlin et al., 2004), which may influence their feelings of loneliness (Kasari & Sterling, 2013).

## **Loneliness and Mental Health in ASD**

Autistic populations experience a disproportionately high incidence and prevalence of anxiety and depression, in comparison to neurotypical populations (Joshi et al., 2013). A recent meta-analysis of 30 studies measuring anxiety and 29 studies measuring depression suggested a pooled estimate of current and lifetime prevalence of 27% and 42% for anxiety disorders, and 23% and 37% for depressive disorders in autistic adults, respectively (Hollocks et al., 2019). Similar rates of comorbid anxiety and depression are reported across child and adolescent autistic samples (Hudson et al., 2019; Vasa & Mazurek, 2015; Wigham et al., 2017), and higher rates are reported in females compared to males (Sedgewick et al., 2020).

Loneliness in autism may be especially important to investigate considering research has evidenced significant associations between loneliness and both depression and anxiety in autistic individuals (Han et al., 2019; Hedley et al., 2018; Schiltz et al., 2020). It is possible that risk, causal and maintaining mechanisms for both loneliness and mental health difficulties reflect the core socio-communicative difficulties inherent in ASD. Additionally, the bi-directional influence of loneliness and mental health difficulties is also important to consider (Nuyen et al., 2020), as negative feelings associated with loneliness, anxiety and/or depression may limit the opportunities to develop meaningful relationships with others, which in turn exacerbate such feelings, impede socio-communication, and drive social withdrawal (Magnuson & Constantino, 2011).

## **The Current Review**

Despite increasing recognition within the autism community that loneliness is experienced by autistic people (National Autistic Society, 2018), the occurrence and degree of loneliness in this population in comparison to neurotypical individuals has not been systematically reviewed or quantitatively synthesised. Understanding the prevalence of loneliness in autism could have important clinical implications, especially given the increasing provision of psychosocial interventions to reduce social isolation and enhance

social functioning and integration of autistic individuals (Pallathra et al., 2019). The disproportionate prevalence of anxiety and depression in the autistic population, and the potential influencing role of loneliness, indicates synthesis of the current evidence is imperative in directing future research in this emerging field.

The primary aim of this review is therefore to examine differences in loneliness rates between autistic and neurotypical samples. The secondary aim is to explore the association between loneliness and mental health (i.e., anxiety and depression) in autistic individuals. These aims were summarised into three research questions: 1) Is there a difference in loneliness rates between autistic and neurotypical individuals? If so, what is the direction and magnitude of this difference? 2) What is the strength of associations between loneliness and anxiety among autistic people? 3) What is the strength of associations between loneliness and depression among autistic people? Conduction of three meta-analyses aimed to address these questions whilst considering the influence of potential moderators.

## **Hypotheses**

It was hypothesised that there would be significant differences in loneliness rates, with autistic individuals reporting increased loneliness when compared with neurotypical individuals. It was further hypothesised that there would be significant positive associations between loneliness and anxiety and loneliness and depression in autistic samples. Due to this being the first meta-analysis of loneliness in autistic individuals, no specific hypotheses were made regarding the potential impact of moderating variables on outcomes.

## **Method**

### **Search Strategy**

As is recommended by the Centre for Reviews and Dissemination (CRD; 2009), this systematic review and meta-analysis was undertaken following the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) guidelines (Liberati et al., 2009). A protocol was published on the PROSPERO database prior to this review's formal commencement (See Appendix A). Four bibliographic electronic databases (Scopus,



PsycINFO, MEDLINE and ProQuest Dissertations and Theses) were searched from their inception until 7<sup>th</sup> February 2021. Forward and backward citation searches were conducted, as well as manual searching of the reference lists of included articles and relevant reviews. Grey literature was also searched. See Table 1 for a search syntax example.

**Table 1**

*Search Syntax Example*

Construct	Search Terms
Autism	Autis* OR Asperger* OR “pervasive development* disorder*” OR “Autistic Disorder” OR “Autis* Spectrum Disorder” OR “Child development* disorder*” OR ASD OR ASC OR PDD
Loneliness	“loneliness” OR Lonel* OR “Social* isolat*” OR “Social disconnect*” OR “alone*”
Anxiety or Depression	Depress* OR “low mood” OR “negative affect” OR “depress* disorder*” OR “affective disorder*” OR “mood disorder” OR “dysthymi*” OR “major depress* disorder*” OR anxi* OR “anxi* disorder*”

*Note.* Terms were searched as keywords and MeSH/thesauri terms in PsychINFO and Medline. The Boolean operator \* was used to identify spelling variations and word-endings. Terms were combined using AND. Following the initial search, search terms for ‘Anxiety’ and ‘Depression’ were added to ensure articles pertaining to the secondary review question were not missed.

**Eligibility Criteria**

See Table 2 for study eligibility criteria specific to the primary review and meta-analysis. Inclusion and exclusion criteria for the second review were identical to those in the first review with the following exceptions: studies did not need to include a neurotypical comparison group or report loneliness rates, however they must have measured anxiety or depression via a symptom severity questionnaire.

**Table 2**

*Inclusion and Exclusion Criteria for the Primary Review and Meta-Analysis*

Inclusion Criteria	Exclusion Criteria
<ul style="list-style-type: none"> <li>• Observational/cross-sectional designs or cross-sectional data from longitudinal designs.</li> <li>• People with diagnosed or self-reported ASD</li> </ul>	<ul style="list-style-type: none"> <li>• Qualitative studies, case-study, or case-series designs.</li> <li>• Utilised an ASD screening tool in general populations in the absence of diagnosed or</li> </ul>

---

<p>(with or without comorbid ID diagnosis).</p> <ul style="list-style-type: none"> <li>• An NT comparison group.</li> <li>• Adults (aged <math>\geq 18</math> years) or Children (aged <math>\leq 17</math> years). If study populations overlap, subgroups will be identified through sample age means.</li> <li>• Utilised measures of subjective loneliness.</li> <li>• Reported the percentage of participants meeting a pre-defined cut-off score or average score obtained in both ASD and NT samples. For inclusion in the meta-analysis, an appropriate effect size must be reported for mean differences between groups (or calculable from available statistics).</li> </ul>	<p>self-reported ASD.</p> <ul style="list-style-type: none"> <li>• Studies measuring/reporting social isolation or social network size only.</li> <li>• Prevalence or mean loneliness scores not reported separately for ASD and NT comparison group.</li> <li>• Comparison groups whereby participants have intellectual disabilities, neurodevelopmental conditions, or mental health diagnoses.</li> <li>• For meta-analyses, relevant data for calculating effect sizes unavailable or not provided by corresponding authors upon request.</li> <li>• Written in languages other than English, with no translated paper or abstract available.</li> </ul>
--	---

---

Note: ASD, Autism Spectrum Disorder; NT, Neurotypical

## Screening

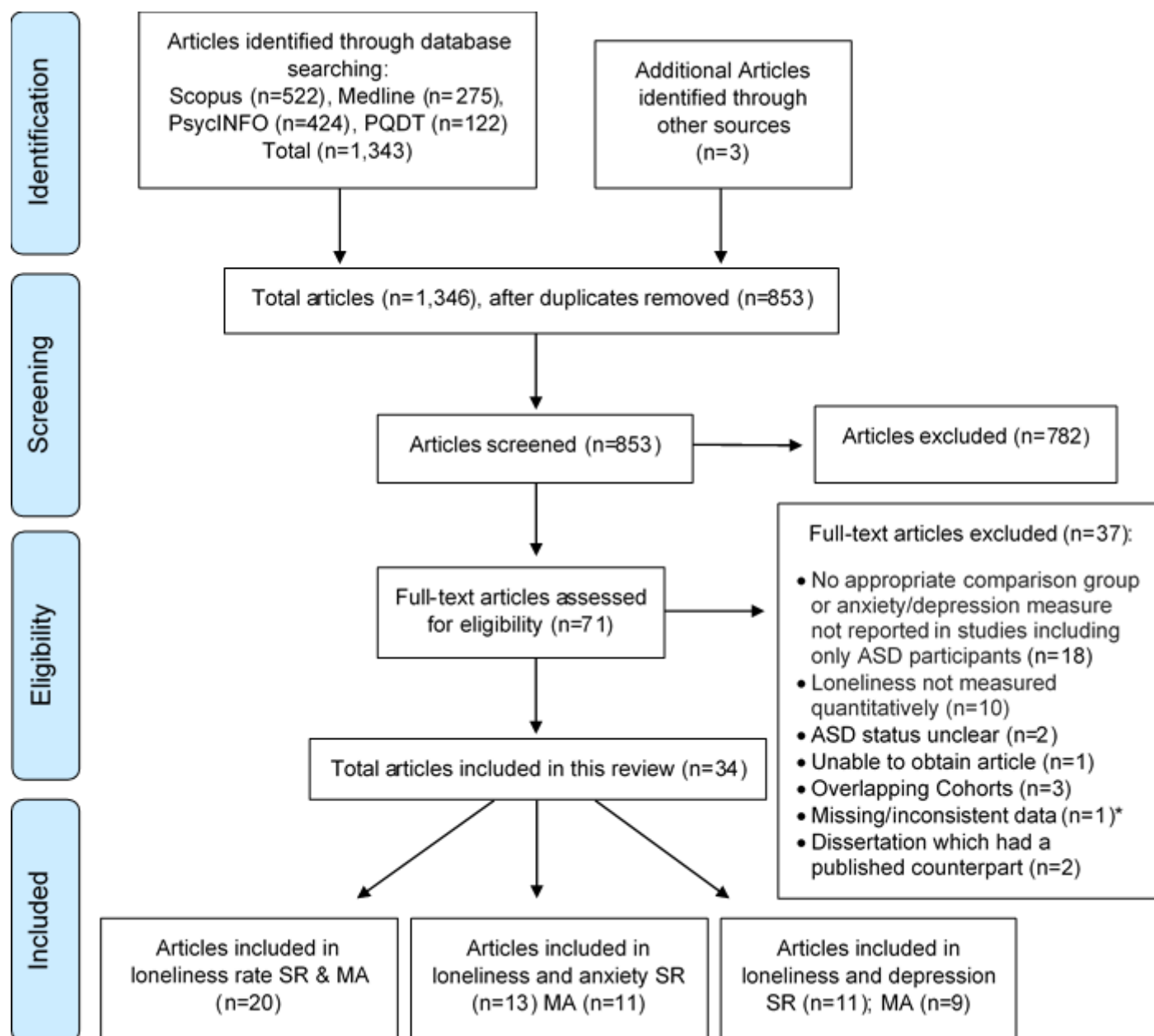
The search yielded 853 articles following deduplication. Study titles and abstracts were screened for relevance and those considered likely to meet selection criteria were reviewed in full ( $n=71$ ). Some studies were deemed to include overlapping participant samples<sup>2</sup>, which resulted in three being excluded from inclusion in this review. Full-text review excluded 37 articles, resulting in 34 studies (33 unique cohorts) included in the final reviews. Figure 1 summarises the selection process.

---

<sup>2</sup> Where studies were thought to have overlapping samples, the first published study or those with most participants were selected (highlighted here in bold) for inclusion in summary tables e.g., (**Bauminger et al., 2003**; Bauminger et al., 2004); (Bohnert et al., 2019; **Lieb & Bohnert, 2017**; Ward et al., 2017). Of note, two studies with overlapping participants (**Lin & Huang, 2019**; **Syu & Lin, 2018**) were included in separate meta-analyses and have been presented separately in tables.

Figure 1

## PRISMA Flow Diagram



Note. n, number; SR, Systematic Review; MA, Meta-Analysis. \*The corresponding author of this study (Pak, 2019) was unable to provide the necessary information for inclusion in the review. Several studies were included in more than one review.

### Data Extraction

As is recommended for systematic reviews, a data extraction tool was developed a priori and amended following piloting on four randomly selected included studies (Boland et al., 2014). Data were extracted verbatim onto an Excel spreadsheet to minimise transcription

errors. This included information on study characteristics (i.e., authors, date, publication status, country, objectives, and population), sample characteristics (i.e., sample size, age, gender, ethnicity and IQ) and study results (i.e., procedures for ascertaining autism diagnosis, loneliness and anxiety/depression measures, key findings and statistical data). Where relevant data were not reported, study authors were contacted via email. Data extracted for the primary meta-analysis included differences between loneliness rates (%) or means (including F, t or Z statistics) between autistic and neurotypical samples. If this was not reported, sample sizes, loneliness mean scores and standard deviations were extracted to allow calculation of an effect size. For the secondary meta-analyses, correlation values (r) or t statistics were extracted from studies. Studies were synthesised narratively where appropriate statistical data were not reported for inclusion in the meta-analyses.

### **Quality Assessment**

Study quality was appraised using the Effective Public Health Practice Project (EPHPP) Tool for Quantitative Studies (Thomas et al., 2004), which was adapted for use within this review. The EPHPP has established content and construct validity (demonstrated through 53%-92% agreement in component ratings in comparison to another highly rated instrument; Thomas et al., 2004), fair inter-rater agreement (Cohen's kappa=0.60) for individual domains, and excellent final rating agreement (Intra-class correlation coefficient=0.77; Armijo-Olivo et al., 2012). This tool includes the essential criteria for methodological quality appraisal (CRD; 2009) and aligns with the recommended reporting of observational studies in epidemiology (Vandenbroucke et al., 2007). Additional criteria were included from the quality evaluation grid developed by Glod et al. (2015) which tailored methodological appraisal for studies including ASD samples. Criteria included: how ASD diagnosis was confirmed for the study, whether cognitive functioning was assessed and reported, and whether the measures used were validated for ASD populations.

Overall, studies were rated across seven domains: selection bias, study design, potential confounders (for studies including an NT comparison group), data collection (validity and reliability of measures used), management of participant drop-out/missing data,

ASD diagnosis confirmation and cognitive functioning. In line with the EPHPP tool, criteria were rated as: Strong, Moderate or Weak. The overall quality of studies consisted of a 'Strong' rating if no weak ratings were present, 'Moderate' if one weak rating was present, and 'Weak' if two or more weak ratings were present. It was decided a priori that no studies would be excluded based on weak global ratings. Due to the nature of this review including studies pertaining to different research questions, an additional 'Not Applicable' option was added to criteria. See Appendix B for details on how component ratings were assigned to studies.

All studies were quality appraised by the first author, with a subset (12 papers; 35%) appraised by an independent reviewer. Agreement in component and overall ratings was evaluated using weighted Cohen's Kappa (Schuck, 2004), with any disagreements resolved following discussion. Inter-rater reliability before consensus ranged between 'fair' and 'very good'. See Appendix C for agreement statistics.

### **Meta-Analytic Strategy**

The meta-analyses were conducted using Comprehensive Meta-Analysis (CMA- Version 3; Borenstein et al., 2013). Random-effects models were employed to account for expected within-study and between-study variance in true effect size estimates (Borenstein et al., 2010). For the primary meta-analysis, Hedges  $g$  was selected as the effect size for standardised mean difference due to its increased (weighted) accuracy when used with small sample sizes ( $n < 20$ ) compared to Cohen's  $d$  (Ellis, 2010). For the secondary meta-analyses, correlation coefficients ( $r$ ) were selected as the effect size due to being easily interpretable and due to their inclusion in prior meta-analyses of associations between loneliness and mental health in neurotypical samples (Erzen & Çikrikci, 2018). Correlational statistics were transformed into Fisher's  $Z$  scores during meta-analytic computations to account for possible skewed data distributions (Cox, 2008). Effect size magnitudes were interpreted according to Cohen (1992) i.e., small, medium, and large effect size estimates of .10, .30, and .50 for  $r$  and .2, .5, and .8 for Hedges'  $g$ , respectively.

## **Heterogeneity**

Effect size variance between studies was assessed using the Cochran Q and  $I^2$  statistics. A significant Q statistic indicates that statistical heterogeneity is present (i.e., more variance is present than can be explained by sampling error alone). An adjusted alpha level of .10 was used due to the low power of this statistical test when few studies are analysed (Israel & Richter, 2011). The  $I^2$  statistic was used to quantify the proportion of variance across studies that was due to true heterogeneity rather than chance, whereby 25%, 50%, and 75% indicates low, moderate, and high heterogeneity respectively (Higgins et al., 2003).

## **Moderator Analysis**

To investigate sources of heterogeneity, moderator analyses (including subgroup analysis for categorical variables and meta-regression for continuous variables) were planned (Borenstein et al., 2010). This included assessing the influence of age, gender, population type (child or adult samples), presence of ID, publication status (given the existence of larger effects being found in published studies; Boland et al., 2014), and the methodological quality of studies (Ioannidis, 2008). In line with previous systematic reviews and meta-analyses in autistic populations, the type of outcome measures used and the diagnostic tools and procedures used to confirm ASD were also planned to be analysed as potential moderating variables<sup>3</sup> (Hollocks et al., 2019; Spain et al., 2018). For subgroup analyses, summary effects for each group were computed and compared through a random-effects approach to allow the total variance to be investigated with respect to within- and between-subgroup means. Meta-regression allowed calculation of the relationship between continuous variables and variation in effect-sizes (Israel & Richter, 2011).

Where multiple outcome measures were reported, the most comprehensive construct and/or reliable measure was selected for meta-analytic computations, due to the reported invalidity of effect size estimates that may occur through averaging effect sizes (Park & Beretvas, 2019). Where studies provided both self- and other-reported measures (e.g. child-

---

<sup>3</sup> The following moderators were prespecified in the registered protocol: age, gender, population, presence of intellectual disability, and the measures/procedures used to assess ASD and loneliness.

and parent), self-reported data were included in meta-analyses, due to discrepancies being common between self and proxy-reports of mental health correlates (Grills & Ollendick, 2003). Of note, gender could not be investigated via subgroup analyses (due to fewer than three studies providing outcome data separately for males/females; Card, 2015) nor meta-regression due to differing percentages of gender distributions between ASD and NT samples. Subgroup analysis based on ID could not be conducted due to insufficient studies including participants with ID.

### **Publication Bias**

Publication bias was mitigated through inclusion of unpublished studies and use of subgroup analyses based on publication status. Egger et al.'s (1997) regression test was also conducted, along with fail-safe analysis to quantify the number of missing studies that would be required to invalidate a significant result (the threshold of which was met if  $N > 5k + 10$ , where  $k$  = number of included studies; Rosenthal, 1979). A funnel plot provided graphical representation of the assessment of each study's precision (i.e., standard error) plotted against its effect-size, whereby asymmetrical patterns of effect-sizes around the mean effect-size indicates publication bias (Sterne & Egger, 2005). Finally, trim and fill methods were employed to account for missing studies and provided an unbiased effect size estimate (Duval & Tweedie, 2000).

## **Results**

Studies retrieved for the primary review (*differences in loneliness rates between ASD and NT samples*;  $N=20$ ) and secondary review (*associations between loneliness and anxiety*;  $N=13$ , *associations between loneliness and depression*;  $N=11$ ) are described separately in the summary tables, narrative synthesis and meta-analyses.

### **Loneliness Rates between ASD and NT Samples**

#### ***Study and Participant Characteristics***

As shown in Table 3, 20 studies with unique cohorts were included in this review; 19 utilised a cross-sectional design and one (Chiang, 2003) employed a pre-post experimental

design (the baseline cross-sectional data were used in this review). All studies provided appropriate data for inclusion in the meta-analysis. Studies were published between 2000-2019 and were conducted across 10 different countries, with the majority conducted in America (N=10). Most studies used child and/or adolescent populations (N=15). Three studies included additional comparison groups, including participants with other neurodevelopmental conditions (Deckers et al., 2017), motor/sensory disabilities (Bossaert et al., 2012) and diagnosed depression (Han et al., 2019); only the NT comparators from such studies were included in this review.

Collectively, studies included 2,096 participants (ASD=791; NT=1,305); sample sizes varied from 12-326 and ages ranged from 7-69 years. Of those that reported the ethnicity of the included sample (N=8), the most represented ethnicity was White/Caucasian. Males were disproportionately represented in the ASD samples in 12 studies and in the NT sample in one study; gender distributions were equal in five studies and unreported in two.



**Table 3***Study and Participant Characteristics for Studies Measuring Loneliness Rates between ASD and NT Samples*

Study Characteristics				Participant Characteristics				
Authors (Year)	Country	Objectives/Focus	Study Sample	Sample Size	Age (M, SD, R)	Gender (% Male)	Predominant Ethnic Group (%)	IQ Measure (M, SD, R)
Bauminger and Kasari (2000)	America	Explored children's understanding of the constructs of loneliness and friendship quality.	Children	ASD: 22 NT: 19	ASD: M= 10.74, SD=2.14, R=7-14 NT: 10.89, SD=2.10, R=7-14	ASD: 95%; NT: 95%	ASD: 21 (95%) White NT: 18 (95%) White	WISC-R; ASD: M=108.14, SD=15.09, R=84-138 NT M=115.73, SD=9.75, R=92-129
Bauminger et al. (2003)*	Israel	Investigated children's spontaneous social interaction with peers in a naturalistic setting and their understanding and feelings of loneliness.	Children	ASD: 18 NT: 17	ASD: M = 11.00, SD= 2.83; R=8-17 NT M= 11.51, SD=2.62, R=8-16	ASD: 89%; NT: 88%	Rates NR. (states "Caucasian families").	WISC-R; ASD: M=93.61, SD=13.61, R= 77-117 NT M=98.35, SD=7.19, R=83-111
Bossaert et al. (2012)	Belgium	Examined whether associations between- and prevalence of- loneliness, number of perceived friends, friendship quality, social self-concept differed among ASD children, NT children and children with motor and/or sensory disabilities.	Children	ASD: 58 NT: 108	Age NR (states "7th Grade classrooms").	ASD: 90%; NT: 76%	NR	NR. States no participants had an intellectual disability (IQ<70).
Bottema-Beutel et al. (2019)	America	Assessed children's endorsement of 12 friendship expectations and explored associations with self-worth, friendship quality and loneliness in ASD and NT samples.	Children	ASD: 20 NT: 21	ASD M=9.90, SD=0.81, R=8-11 NT M=9.30, SD=0.66, R=8-11	ASD: 70%; NT: 42.9%	ASD: 57.9% Caucasian NT: 52.4% Caucasian	Mental Age derived from WASI-II. ASD: M=10, SD=1.77, R=7.7-13.2 NT: M=10.3, SD=1.22, R=7.5-12.2

Brooks (2014)	America	Explored gender differences in socio-emotional functioning among women and men with High Functioning ASD and NT women and men. [Dissertation].	Adults	ASD: 56 NT: 56	ASD: M=26.3, SD=6.0, R=18-40 NT M=26.4, SD=4.6, R=NR.	ASD: 50%; TD: 50%	ASD: 86% Caucasian NT: 80% Caucasian	WASI-II administered to ASD group only. FSIQ not reported. VCI Female: M=107, SD=14.8 VCI Male: M=105, SD=20.7
Chamberlain et al. (2007)	America	Used social network methods to explore friendship qualities, peer acceptance and loneliness in ASD children in mainstream classrooms, compared to NT children.	Children	ASD: 17 NT: 17	NR (states "2nd through 5th grade classes")	ASD: 82%; NT: 44%	NR	IQ measured in ASD group only (no details on specific assessment measure). M=FSIQ M= 107.3, R=89-129
Chang et al. (2019)	Taiwan	Explored the relationships between friendship quality and emotional well-being of ASD and NT adolescents.	Children	ASD: 101 NT: 101	ASD: M=16.6, R=10-19 M=16.1, R=10-19	ASD: 83%; NT: 52%	NR	NR. States no participants had an intellectual disability (IQ<70).
Chiang (2003)	America	Examined the impact of a therapeutic recreation intervention, within a technology-based physical activity context, on the social interaction of ASD boys, in comparison to NT peers. [Dissertation].	Children	ASD: 6 NT: 6	ASD: M=12.1, SD=1.8, NT: M=12.2, SD=1.7.	ASD: 100%; NT: 100%	NR	NR. States "All participants were intellectually average"
De Gennaro (2016)	America	Explored whether ASD adolescents experience higher rates of loneliness than NT peers and potential contributing factors. [Dissertation].	Children	ASD: 17 NT: 25	ASD: M=14.58, SD=1.46 NT: M=13.0, SD=0.	ASD: 82.4%; NT: 68.75%	NR	NR
Deckers et al. (2017)	Netherlands	Examined loneliness and social correlates, including social anxiety in ASD and NT children and adolescents, in comparison to clinical and NT control groups using a multi-informant approach (children, parents, and teachers).	Children	ASD: aged 7-11= 47, aged 12-18= 26 NT: 54, 52, as above	ASD: M=11.2, SD=2.42 NT: M=11.61, SD=2.63	ASD: 85%; NT: 58%	NR. Stated "predominantly Caucasian participants".	NR those with estimated IQ <70 were excluded.

Han et al. (2019)	America	Examined individual differences and associations in social and non-social pleasure, autism traits, loneliness, and depressive symptoms across samples of ASD adults and NT controls (with and without depression).	Adults	ASD: 49 NT: 28	ASD: M=23.98, SD=26.23 NT: M=25.32, SD=5.28, R=18–35.	ASD: 61%; NT: 50%	NR	Unreported IQ measure. ASD: Verbal M=103.63, SD=12.75; Non-Verbal M=103.04, SD=19.11  NT: Verbal M=114.93, SD=14; Non-Verbal M=109.11, SD=15.30
Kalyva (2010)	Greece	Examined social skills of children with Asperger's Syndrome and matched NT peers via self-report as well as reports from their mothers, fathers, and teachers.	Children	ASD: 21 NT: 21	ASD: M=12.56, SD=2.34 NT: M=12.53, SD=2.39	ASD: 81%; NT: 81%	NR	WISC-III. ASD: Verbal IQ M=93.95, SD=12.70  NT: Verbal IQ M=101.38, SD=12.05
Lasgaard et al. (2010)	Denmark	Compared the prevalence of loneliness in ASD and NT boys and examined the value of multiple social support sources in relation to such loneliness.	Children	ASD: 39 NT: 199	ASD: M=14.2, SD=1.03, R=13–17) NT: M=14.1, SD=0.43, R=13–16	ASD: 100%; NT: 100%	NR	NR. The participant's main teacher to rate their scholastic difficulties on a scale from 1 (few difficulties) to 3 (many difficulties).
Lin and Huang (2019)	Taiwan	Explored demographic and psychosocial factors associated with quality of life in ASD adults, compared to NT adults.	Adults	ASD: 66 NT: 85	ASD: M=27.8, R=20–38, SD=5.2 NT: M=27.8, R=20–38, SD=4.3	ASD: 65%; NT: 61%	NR	NR. States no participants had an intellectual disability (IQ<70).

Locke et al. (2010)	America	Examined the social–emotional relationships (loneliness, friendship quality and social networks) of ASD adolescents and their NT classmates.	Children	ASD: 7 NT: 13	ASD: M=14.71, SD= 1.11 NT: M=14.20, SD=0.63	ASD: 57%; NT: NR	ASD: 72% Caucasian, 14% African American and 14% Latino  NT: NR	NR
Merkler (2007)	America	Developed and tested a new measure of loneliness, incorporating dyadic and social group isolation and distress resulting from isolation and compared this between ASD and NT samples. [Dissertation].	Adults	ASD: 37 NT: 82	ASD: M=29.65, SD=10.19, R=18-52. NT: M=18, SD=0.33, R=17-19.	ASD: 81%; NT: 32%	ASD: 89% Caucasian  NT: 83% Caucasian	BETA III. ASD: M=93.13, SD=12.59, R=69-118  NT: M=107.45, SD=11.41, R=84-139
Nomura et al. (2012)	Japan	Explored the developmental differences in feelings of loneliness and its relationship to competence in children with High Functioning PDD, and NT peers.	Children	ASD: 45 (15 Elementary, 16 Higher Elementary, 14 Junior High) NT: 281 (89; 87; 105, as above)	ASD: Elementary School M=8.03, R=6-9; Higher Elementary school M=10.66, R=9-12; Junior High School M=14.16, R=12-15  NT: NR	NR	NR	NR. States Verbal Score above 70 on Japanese version of WISC-III.
Sundberg (2018)	Sweden	Investigated the associations between online gaming, loneliness and friendships in ASD adults and NT controls.	Adults	ASD: 85 NT: 66	ASD: M=28.83, SD=11.43, R=14-60 NT: M=28.5, SD=9.78, R=15-69	ASD: 58%; NT: 52%	NR	NR

Whitehouse et al. (2009)	Australia	Explored the relationship between friendship, loneliness and depressive symptoms in adolescents with and without Asperger's Syndrome.	Children	ASD: 35 NT: 35	ASD: M=14.17, SD=0.67, R=12-17 NT: M=14.33, SD=0.83, R=13-16	ASD: 80%; NT: 83%	NR	NR
Yeung (2009)	America	Examined the quality of friendships and wellbeing (i.e., loneliness and depression) of children with Asperger's Disorder, in comparison to their NT siblings. [Dissertation].	Children	ASD: 19 NT: 19	ASD: M=10.05, SD=1.38, R=8-12. NT: M=10.05 years, SD=1.69, R=8-12	ASD: 85.7%; NT: 57.9%	ASD: 85.7% Caucasian NT: 84.2% Caucasian	NR

*Note.* Three studies (Merkler, 2007; Sundberg, 2018; Chang et al., 2019) had overlapping participant age ranges including both children and adults, therefore population categorisation was decided based on mean age. M, Mean; SD, Standard Deviation; R, Range; NR, Not Reported; FSIQ, Full Scale Intelligence Quotient; VCI, Verbal Comprehension Index; BETA III, Revised Beta Examination (Kellogg & Morton, 1999); WASI, Wechsler Adult Intelligence Scale (Wechsler, 2011); WISC, Wechsler Intelligence Scale for Children (Wechsler, 2008).

### **Quality Assessment**

Nine studies received an overall 'moderate' rating, nine a 'weak' rating and two a 'strong' rating in methodological quality (see Table D1, Appendix D). All studies appeared to have clear aims and objectives and utilised an appropriate study design. Most studies were deemed somewhat likely to be representative of the studied population. Two studies achieved a 'weak' selection bias rating due to including clinical samples and not reporting selection processes (Deckers et al., 2017; Lasgaard et al., 2010). Studies were mainly scored down due to lack of reporting of the proportion of individuals taking part out of those selected. All studies attained 'moderate' ratings for study design due to being cross-sectional. Most studies (N=16) were deemed to 'moderately' or 'strongly' control for confounders between ASD and NT groups, namely controlling for age and gender and to a lesser extent ethnicity and Intelligence Quotients (IQ). Those that received 'weak' ratings (N=4) were deemed to have controlled for less than 60% of confounders or did not clearly report how potential confounders were controlled for. Eleven studies had a higher proportion of male participants in the ASD groups, compared with NT comparators, although nine studies matched for gender distributions across groups.

Most studies were deemed moderate in their data collection methods due to reporting reliability of the loneliness measures used in their samples and using measures which had been validated in NT populations (but not ASD populations). Only one study used an adapted loneliness measure designed for use with an ASD sample to differentiate between social and emotional components of loneliness (Bauminger et al., 2003). One study attained a 'weak' rating due to not providing reliability or validity information on the loneliness measure used (Nomura et al., 2012). Few studies provided information regarding the presence of- or reasons for- non-completion and/or missing data for participants who agreed to participate; therefore most (N=14) received a 'weak' rating in the attrition domain.

Only four studies used a gold-standard assessment of ASD, attaining 'strong' ratings for this domain. Ten studies used self-report or other-informant screening questionnaires in the absence of gold-standard procedures or obtained medical documentation to confirm

diagnosis, the most common (N=4) screening questionnaire was the AQ (Baron-Cohen et al., 2001). The remaining studies (N=6) did not report diagnostic procedures sufficiently to characterise participants as having an ASD diagnosis. Full-scale IQs were reported for both samples in three studies and in the ASD sample only in one study; a further three studies reported verbal IQ scores or mental-age equivalents for both samples. Only studies which measured IQ as part of study procedures or within the preceding 3 months (N=5) attained a strong rating for this domain. The remaining studies did not report any information on IQ (N=6) or stated participants were intellectually average or had an IQ>70. No studies reported including participants with intellectual disability.

### **Outcomes**

Eleven different self-report loneliness measures were used across the 20 studies, the most frequently used (N=5) was the Children's Loneliness Scale (Asher et al., 1984). Of the 20 studies, 16 showed significant differences in average loneliness scores, with the ASD samples scoring higher, and four reported non-significant differences between groups, although all displayed a trend towards higher loneliness scores in the ASD group. Of note, two studies (Deckers et al., 2017; Nomura et al., 2012) included subsamples of differing aged children and both reported a significant age by group interaction whereby there were no group differences in perceived loneliness between ASD and NT samples in the younger children, but a significant difference as age increased into adolescence/ a higher school grade, with higher loneliness in ASD samples. However, both these studies received 'weak' global quality ratings and did not evidence sufficient management of potential confounders between groups (including gender and intellectual ability), limiting the inference from such findings.

Four studies reported loneliness prevalence according to predetermined cut-off rates, of which three statistically compared rates between ASD and NT samples. Results showed ASD samples reported significantly higher levels of loneliness (i.e., reported feeling

a higher magnitude or frequency of loneliness symptoms). See Table 4 for an overview of study measures, outcomes, and overall quality appraisal score.



**Table 4***Measures and Outcomes for Studies Measuring Loneliness Rates between ASD and NT Samples*

Authors (Year)	Autism Measure	Loneliness Measure	ASD Loneliness score (M, SD, R) and/or %	NT Loneliness score (M, SD, R) and/or %	Key Findings	Statistical difference between ASD and NT sample	Global Quality Rating
Bauminger and Kasari (2000)	• ADI-R	CLS	M=43, SD=14.21 R=21-71; Loneliness score <sup>4</sup> • Low=27.3% • Low-mid=36.3% • Mid-high=27.3% • High=9.1%	M=27, SD=6.42, R=16-37; Loneliness score • Low = 68.4% • Low-mid = 31.6% • Mid-high = 0 • High = 0	ASD children reported greater feelings of loneliness than did NT children.	F(1, 39) = 19.4, p < .001  Statistical analysis on % NR	Moderate
Bauminger et al. (2003)	• ADI-R	Adapted CLS	Global Loneliness: M = 2.61, SD = .82; Emotional Loneliness M = 2.44, SD = .87; Social loneliness M = 2.73, SD = .85,	Global Loneliness: M = 1.59, SD = .39; Emotional Loneliness M = 1.53, SD = .47; Social Loneliness: M = 1.64, SD = .43;	ASD children presented higher feelings of global, emotional and social loneliness.	Global Loneliness: F(1,33) = 21.11, p < .001; Emotional Loneliness: F(1,33) = 14.35, p < .001; Social Loneliness: F(1,33) = 22.17, p < .001	Moderate

<sup>4</sup> These figures were obtained via Bauminger (1997)

Bossaert et al. (2012)	<ul style="list-style-type: none"> <li>• Teacher report</li> </ul>	LACA (peer-related subscale); Scores higher than 1 SD from M='high Loneliness'	ASD: M=12.45, SD=4.12, R=6-23; High Loneliness category: 31.03%	NT: M=9.80, SD=4.22, R=6-24; High Loneliness category: 13.89%;	ASD students reported higher feelings of loneliness than typically developing students ( $p < .001$ ). ASD students were twice as often lonely than typically developing students.	Full statistics NR  $\chi^2(1, N=166) = 6.97, = p < .05$ .	Weak
Bottema-Beutel et al. (2019)	<ul style="list-style-type: none"> <li>• Teacher report</li> <li>• Parent/caregiver report</li> <li>• CARS-2</li> <li>• SRS-2.</li> </ul>	CLSD	ASD M=38.47, SD=16.45, R=16-80	NT M=27.00, SD=5.93, R=16-38	There were no group differences in overall loneliness.	NS ( $P=0.10$ Hedges $g = -0.93$ )	Strong
Brooks (2014)	<ul style="list-style-type: none"> <li>• ADOS-G</li> <li>• Parent/caregiver report</li> <li>• ASSQ-REV</li> <li>• AQ.</li> </ul>	ULS-3	M=50, SD=10.4	M=39.1, SD=9	ASD participants reported significantly higher levels of loneliness	( $F(1, 110) = 35.23, p < .001$ )	Moderate
Chamberlain et al. (2007)	<ul style="list-style-type: none"> <li>• Parent report (including document check)</li> </ul>	CLS	M= 30.12, SD = 10.8	M= 27.92, SD = 12.75	ASD children did not report any greater loneliness than the matched peers group.	NS $F(1,32) = 0.28$	Moderate
Chang et al. (2019)	<ul style="list-style-type: none"> <li>• Parent report</li> <li>• Document check</li> <li>• AQ (Chinese version)</li> </ul>	ULS-8 (Chinese version); Loneliness $\geq 17$ = high loneliness	M=16.3, SD=5.4  Loneliness $\geq 17$ : 47 (46.5%)	M=12.0, SD=2.6  Loneliness $\geq 17$ : 8 (7.9%)	ASD participants reported significantly higher loneliness.  ASD participants report greater prevalence of 'high' loneliness (i.e., at or greater than 17).	$t=7.11, p<.001$  Statistics NR in paper. Calculated as: $\chi^2(1, N=202)=38.00, p < .001$	Moderate
Chiang (2003)	NR	CLS	M=45.7, SD=11.0;	M=28.2, SD=10.0	ASD participants reported significantly higher levels of loneliness	Z= -2.17 $p=.013$	Weak

De Gennaro (2016)	<ul style="list-style-type: none"> <li>• Clinician report</li> <li>• CARS-2</li> </ul>	ULS-3	Overall ASD: M=41.71, SD=9.43; Male ASD: 40.64, SD=10.10; Female ASD: M=46.67, SD=2.31	Overall NT: M=37.04, SD=8.58; Male NT: M=36.18, SD=8.16; Female NT: M=38.88, SD=9.73	No statistical difference between groups as identified by diagnosis or between groups as identified by gender.	NS $F(1, 38) = 3.17, p = .083$  NS $F(1, 38) = 1.65, p = .213$ .	Moderate
Deckers et al. (2017)	<ul style="list-style-type: none"> <li>• Multi-informant (i.e., interviews with the child, parents and teacher, psychiatric examination, psychological assessment, and clinical observations).</li> </ul>	LACA (peer-related subscale)	Child: M=21.77, SD=7.98 Adolescent: M=23.50, SD=7.04	Child: M=20.32, SD=6.14. Adolescent: M=18.12, SD=4.58	The ASD group showed increased loneliness compared to the NT group. In the child group, no group differences in loneliness were noted. In the adolescent group, the ASD group displayed the highest loneliness. Children reported significantly higher levels of loneliness than adolescents in the NT group. In the ASD group, no significant difference in loneliness between age groups was found.	Significant results are reported between the three groups (including an ADHD clinical control group) rather than comparing ASD and NT groups directly.	Weak
Han et al. (2019)	<ul style="list-style-type: none"> <li>• ADOS-2</li> <li>• SRS-2</li> <li>• AQ.</li> </ul>	LiCQ	M=22.94, SD=7.40	M=13.70, SD=4.27	The ASD group scored significantly higher on the loneliness measure compared to both control groups.	Significant results are reported between the three groups (including a Depressed-NT group) rather than comparing ASD and NT groups directly.	Moderate

Kalyva (2010)	<ul style="list-style-type: none"> <li>Medical record check.</li> </ul>	MESSY (Loneliness/Social Anxiety Subscale)	M=21.57, SD=3.94	M=17.91, SD=4.61	ASD participants scored significantly higher on the loneliness measure.	F(1,40) =13.12, p=.001.	Strong
Lasgaard et al. (2010)	<ul style="list-style-type: none"> <li>Recruited from school supporting ASD children.</li> <li>Document check (unclear what/where from)</li> </ul>	ULS-3 (Danish version) and single-item prevalence scale	M=43.54, SD=8.84; % of those feeling lonely often or always: 8 (21%)	M=37.65, SD=10.30; % of those feeling lonely often or always: 7 (4%)	ASD boys reported significantly higher feelings of loneliness. Feeling lonely (often or always) was strongly associated with ASD.	F(1,229) = 11.1, p<.01 OR: 7.08 [95% CI: 2.40–20.91], p<.001	Weak
Lin and Huang (2019)	<ul style="list-style-type: none"> <li>Document check.</li> <li>AQ (Chinese version)</li> </ul>	ULS-8 (Chinese version)	M=22.2, SD=4.8	M=18.3, SD=3.9	Autistic adults had significantly higher loneliness scores.	t=5.4, p<.001	Moderate
Locke et al. (2010)	<ul style="list-style-type: none"> <li>Recruited from a school programme which required ASD diagnosis.</li> </ul>	CLS	ASD: M=37.71, SD=10.93	NT: M=26.25, SD=7.02	Autistic participants has significantly higher loneliness scores.	F(1, 16)=7.40, P < 0.05.	Weak
Merkler (2007)	NR	Isolation and Affect measure based on the PNDLS. Two of four subscales were deemed appropriate for inclusion in this review. <sup>5</sup>	Social Network Distress: M=9.91, SD=3.90; Dyadic Distress: M=10.69, SD=3.17	Social Network Distress: M=7.15, SD=2.20; Dyadic Distress: NT=9.42, SD=1.49	No significant differences between ASD and NT groups on distress related to isolation.	NS	Weak

<sup>5</sup> These subscales were amalgamated within Comprehensive Meta-Analysis. Following sensitivity analyses, this study was kept in the meta-analysis due to its removal not having any significant influence on the pooled effect size.

Nomura et al., (2012) <sup>6</sup>	<ul style="list-style-type: none"> <li>Stated children had been diagnosed according to established diagnostic criteria by psychiatrists, however confirmation not reported.</li> </ul>	Adapted CLSD	Elementary: M=16.94, SD=3.95; Higher Elementary: M=20.56, SD=4.63; High School: M=19.38, SD= 6.23	Elementary: M=15.27, SD=4.06; Higher Elementary: M=14.31, SD=3.27; High School: M=15.52, SD=4.08	Overall, ASD participants had higher loneliness scores than NT participants.  There was a significant interaction between group and school grade.  Further analyses showed significant differences between ASD and NT groups in Higher Elementary and Junior High, but not Lower Elementary.	F (1, 302)=36.32, p<.01  F (2, 302)=3.488, p<.05  Specific test results NR	Weak
Sundberg (2018)	<ul style="list-style-type: none"> <li>Self-report</li> </ul>	ULS-8	M=20.13, SD=4.20,	M=16.61, SD=3.58	ASD participants were found to score significantly higher on loneliness measure than NT participants	t(149) = 5.45, p < 0.001.	Weak
Whitehouse et al. (2009)	<ul style="list-style-type: none"> <li>Clinician report</li> <li>CAST</li> </ul>	LS	M=18.29, SD=8.49	M=11.91, SD=6.19	ASD adolescents reported greater levels of loneliness than the NT adolescents.	F(1,67)= 12.92, p < 0.001.	Moderate
Yeung (2009)	NR	CLS	M=44.21, SD=13.87	M=30.74, SD=9.79.	ASD children reported significantly higher loneliness than their NT siblings.	t(18)=3.42, p=0.002.	Weak

*Note.* M, Mean; SD, Standard Deviation; R, Range; NR, Not Reported. ADI-R, Autism Diagnostic Interview-Revised (Rutter et al., 2008); ADOS, Autism Diagnostic Observation Schedule (Gotham et al., 2006); AQ, Autism Quotient (Baron-Cohen et al., 2001); ASSQ-REV, Autism Spectrum Screening Questionnaire-Revised Extended Version (Kopp & Gillberg, 2011); CARS-2, Childhood Autism Rating Scale-2<sup>nd</sup> Edition (Schopler et al., 2010); CAST,

<sup>6</sup> Loneliness scores for this study were obtained via correspondence with the first author, due to this not being reported in the article.

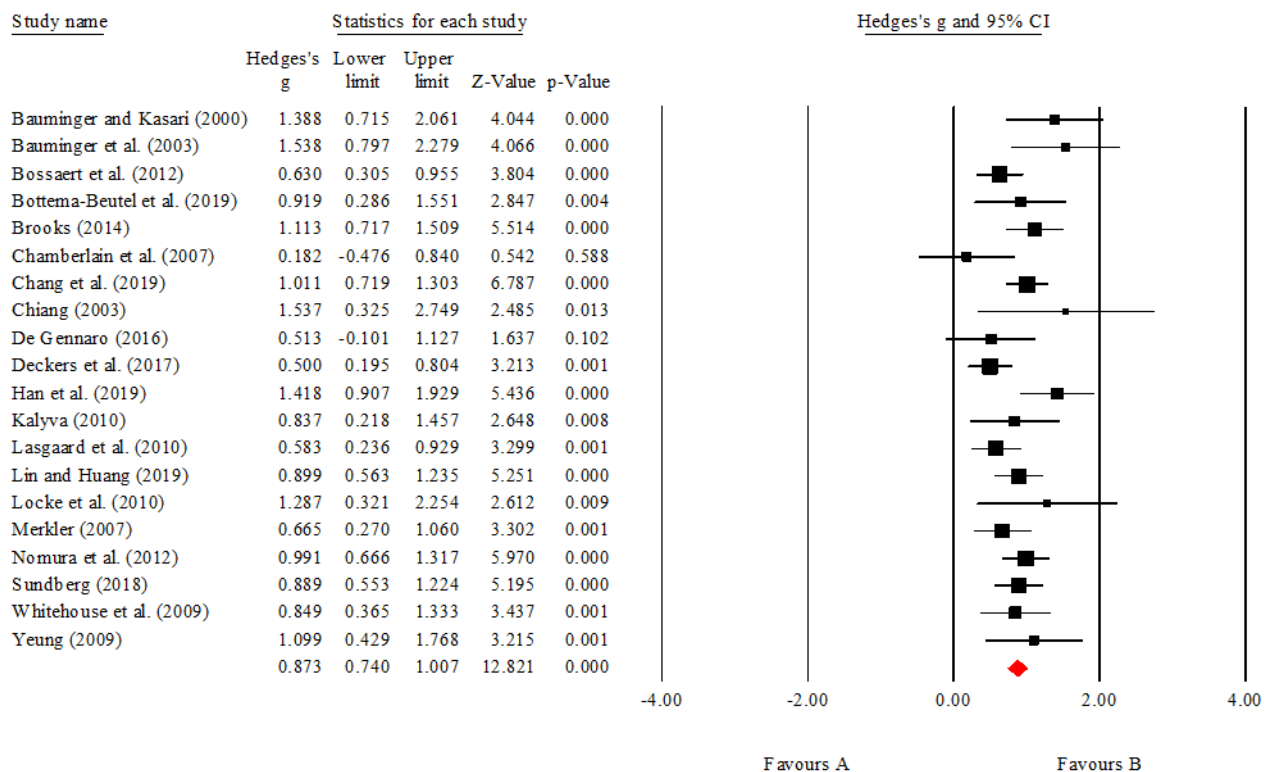
Childhood Asperger Syndrome Test (Scott et al., 2002); CLS, Children's Loneliness Scale (Asher et al., 1984); CLSD, Children's Loneliness and Dissatisfaction Scale (Asher & Wheeler, 1985); LACA, Loneliness and Aloneness Scale for Children and Adolescents (Marcoen et al., 1987); LiCQ, Loneliness in Context Questionnaire (Asher & Weeks, 2013); LS, Loneliness Scale (de Jong-Gierveld & Kamphuls, 1985); MESSY, Matson Evaluation of Social Skills with Youngsters (Matson et al., 1983); PNDLS, Peer Network and Dyadic Loneliness Scale (Hoza et al., 2000); SASA, Social Anxiety Scale for Adolescents (La Greca & Lopez, 1998); SELSA, Social and Emotional Loneliness Scale for Adults (DiTommaso & Spinner, 1997); SRS-2, Social Responsiveness Scale (Constantino, 2012); ULS-3, UCLA Loneliness Scale-Version 3 (Russell, 1996); ULS-3 Danish Version (Mathias Lasgaard, 2007); ULS-8, UCLA Loneliness Scale-Version 8 (Hays & Dimatteo, 1987).

## Meta-Analysis

Figure 2 shows individual studies' mean effect sizes and the pooled mean effect size. As predicted, there were differences in mean loneliness rates between ASD and NT samples, with ASD participants scoring significantly higher than NT participants, with a large weighted pooled effect (Hedges'  $g=0.87$ ; 95% CI  $[.74,1.01]$ ;  $Z=12.82$ ,  $p<.001$ ). Effect sizes ranged between  $g=.18-1.54$ . Two studies (Deckers et al., 2017; Nomura et al., 2012) included differing age groups. As the subgroups were all aged  $<18$ , these were combined within each study for the purpose of meta-analytic computations at the study-level.

**Figure 2**

Forest Plot for Meta-Analysis on Loneliness Rates between ASD and NT Samples



## Heterogeneity

As anticipated, significant heterogeneity was identified  $Q(19)=31.92$ ,  $p=.03$ . The  $I^2$  statistic indicated low-moderate heterogeneity with 40.47% of the dispersion between studies estimated to be real differences in the study effects. Heterogeneity was explored through categorical moderator analyses and meta-regression and outlined in Table 5. Across studies, 11 unique loneliness measures were used, with only one (the CLS; Asher et al.,

1984) being used in enough studies to warrant sub-group analyses; the moderator analysis, therefore, investigated CLS against the other measures used. An insufficient number of studies (N=2) received 'strong' ratings of overall methodological quality to enable them to occupy a separate subgroup, based on a priori criteria (Card, 2015). Therefore, subgroup analyses were conducted on studies appraised as methodologically 'moderate-strong' (N=11) or 'weak' (N=9). Only one moderator was evidenced to significantly explain between-group heterogeneity; studies that reported using gold-standard methods for confirming ASD diagnosis of participants (n=4) attained a significantly higher pooled effect size than studies that did not.

**Table 5***Categorical Moderator Analyses*

Moderator	Subgroup	<i>k</i>	Effect Size	95% CI	<i>p</i> -value	Q statistic and <i>p</i> -value
Population	Adult	5	.97	[.73-.1.12]	<.001	Q(1)=.87, p=.35
	Child	15	.83	[.67-.99]	<.001	
	Overall	20	.87	[.74-1.01]	<.001	
Loneliness Measure	CLS	5	1.00	[.61-1.39]	<.001	Q(1)=.46, p=.50
	Other Loneliness Measure	15	.86	[.71-1.00]	<.001	
	Overall	20	.87	[.74-1.01]	<.001	
ASD Diagnosis Confirmation	Gold-Standard	4	1.29	[1.03-1.56]	<.001	Q(1)=11.75, P=.001
	Not Gold-Standard	16	.78	[.67-.90]	<.001	
	Overall	20	.87	[.76-.98]	<.001	
Study Quality	Moderate-High	11	.98	[.80-1.15]	<.001	Q(1)=2.76, p=.097
	Low	9	.76	[.59-.94]	<.001	
	Overall	20	.87	[.66-1.08]	<.001	
Publication Status	Published	15	.87	[.72-1.03]	<.001	Q(1)=.02, p=.90
	Unpublished	5	.89	[.59-1.20]	<.001	
	Overall	20	.88	[.74-1.01]	<.001	

Note. *k*=Number of studies; CI=Confidence Interval

**Age.** In line with the moderator analysis that investigated whether loneliness prevalence differed according to population type (i.e., child or adult), meta-regression analysis showed age was not a significant moderator of effect-size across the 17 studies that provided relevant statistical information on participant ages (Q(1)=.31,  $b=0.01$ ,  $p=.58$ , 95% CI [-.02, 0.03],  $Z=.55$ ). This finding was equivalent in a further meta-regression which was



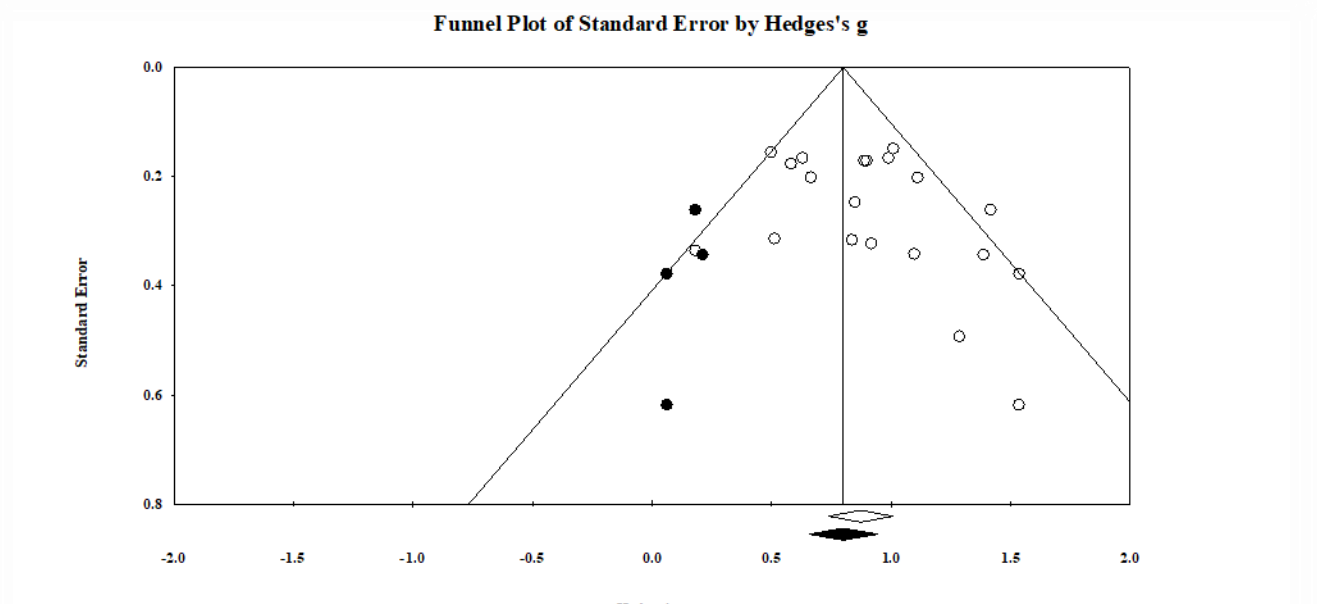
conducted at the subgroup level for one study which provided relevant statistics for two subgroups i.e., children and adolescents (Deckers et al., 2017).

### **Publication Bias**

The funnel plot in Figure 3 shows some asymmetry of study effect sizes around the effect size mean, with two studies falling outside of the 95% confidence limits. Trim and fill analysis corrected for asymmetry by imputing four studies to the left of the mean, however this did not significantly alter the overall effect ( $t(18)=1.53$ ,  $p=.14$ ). Moreover, fail-safe analysis indicated that 1457 missing studies with a mean effect of zero would be required to nullify the overall effect, exceeding the fail-safe threshold of  $k=110$ . Taken together, these findings suggest no evidence of publication bias in this meta-analysis.

**Figure 3**

*Funnel Plot of Standard Error against Hedges' g for Meta-Analysis on Loneliness Rates between ASD and NT samples, including imputed studies.*



### **Loneliness and Anxiety/Depression in ASD**

The results outlined below relate to the second review pertaining to studies reporting associations between loneliness and anxiety and/or depression.

#### **Study and Participant Characteristics**

Table 6 outlines the characteristics of each study. Of the 18 studies with unique cohorts included in the second review, seven measured anxiety only, five depression only and six measured both anxiety and depression. Overall, 13 utilised a cross-sectional design and five employed a longitudinal or pre-post experimental design, for which baseline cross-sectional data were extracted. Of the 13 studies measuring anxiety, 11 provided appropriate data for inclusion in the meta-analysis (N=798) and nine out of 11 studies were included in the loneliness and depression meta-analysis (N=774).

Studies were published between 2009-2021 and were conducted across five countries, predominantly in America (N=12). Most studies were conducted using child samples (N=11). Collectively, studies included 1,326 participants; sample sizes varied from 18-185 participants and ages ranged from 7-80 years. In the 12 studies that reported sample

ethnicity, the most represented ethnicity was White/Caucasian. All studies reported gender distribution, which ranged from 45%-90% Male, with only two studies reporting a higher proportion of females in their sample.

**Table 6**

*Study and Participant Characteristics for Studies Measuring Loneliness, Anxiety and/or Depression in ASD Samples*

Study Characteristics					Participant Characteristics			
Authors (Year)	Country	Objectives/Focus	Study Population	Sample Size	Age (M, SD, R)	Gender (% Male)	Predominant Ethnic Group(s) (%)	IQ Measure (M, SD, R)
Chang et al. (2019)	Taiwan	Explored the relationships between friendship quality and emotional well-being of ASD and NT adolescents.	Children	101	M=16.6, R=10-19	83%	NR	NR. States no participants had an intellectual disability (IQ<70).
Deckers et al. (2017)	Netherlands	Examined loneliness and social correlates, including social anxiety, ASD children and adolescents, in comparison to clinical and NT control groups using a multi-informant approach (children, parents, and teachers).	Children	Aged 7–11 years= 47; Aged 12–18 years = 26	M=11.2, SD=2.42	85%	NR "The sample consisted predominantly of Caucasian participants".	NR those with estimated IQ <70 were excluded.
Han et al. (2019)	America	Examined individual differences and associations in social and non-social pleasure, autism traits, loneliness, and depressive symptoms across samples of ASD adults and NT controls (with and without depression).	Adults	49	M=23.98, SD=26.23	61%	NR	Unknown IQ measure: Verbal M=103.63, SD=12.75; Non-Verbal M=103.04, SD=19.11
Hedley , Uljarević, Foley, et al. (2018)	Australia	Examined loneliness, social support and ASD trait severity as risk and protective factors associated with depression and suicidal ideation.	Adults	185	M= 37.11, SD= 15.41, R=14–80	45%	NR	NR
Hedley, Uljarević, Wilmot, et al. (2018)	Australia	Examined the associations between ASD traits, loneliness, depression, and thoughts of self-harm, in ASD adults.	Adults	71	M=26.14, SD=8.20, R=17–56	89%	Non-Aboriginal Australian (84.5%)	NR

Jackson et al. (2018)	America	Examined self-reported academic, social, and mental health experiences in post-secondary ASD students.	Adults	56	M=22.98, SD=6.01, R=18-57	46.4%	80.4% White	NR, however all participants enrolled in post-secondary education.
La Buissonniere Ariza et al. (2021)	America	Explored the risk factors associated with suicidal ideation in ASD children with comorbid anxiety disorders and assessed the unique contribution of externalizing behaviours.	Children	166	Age M=10, SD=1.8, R=7-13.	81.3%	75.9% White, 81.3% Non-Hispanic	WISC-IV: FSIQ: M=100.6, SD=16.3, R=54-146. 19.9% presented with mild intellectual disability.
Lieb and Bohnert (2017)	America	Explored associations between several Executive Function (EF) domains, social impairment, and friendship quality on depressive symptoms and loneliness in ASD adolescents.	Children	127	M=13.95, SD=1.60, R=12-17.	81%	Caucasian (86.6%).	Assumed WISC-IV: FSIQ M=104.76, SD=20.24 based on parent-report of prior IQ testing. <sup>7</sup>
Maddox et al. (2017)	America	Evaluated impact of a CBT intervention on the social skills of ASD adolescents with anxiety, considering pre-treatment social anxiety and loneliness.	Children	25	M=14.42, SD=1.55, R=12-17	76%	84% Caucasian)	WISC-IV: Verbal IQ M=98.32, SD=15.18 R=73-126
Mahjouri (2011)	America	Explored the social and emotional experience (including loneliness, anxiety and depression) in ASD adolescents. [Dissertation]	Children	18	M=15.1, SD=2.17, R=12-18	86%	58.1% Caucasian	SB-5: M=99.33, SD=17.93, R=67-139
Mazurek (2014)	America	Examined the associations among loneliness, friendship, and emotional functioning in ASD adults.	Adults	108	M=32.4, SD=12.5, R=18-62	52.8%	Caucasian (88.0%).	NR
Schiltz et al. (2020)	America	Explored associations between loneliness, anxiety, depression, autism features, and social contact among ASD adults.	Adults	69	M=20.24, SD=2.77, R=17-29	81%	85.5% White. 88.4% Non-Hispanic	KBIT-2: M=95.01, SD=17.43

<sup>7</sup> Information ascertained through sister paper (Bohnert et al., 2019).

Syu and Lin (2018)	Taiwan	Investigated the relationships among sensory avoidance, anxiety, and loneliness in ASD adults.	Adults	70	M=27.8, SD=5.0, R=20-39	66%	NR	NR. States no participants had IQ<70.
Wendler (2019)	America	Explored the impact of improv theatre classes on social-emotional functioning for autistic individuals, including impacts on depressive symptoms, anxiety symptoms, and loneliness. [Dissertation]	Children	21	M=15, SD=5.11	67%	90% European-heritage	NR
White and Roberson-Nay (2009)	America	Explored relationships between loneliness, degree of social skill deficit and anxiety in ASD children.	Children	20	M=12.08, SD=1.78, R=7-14	90%	NR	Unknown IQ Measure: M=92.24, SD=14.41
Wood (2014)	UK	Explored whether cognitive distortion in self-assessment of social performance occurred in ASD young people with social anxiety. [Dissertation]	Children	20	M=17.5, SD=2.134, R=14-21	75%	NR	NR
Wright (2017)	America	Investigated the effect of parental mediation on the associations between cyber victimization and depression, anxiety, and loneliness in children .	Children	128	R=11-16	89%	White (86%)	NR
Yeung (2009)	America	Examined the quality of friendships and the wellbeing (i.e., loneliness and depression) of children with Asperger's, in comparison to their NT siblings. [Dissertation]	Children	19	M=10.05, SD=1.38, R=8-12.	85.7%	85.7% Caucasian	NR

*Note.* M, Mean; SD, Standard Deviation; R, Range; NR, Not Reported; FSIQ, Full Scale Intelligence Quotient; KBIT-2, Kaufman Brief Intelligence Test, Second Edition (Kaufman & Kaufman, 2004); WISC, Wechsler Intelligence Scale for Children (Wechsler, 2008).

### **Quality assessment**

Overall, 13 studies received a 'moderate' global rating, four a 'weak' rating and one a 'strong' rating in methodological quality (see Table D2, Appendix D). All studies appeared to employ an appropriate study design to address the study's aims. Most studies (N=15) were deemed at least somewhat likely to be representative of the studied population and recruited community or non-treatment seeking participants. The remaining three studies received a 'weak' rating due to including only clinical samples. Few studies reported the proportion of individuals taking part out of those selected, or this item was not applicable due to opportunistic sampling. Two studies employed a RCT design and attained a 'strong' rating for this component; the remaining studies attained 'moderate' ratings due to being cross-sectional.

Most studies (N=17) received 'moderate' ratings for their data collection methods, due to using loneliness and anxiety and/or depression measures that were deemed reliable, although not validated in ASD samples. Only one study achieved 'strong' rating in this domain due to using both a loneliness and anxiety measure which was validated for use in ASD samples (Maddox et al., 2017). Half of the studies did not provide adequate information regarding the presence of- or reasons for- non-completion and/or missing data for participants who agreed to participate, thus receiving a 'weak' rating in the attrition domain. Six studies indicated 80-100% of participants completed the study and received strong ratings; the remaining studies (N=3) indicated at least 60% of participants completed the study.

Six studies reported using a gold-standard assessment of ASD, attaining 'strong' ratings for this domain. Nine studies used self- or other- report or screening questionnaires in the absence of gold-standard procedures or obtained medical documentation to confirm diagnosis; the most commonly used (N=8) was the AQ (Baron-Cohen et al., 2001). The remaining studies (N=3) demonstrated weak assessment and/or reporting of participants' ASD diagnoses. Seven studies reported participants' average IQ scores, although strong

ratings were only applied to those that reported measuring IQ as part of study procedures or within the preceding 3 months (N=4). Seven studies did not report any IQ information and four indicated including participants who were intellectually average or had an IQ>70. Only one study (La Buissonniere Ariza et al., 2021) mentioned including individuals with ID.

### **Outcomes**

Eight different self-report loneliness measures were used across the 18 studies, the most frequently used were the Children's Loneliness Scale (Asher et al., 1984) and the UCLA Loneliness Scale-8 (Hays & Dimatteo, 1987), both used in four studies. Nine different anxiety measures and seven depression measures were used across studies; the most common were the Multidimensional Anxiety Scale for Children (March et al., 1997) and the Patient Health Questionnaire-9 (Kroenke et al., 2001), used in three studies each. Two studies (Jackson et al., 2018; Wendler, 2019) did not report appropriate anxiety or depression subscale scores for inclusion in meta-analytic computations, however they both reported at least one positive correlation between measures of emotional distress and loneliness. See Table 7 for an overview of study measures, outcomes and overall quality appraisal score. Where multiple measures and/or outcomes were reported, those in bold were used in the meta-analyses.



**Table 7***Measures and Outcomes for Studies Measuring Loneliness and Anxiety/Depression*

<b>Authors (Year)</b>	<b>Autism Measure</b>	<b>Loneliness Measure (M, SD, R) and/or % cut-off</b>	<b>Anxiety Measure (M, SD, R)</b>	<b>Depression Measure (M, SD, R)</b>	<b>Key Findings</b>	<b>Statistical Results</b>	<b>Global Quality Rating</b>
Chang et al. (2019)	<ul style="list-style-type: none"> <li>Parent report</li> <li>Document check</li> <li>AQ (Chinese version)</li> </ul>	ULS-8 (Chinese version); M=16.3, SD=5.4	BAI (Chinese version) M=11.8, SD=12.6	N/A	Significant association between anxiety and loneliness.	r=0.442***	Moderate
Deckers et al. (2017)	<ul style="list-style-type: none"> <li>Multi-informant (i.e., interviews with the child, parents and teacher, psychiatric examination, psychological assessment, and clinical observations).</li> </ul>	LACA (peer-related subscale); Child: M=21.77, SD=7.98 Adolescent: M=23.50, SD=7.04	Social anxiety subscale of the SCARED-71(parent report).  Child M=8.50, SD=5.20; Adolescent M=7.77, SD=5.00	N/A	Loneliness was positively associated with parent ratings of social anxiety	r=0.16 (NS)	Weak
Han et al. (2019)	<ul style="list-style-type: none"> <li>ADOS-2</li> <li>SRS-2</li> <li>AQ</li> </ul>	LiCQ; M=22.94, SD=7.40	N/A	BDI-II; M=11.83, SD=9.89	Loneliness was the strongest predictor of depressive symptoms.	t(41) = 3.41, P=0.001, adjusted R <sup>2</sup> =0.33.	Moderate
Hedley , Uljarević, Foley, et al. (2018)	<ul style="list-style-type: none"> <li>Self-report</li> <li>AQ-Short</li> </ul>	ULS-8; M=22.80, SD=4.87, R=11–32	N/A	PHQ-9; M=9.52, SD=6.35, R=0–24	Significant correlations between loneliness and depression for overall sample and when split by gender.  Loneliness emerged as a unique predictor of depression scores.	<b>Overall =.437**</b> Males=.502** Females=.409**.  t = 3.11, $\beta$ = .24, P = .002	Moderate

Hedley, Uljarević, Wilmot, et al. (2018)	<ul style="list-style-type: none"> <li>• Self-report</li> <li>• AQ-Short</li> </ul>	ULS-3; M=51.35, SD=11.45, R=27-74	N/A	PHQ-9. M=6.52, SD=5.01, R=0-19	UCLA Loneliness was positively associated with PHQ depression	r=.392*	Moderate
Jackson et al. (2018)	<ul style="list-style-type: none"> <li>• Self-report</li> <li>• AQ-10</li> </ul>	UCLA (3-item); M=6.52, SD=1.96	DASS-21; Anxiety M=10.82, SD=7.73	DASS-21; Depression M=15.71, SD=11.77	Overall loneliness emerged as a significant predictor of overall emotional distress in the study sample. Did not report depression or anxiety subscales separately.	$\beta = 0.417$ , p<.001	Moderate
La Buissonniere Ariza et al.	<ul style="list-style-type: none"> <li>• ADOS-2</li> </ul>	CLS; M=37.8, SD=14.6, R=16-80	PARS (Parent Report); M=19.3, SD=3.2, R=12-28	N/A	Significant correlation between anxiety and loneliness	r=-.17, p<.05	Moderate
Lieb and Bohnert (2017)	<ul style="list-style-type: none"> <li>• Parent report</li> <li>• SRS</li> </ul>	CLS (Parent and Child); Parent report: M=31.63, SD=9.14, R=3-52 Adolescent report: M=23.83, SD=11.99, R=0-51	N/A	CBCL-D (Parent Report); M=0.71, SD=0.39, R=0-1.62 YSR-D (Youth Report); M=0.70, SD=0.39, R=0-1.69	Significant correlation between depression and loneliness in both parent and child report.	Parent: r=.48** Child: r=.60**	Moderate
Maddox et al. (2017)	<ul style="list-style-type: none"> <li>• ADI-R</li> <li>• ADOS</li> </ul>	Adapted CLS M=35.80, SD=12.60, R=15-61	The ADIS-C/P Social Phobia module (joint clinician, parent and child report); M=4.96, SD=1.40, R=3-7.	N/A	Loneliness and social anxiety were not significantly correlated	r = -.02, p=.95	Moderate
Mahjouri (2011)	<ul style="list-style-type: none"> <li>• ADOS</li> </ul>	CLS; M=41.39, SD=12.31, R=21-71	SASA; M=26.71, SD=19.62, R=7-65 MASC; M=55.28, SD=11.07, R=32-71	CDI; M=49.06, SD=8.36, R=39-68.	Positive correlation between Loneliness and SASA, MASC and CDI	SASA: r=.503 p<.05; <b>MASC: r=.364</b> (NS); CDI: r=.683 P<0.01.	Strong

Mazurek (2014)	<ul style="list-style-type: none"> <li>AQ-Short</li> </ul>	ULS-8; M=20.9, SD=4.7	PHQ 7-item Anxiety Scale M=7.4, SD=5.4	PHQ 9-item Depression Scale M=8.4, SD=6.2	Loneliness was positively correlated with anxiety and depression. Loneliness also provided significant main effects in the models predicting anxiety and depression.	Anxiety: $r=.34$ , $p=.001$ ; $\beta=.32$ , $p=.002$ Depression: $r=.48$ , $p<.001$ ; $\beta=.49$ , $p<.001$	Weak
Schiltz et al. (2020)	<ul style="list-style-type: none"> <li>ADOS</li> <li>AQ</li> </ul>	SELSA; Social Loneliness (SOC): M=47.26, SD=21.13; Emotional Family Loneliness (EFAM): M=25.35, SD=12.81; Emotional Romantic Loneliness (EROM): M=56.19, SD=13.19	SPIN: M=28.06, SD=16.14 LSAS: M=57.35, SD=30.21	BDI-II M=12.58, SD=10.99	<b>SELSA SOC:</b> positive correlation with SPIN, LSAS and BDI-II <b>SELSA EFAM:</b> positive correlation with SPIN, LSAS and BDI-II <b>SELSA EROM:</b> positive correlation with SPIN, LSAS and BDI-II.	SPIN: $r=0.52^{**}$ ; <b>LSAS: <math>r=0.59^{**}</math></b> , BDI: $r=0.44^{**}$ SPIN: $r=0.40^{**}$ , LSAS: $r=0.47^{**}$ , BDI-II: $r=0.72^{**}$ . SPIN: $r=0.22$ (NS), LSAS: $r=0.25^*$ , BDI-II: $r=0.31^*$	Moderate
Syu and Lin (2018)	<ul style="list-style-type: none"> <li>Document check.</li> <li>AQ (Chinese version)</li> </ul>	ULS-8 (Chinese version); M=21.9, SD=4.9, R=11–31	BAI (Chinese version); M=21.2, SD=11.9, R=2–43.	N/A	Positive correlation between loneliness and Anxiety	$r=0.501^{***}$	Moderate
Wendler (2019)	<ul style="list-style-type: none"> <li>Parental report</li> <li>SRS-2</li> </ul>	UCLA (3-item); M=5.18, SD=1.37	PHQ-4 (reported at overall and item-level only); Overall M=7.38, SD=2.65 Nervous item; M=2.32, SD=1.03 Worrying item; M=1.85, SD=0.95	Pleasure item; M=1.35, SD=.79 Down item; M=1.85, SD=.95	Positive correlation between loneliness and total PHQ-4 and between loneliness and Nervous and Worrying items. Negative correlation between loneliness and Pleasure item and positive correlation with Down Item.	PHQ-4; $r=.62$ Nervous; $r=.44$ Worrying; $r=.63$ Pleasure; $r=-.08$ Down; $r=.77$	Moderate

White and Roberson-Nay (2009)	• ADOS	Adapted CLS; Global Score: M=2.73, SD=0.71; Social Score: M=2.72, SD=0.80; Emotional Score: M=2.74, SD=0.76	MASC; M = 56.65, SD=15.19, R=28-83  Social Anxiety: M=52.65, SD=13.69, R=32-74  High anxiety (i.e., MASC ≥ 61) n=5.	N/A	Positive correlation between total anxiety and global loneliness.  Social anxiety was significantly correlated with social and global loneliness.  The high-anxiety group self-reported more 'social' loneliness, compared to their less anxious peers.	r = .325, NS  Social Loneliness: r=.59, p=.01; Global loneliness: r=.50, p=.04  t = 2.57, p<.05	Moderate
Wood (2014)	• Confirmed by professionals who worked with participants.	CLS; M=48.53, SD=15.01, R=22-73	SASA; M=48.45, SD=15.80, R=18-74	N/A	A significant positive correlation was found between social anxiety and loneliness.	r= 0.482, p<0.05.	Weak
Wright (2017)	• Clinician report	ULS-3; M=2.16, SD=1.00	MASC; M=1.81, SD=.79	CES-D; M=1.98, SD=.68	Significant positive correlation between loneliness and both anxiety and depression.	Anxiety: r=.19*  Depression: r=.27**	Moderate
Yeung (2009)	• NR	CLS; M=44.21, SD=13.87	NR	CDI; M=12.72, SD=10.44	Significant positive correlation between depression and loneliness.	r=0.81, p<.001.	Weak

*Note.* M, Mean; SD, Standard Deviation; R, Range; NR, Not Reported. ADI-R, Autism Diagnostic Interview-Revised (Rutter et al., 2008); ADOS, Autism Diagnostic Observation Schedule (Gotham et al., 2006); ADIS-C/P, Anxiety Disorders Interview Schedule for Children/Parents (Silverman & Albano, 1996); AQ, Autism Quotient (Baron-Cohen et al., 2001); AQ Short, Autism Quotient Short (Hoekstra et al., 2011); BAI, Beck Anxiety Inventory (Chinese version; Che et al., 2006); BDI-II, Beck Depression Inventory (Beck et al., 1996); CBCL-D, Child Behaviour Checklist-Depression Scale (Clarke et al., 1992); CDI, Children's Depression Inventory (Kovacs, 1992); CES-D, Center for Epidemiological Studies Depression Scale (Radloff, 1977); CLS, Children's Loneliness Scale (Asher et al., 1984); DASS-21, Depression, Anxiety and Stress Scale 21-item version (Lovibond & Lovibond, 1995); LACA, Loneliness and Aloneness Scale for Children and Adolescents (Marcoen et al., 1987); LiCQ, Loneliness in Context Questionnaire (Asher & Weeks, 2013); MASC, Multidimensional Anxiety Scale for Children (March et al., 1997); PARS, Pediatric Anxiety Rating Scale (Pediatric Psychopharmacology Anxiety Study Group, 2002); PHQ-4,

Public Health Questionnaire-4 (Kroenke et al., 2009); PHQ-7, Public Health Questionnaire-7 (Spitzer et al., 1999); PHQ-9, Public Health Questionnaire-9 (Kroenke et al., 2001); SCARED-71, Screen for Child Anxiety and Related Emotional Disorders (Bodden et al., 2009); SPIN, Social Phobia Inventory (Connor et al., 2000); SRS-2, Social Responsiveness Scale (Constantino, 2012); ULS-3, UCLA Loneliness Scale-Version 3 (Russell, 1996); ULS-8, UCLA Loneliness Scale-Version 8 (Hays & Dimatteo, 1987); LSAS, Liebowitz Social Anxiety Scale (Heimberg et al., 1999); UCLA 3-Item Scale (Hughes et al., 2004); YSR-D, Youth Self Report-Depression Scale (Achenbach & Rescorla, 2001). Three studies (White & Roberson-Nay, 2009; Mahjouri, 2011; Schiltz et al., 2020) reported multiple anxiety measure/subscale outcomes and two studies (White & Roberson-Nay, 2009; Schiltz et al., 2020) reported outcomes for three or more loneliness measures/subscales; the most internally consistent measure was used for the purposes of meta-analytic computations.

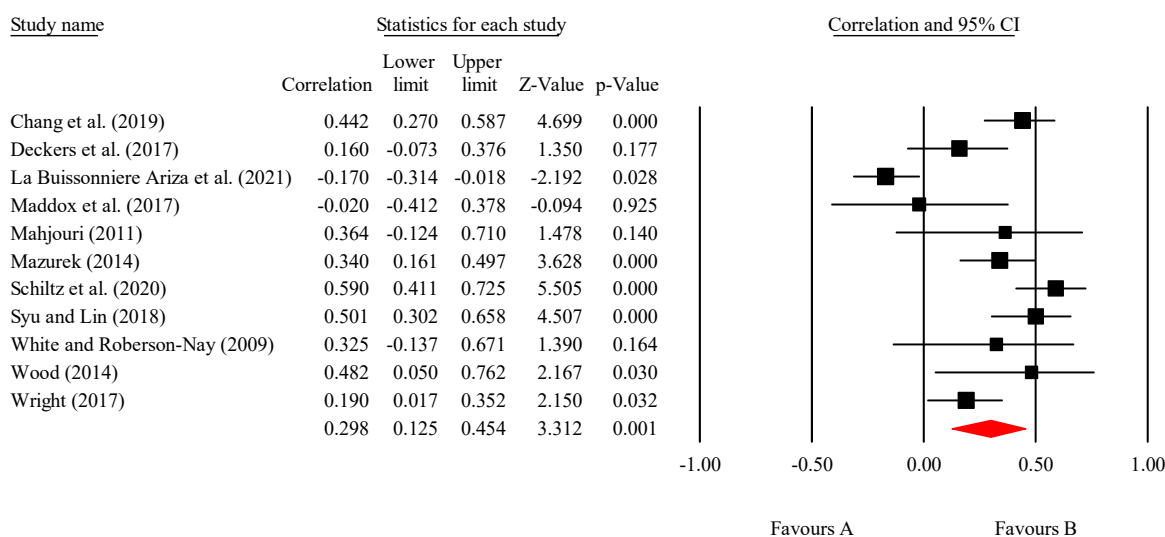
## Meta-analyses

### Anxiety

As can be seen in Figure 4, and in line with expectations, there was a significant positive association between mean loneliness scores and mean anxiety scores across most studies, with a medium pooled effect size ( $r=.30$ ; 95% CI [.13, .45];  $Z=3.31$ ,  $p=.001$ ). Effect sizes ranged between  $r=-.17$ -.59. Of note, one study found a significant negative correlation between loneliness and anxiety (La Buissonniere Ariza et al., 2021). Significant heterogeneity was identified between studies  $Q(10)=57.44$ ,  $p<.001$ . The  $I^2$  statistic indicated high heterogeneity, with 82.59% of the dispersion between studies suggested to be due to real differences in the study effects. The relatively small number of studies in the secondary meta-analyses (<20) precluded the use of comprehensive moderator analyses to investigate this heterogeneity (Rubio-Aparicio et al., 2017).

### Figure 4

#### Forest Plot for Meta-Analysis on Loneliness and Anxiety

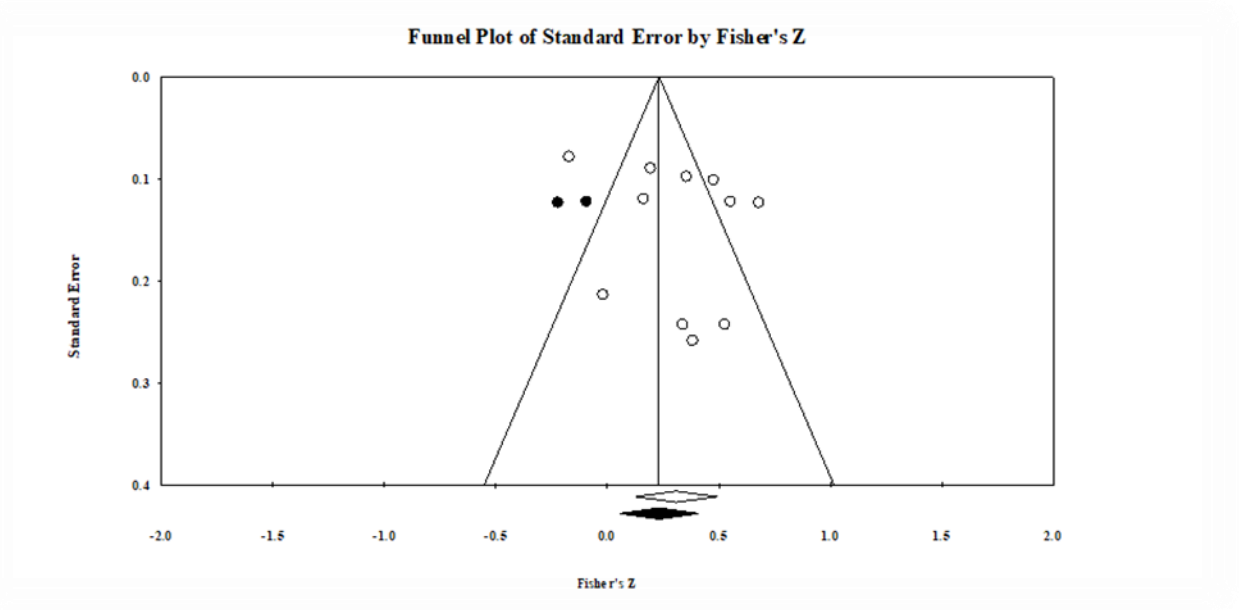


**Publication Bias.** Some asymmetry of study effect sizes around the effect size mean were apparent in the funnel plot in Figure 5, with four studies falling outside of the 95% confidence limits. Trim and fill analysis corrected for asymmetry by imputing 2 studies to the left of the mean, however this did not significantly alter the overall effect ( $t(9)=1.07$ ,  $p=.31$ ).

Fail-safe analysis indicated that 147 missing studies with a mean effect of zero would necessitate nullifying the overall effect, exceeding the fail-safe threshold of  $k=65$ . Therefore, there is no evidence of publication bias in this meta-analysis.

### Figure 5

*Funnel Plot of Standard Error against Fisher's Z for Meta-Analysis on Loneliness and Anxiety, including imputed studies.*

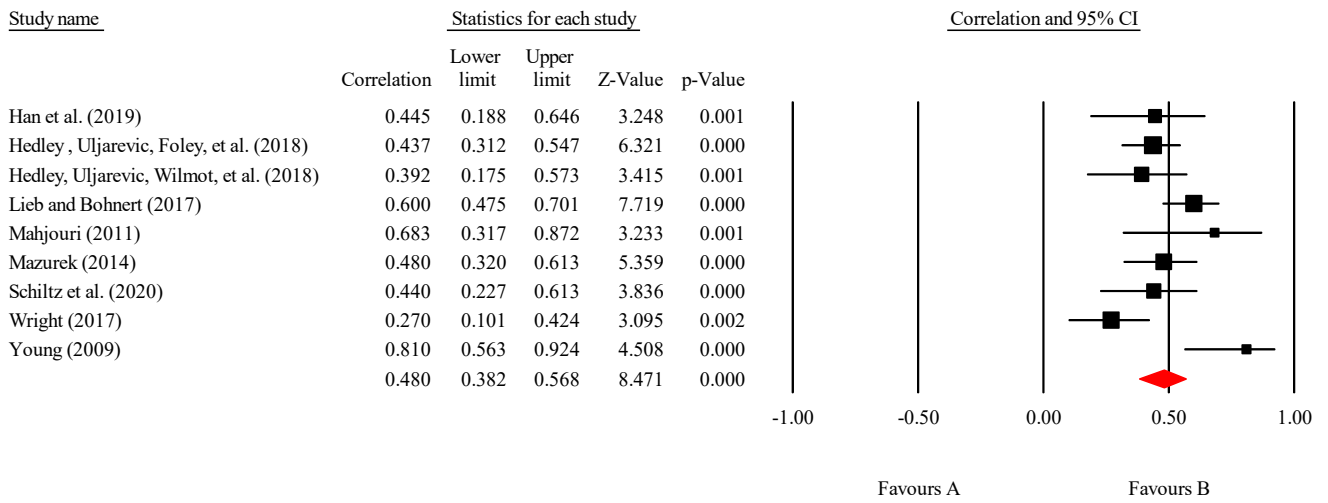


### Depression

Figure 6 outlines the significant positive relationship, with medium-large effect, between loneliness and depression ( $r=.48$ ; 95% CI [.38, .57];  $Z=8.47$ ,  $p<.001$ ). Effect sizes of studies ranged between  $r=.27$ -.81, all in the expected direction. Again, there was evidence of significant heterogeneity identified between studies ( $Q(8)=19.63$ ,  $p=.01$ ). The  $I^2$  statistic indicated moderate heterogeneity, with 59.24% of the dispersion between studies suggested to be due to real study effect differences. This was not investigated further due to insufficient number of studies (Rubio-Aparicio et al., 2017).

**Figure 6**

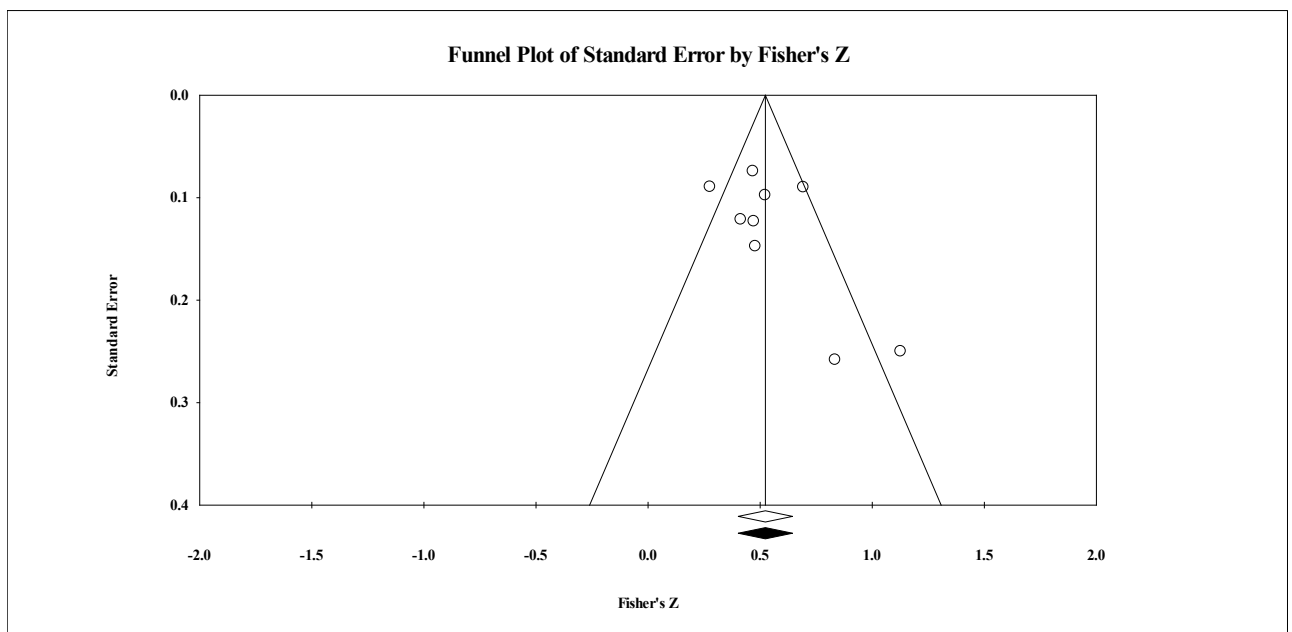
*Forest Plot for Meta-Analysis on Loneliness and Depression*



**Publication Bias.** Some asymmetry of study effect sizes around the effect size mean was apparent in the funnel plot in Figure 7, with two studies falling outside of the 95% confidence limits. However, no studies were imputed to correct for asymmetry based on trim and fill analysis and the regression test was non-significant ( $t(7)=1.54, p=.17$ ). Fail-safe analysis indicated that 423 missing studies with a mean effect of zero would necessitate nullifying the overall effect, exceeding the fail-safe threshold of  $k=55$ . Overall, this demonstrated a lack of publication bias in this meta-analysis.

**Figure 7**

*Funnel Plot for Meta-Analysis on Loneliness and Depression*





## Discussion

This systematic review used meta-analytic methodology to examine differences in loneliness rates between autistic and neurotypical samples and investigated the association between loneliness and anxiety/depression in autistic individuals.

### Overview of Findings

Of the 20 studies included in the initial meta-analysis, all found autistic individuals scored higher on mean loneliness rates compared to neurotypical samples (this was a significant difference in 18 studies). The combined weighted effect size for this difference was large (Hedges'  $g=.87$ ). Eight of the 11 studies included in the meta-analysis of loneliness and anxiety found a significant correlation (seven in the expected direction) with an overall medium effect size ( $r=.30$ ). In the final meta-analysis, a pooled medium-large effect ( $r=.48$ ) was found for the association between loneliness and depression, with all nine studies finding a significant positive correlation. Collectively, these results support all three hypotheses; autistic individuals scored higher on loneliness measures compared with neurotypical individuals and, among autistic samples, those with higher scores on loneliness also reported increased anxiety and depressive symptoms.

This is the first review to quantify differences in loneliness ratings between autistic and neurotypical samples. The consistent finding that autistic individuals report more loneliness than neurotypical individuals contradicts literature that implies autistic individuals are compromised in their desire to seek social connection (Chevallier et al., 2012). It may be that autistic individuals' 'atypical' social behaviour is not indicative of social disinterest (Jaswal & Akhtar, 2018), but manifests from reciprocal interactions within multiple ecological contexts (Bronfenbrenner, 1977). For example, autistic individuals are more susceptible to experiencing negative social interaction e.g., through direct bullying and victimisation experiences and indirect broader societal stigmatisation (Schroeder et al., 2014). Such aversive experiences may lead to social withdrawal and fewer opportunities for social skill development and successful social experiences.

The finding that loneliness was significantly positively correlated with both anxiety and depression is in line with previous research in neurotypical populations (Danneel et al., 2019; Erzen & Çikrikci, 2018; Leigh-Hunt et al., 2017). However, the cross-sectional nature of studies included in the meta-analyses precludes the interpretation of the direction of causality between loneliness, anxiety and depression. In the neurotypical population, the causal association between loneliness and mental health is considered to be bidirectional (Flett et al., 2016; Hawkley & Cacioppo, 2010), although evidence from longitudinal research has indicated loneliness being unidirectionally predictive of depressive symptoms over 1-year intervals (Cacioppo et al., 2010). Future research is required to establish whether loneliness shows a similar predictive effect in autistic individuals.

Significant between-study heterogeneity was found in all meta-analyses (ranging from 40.47%-82.59%). Due to the number of studies included in meta-analytic computations, this could only be explored through moderator analysis in the first meta-analysis. In this analysis, only the use of gold standard procedures for confirming autism diagnosis was found to significantly explain some between-study heterogeneity, suggesting that studies employing gold-standard procedures, with more accurate characterisation of autistic participants, had a greater effect size of mean differences in loneliness scores. The lack of significant findings for the other moderators is notable. For example, quality variance may not have significantly explained between-study heterogeneity due to the majority of included studies being considered methodologically weak-moderate, with very few achieving strong ratings. Most studies utilised differing loneliness measures which were not validated in autistic samples which may explain why moderator analysis on loneliness measures did not explain significant heterogeneity. Likewise, most studies were conducted on younger samples (namely adolescents), potentially inflating the occurrence of type 2 errors for the moderator analyses on age and population type.

### **Strengths and Limitations of Included Studies**

There were numerous limitations in the literature included in this review. Measurement and reporting of participant characteristics across studies was inconsistent. Some studies did not report ethnicity data; in those that did, there appeared to be an over-representation of Caucasian participants from western cultures. As the meaning, experience and presentation of loneliness may vary across cultures, with research suggesting increasing loneliness rates among individualistic cultures (versus collectivist cultures), the findings of this review may not be generalisable to non-Caucasian and non-western participants (Barreto et al., 2021). Most participants were male, and although this aligns with gender ratios in autism research (Loomes et al., 2017), the findings of the review may not accurately capture the experiences of autistic females. Furthermore, the lack of subgroup analysis by gender within studies and the non-inclusion of individuals diagnosed with ID or reporting of IQ scores across studies, prevents confidence that these were appropriately controlled for in studies and precluded investigation of these as potential sources of heterogeneity.

Most studies adequately reported their recruitment procedures, however the reporting of participant selection and attrition was particularly weak across studies. The rate of participation in the studies out of those selected was unclear, and rates of non-completers or missing data were not reported which may have biased findings e.g., participants who were particularly lonely may be more motivated to take part and complete the studies. It is important to note that the findings of this review may be more generalisable to autistic individuals in the community, as opposed to clinical samples, given most samples were recruited from community and non-treatment seeking populations. Consistent with other systematic reviews on autistic individuals across the lifespan, most studies recruited child or adolescent samples (Spain 2018), which reduces the generalisability of these findings to adult samples; nevertheless, findings were consistent across age groups in this review.

The varied assessment and outcome measures used across studies may have resulted in different operationalisations of constructs (Offord & Kraemer, 2000). For example, the lack of gold standard procedures in confirming ASD diagnoses decreases the assurance of the diagnostic characterisation of most participants included in this review. Moreover, few studies reported whether the measures used to assess anxiety and depression had been validated within an autistic population, and participants exceeding clinical cut-off in studies were rarely reported, limiting the generalisation of findings in this review to participants with sub-clinical anxiety and/or depression. Studies may also have introduced bias by not considering diagnostic overshadowing i.e., the overlapping symptomatology of anxiety, depression and ASD inflating estimates of association (Rosen et al., 2018). This is further confounded by the greater co-occurrence of alexithymia in autistic individuals, characterised by difficulties in identifying and/or describing one's emotional experiences (Poquérousse et al., 2018), which can lead to inaccurate self-reporting on measures that have only been validated in neurotypical samples. Only one study reported accounting for diagnostic overshadowing (Maddox et al., 2017) and they found no significant correlation between anxiety and loneliness. It is notable that no studies reported accounting for possible alexithymia in participants.

Importantly, despite autistic individuals scoring higher on loneliness measures compared to neurotypical individuals across included studies, we cannot infer that the magnitude of loneliness is severe and/or *clinically* relevant. Only three studies reported loneliness prevalence according to predetermined cut-off rates, which all reported autistic individuals had increased prevalence of 'high' loneliness. However, all studies used different loneliness measures and cut-off criteria, and achieved weak or moderate quality ratings, making comparisons between studies difficult. Future studies would benefit from including a standardised measure of loneliness duration, distress and frequency, in line with recommendations for measuring loneliness in the general population (Office for National

Statistics, 2018). This will aid understanding of the clinical magnitude of loneliness felt by autistic individuals.

Moreover, this review cannot confirm that autistic individuals define, experience or express loneliness in the same way that neurotypical individuals may. Only three studies utilised loneliness measures which encapsulated multiple loneliness dimensions, which precluded this from being explored as a potential moderator in meta-analyses. Future studies would benefit from exploring differing dimensions of loneliness through utilisation of multidimensional measures of loneliness, especially when comparing autistic and neurotypical samples, as it may be that autistic individuals score higher than neurotypical individuals on a certain dimension of loneliness, rather than loneliness as a global construct.

### **Strengths and Limitations of this Review**

This review is strengthened by the employment of a comprehensive search strategy and the use of stringent eligibility criteria which fosters confidence that the included studies are representative of the current evidence base. The inclusion of unpublished literature reduces the likelihood of publication bias (Sterne & Egger, 2005); indeed there was no evidence of publication bias within any of the meta-analyses. In addition, having independent ratings of methodological bias which resulted in 'fair' to 'very good' inter-rater agreement across all domains gives credibility to the reliability of the quality appraisal results.

Nevertheless, bias may have been inadvertently introduced during selection of studies due to this being conducted by only the first author, and a subsample was not cross-checked against the eligibility criteria by an independent reviewer (Boland et al., 2014). A further limitation is that due to the limited number of studies retrieved and included in the meta-analyses on the association between loneliness and mental health, the influence of potential moderators in explaining the moderate-high between-study heterogeneity was unable to be investigated. Given the relative paucity of the literature, additional data is required to support further exploration of between-study heterogeneity.

## **Clinical and Research Implications**

Given the findings of a large effect for increased loneliness in autistic individuals compared to neurotypical individuals, clinicians should consider the implications of autistic individuals' experience of loneliness. Assessment of loneliness presence and severity should be incorporated in relevant settings (e.g., school or mental health settings) and interventions to alleviate loneliness should be considered and implemented if this is warranted. For example, interventions aimed at developing social relationships (e.g., social skills training groups) have been found to decrease feeling of loneliness in autistic children and adults (Deckers et al., 2016; Spain & Blainey, 2015). Further research is necessary to ascertain whether evidence-based loneliness interventions in neurotypical samples, such as mindfulness-based interventions (Teoh et al., 2021), and interventions to increase social contact and support (Masi et al., 2011) are also beneficial for autistic individuals. Within Bronfenbrenner's (1977) ecological model, social experiences are reciprocal in nature and therefore it is also necessary to create inclusive community environments that will nurture social relationships and encourage neurotypical individuals to develop their own skills in integrating autistic individuals within social settings such as schools and workplaces e.g., through social inclusion and community participation programmes (Amado et al., 2013). Notably, the included studies were published between 2000-2019. Future research in this area would benefit from exploring the impact of cohort effects, such as the influence of expanding internet use which has been linked to increasing loneliness (Moretta & Buodo, 2020). This is especially pertinent when considering the discrepancies in internet use among ASD and NT populations (Gillespie-Lynch et al., 2014).

Findings from the secondary meta-analyses point to the importance of mental health clinicians assessing social relationships and subjective loneliness when autistic individuals present to services with symptoms of anxiety and/or depression. However, the findings of this review may not generalise to individuals with clinical levels of anxiety or depression, thus further research on such samples will be necessary to guide clinical practice and develop

tailored psychological interventions. Future research may wish to compare the magnitude of the relationship between loneliness and mental health in autistic individuals to the magnitude of this relationship in neurotypical individuals, as this was beyond the scope of this review.

Future studies should also implement outcome measures that have been validated in autistic populations. Given the absence of validated loneliness measures in autistic people, further research is necessary to ascertain how loneliness can be measured in autistic individuals. This should be done in collaboration with autistic people to capture their understanding and experiences more accurately (Cassidy et al., 2018).

Using gold-standard procedures for confirming autism diagnoses such as the ADOS (Gotham et al., 2006) and ADI-R (Rutter et al., 2008) would enable better generalisation of study findings to diagnosed autistic individuals. The lack of current valid and reliable measures of mental health in autism is a recognised research gap, especially within adult populations (Brugha et al., 2015), although recent research is addressing this (Rodgers et al., 2020). Future studies would benefit from including validated mental health and alexithymia measures (e.g., the Bermond-Vorst Alexithymia Questionnaire; Vorst & Bermond, 2001). More consistent use of measures and transparent reporting of all research procedures in future studies will enable better between-study comparisons.

Finally, longitudinal research could advance understanding of the mechanisms, course and predictors of loneliness, as well as factors which may mediate or moderate its association with anxiety and depression. This would help identify autistic individuals most vulnerable to experiencing loneliness and anxiety/depression, thus allowing early intervention to help mitigate the potential deleterious consequences.

## **Conclusions**

Loneliness is an important yet overlooked construct in the socio-emotional experiences of autistic individuals. This is the first systematic review using meta-analytic procedures to compare loneliness rates between autistic and neurotypical samples. This review also quantified the association between loneliness and anxiety/depression in autistic

individuals. Findings highlighted consistently elevated loneliness scores reported by autistic individuals compared with neurotypical individuals, and demonstrated significant correlations between loneliness scores and anxiety and depressive symptoms in autistic individuals. The unexplained heterogeneity, as well as the variance in study quality should be considered when interpreting these findings. Nevertheless, this review demonstrates significant preliminary findings within the field and has important clinical and research implications.



## References

References marked with an asterisk (\*) were included in the review.

- Achenbach, T. M., & Rescorla, L. A. (2001). *Manual for the ASEBA school-age forms & profiles*. Research Center for Children, Youth & Families. [https://doi.org/10.1007/978-0-387-79948-3\\_1529](https://doi.org/10.1007/978-0-387-79948-3_1529)
- Achterbergh, L., Pitman, A., Birken, M., Pearce, E., Sno, H., & Johnson, S. (2020). The experience of loneliness among young people with depression: A qualitative meta-synthesis of the literature. *BMC Psychiatry*, *20*(1), 1–23. <https://doi.org/10.1186/s12888-020-02818-3>
- Amado, A. N., Stancliffe, R. J., McCarron, M., & McCallion, P. (2013). Social inclusion and community participation of individuals with intellectual/developmental disabilities. *Intellectual and Developmental Disabilities*, *51*(5), 360–375. <https://doi.org/10.1352/1934-9556-51.5.360>
- American Psychiatric Association. (1994). *American Psychiatric Association. Diagnostic and Statistical Manual of Mental Disorders: DSM-IV*. American Psychiatric Association.
- American Psychiatric Association. (2013). *Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition: DSM 5 (Fifth)*. American Psychiatric Publishing. <http://www.psyweb.com/content/main-pages/dsm-5-fifth-edition-of-the-diagnostic-and-statistical-manual-of-mental-disorders>
- Armijo-Olivo, S., Stiles, C. R., Hagen, N. A., Biondo, P. D., & Cummings, G. G. (2012). Assessment of study quality for systematic reviews: a comparison of the Cochrane Collaboration Risk of Bias Tool and the Effective Public Health Practice Project Quality Assessment Tool: methodological research. *Journal of Evaluation in Clinical Practice*, *18*, 12–18. <https://doi.org/10.1111/j.1365-2753.2010.01516.x>
- Asher, S., Hymel, S., & Renshaw, P. D. (1984). Loneliness in children. *Child Development*, *55*(4), 1464. <https://doi.org/10.2307/1130015>
- Asher, S., & Weeks, M. S. (2013). Loneliness and belongingness in the college years. In R. Coplan & J. Bowker (Eds.), *The Handbook of Solitude* (pp. 283–301). Wiley.

<https://doi.org/10.1002/9781118427378.ch16>

- Asher, S., & Wheeler, V. (1985). Children's loneliness: A comparison of rejected and neglected peer status. *Journal of Consulting and Clinical Psychology, 53*(4), 500–505.  
<https://psycnet.apa.org/buy/1985-30488-001>
- Baron-Cohen, S., Wheelwright, S., Skinner, R., Martin, J., & Clubley, E. (2001). The autism-spectrum quotient (AQ): Evidence from asperger syndrome/high-functioning autism, males and females, scientists and mathematicians. *Journal of Autism and Developmental Disorders, 31*(1), 5–17. <https://doi.org/10.1023/A:1005653411471>
- Barreto, M., Victor, C., Hammond, C., Eccles, A., Richins, M. T., & Qualter, P. (2021). Loneliness around the world: Age, gender, and cultural differences in loneliness. *Personality and Individual Differences, 169*. <https://doi.org/10.1016/j.paid.2020.110066>
- Bauminger, N. (1997). Loneliness, friendship and theory of mind in high-functioning children with autism. [ProQuest Information & Learning]. In *ProQuest Dissertations and Theses* (Vol. 57, Issues 10-A).  
<http://ovidsp.ovid.com/ovidweb.cgi?T=JS&PAGE=reference&D=psyc3&NEWS=N&AN=1997-95007-036>
- \*Bauminger, N., & Kasari, C. (2000). Loneliness and friendship in high-functioning children with autism. *Child Development, 71*(2), 447–456. <https://doi.org/10.1111/1467-8624.00156>
- Bauminger, N., & Kasari, C. (2001). The experience of loneliness and friendship in autism: Theoretical and practical issues. In E. Schopler, N. Yirmiya, C. Shulman, & L. M. Marcus (Eds.), *The research basis for autism intervention*. (pp. 151–168). Kluwer Academic/Plenum Publishers.  
<http://ovidsp.ovid.com/ovidweb.cgi?T=JS&PAGE=reference&D=psyc3&NEWS=N&AN=2001-18055-010>
- \*Bauminger, N., Shulman, C., & Agam, G. (2003). Peer Interaction and Loneliness in High-Functioning Children with Autism. *Journal of Autism and Developmental Disorders, 33*(5), 489–507. <https://doi.org/10.1023/A:1025827427901>

- Bauminger, N., Shulman, C., & Agam, G. (2004). The link between perceptions of self and of social relationships in high-functioning children with autism. *Journal of Developmental and Physical Disabilities, 16*(2), 193–214.  
<https://doi.org/10.1023/B:JODD.0000026616.24896.c8>
- Beck, A. T., Steer, R. A., & Brown, G. (1996). Manual for the Beck depression inventory-II. In *Psychological Corporation*. <https://doi.org/https://doi.org/10.1037/t00742-000>
- Beutel, M. E., Klein, E. M., Brähler, E., Reiner, I., Jünger, C., Michal, M., Wiltink, J., Wild, P. S., Münzel, T., Lackner, K. J., & Tibubos, A. N. (2017a). Loneliness in the general population: Prevalence, determinants and relations to mental health. *BMC Psychiatry, 17*(1), 1–7. <https://doi.org/10.1186/s12888-017-1262-x>
- Beutel, M. E., Klein, E. M., Brähler, E., Reiner, I., Jünger, C., Michal, M., Wiltink, J., Wild, P. S., Münzel, T., Lackner, K. J., & Tibubos, A. N. (2017b). Loneliness in the general population: Prevalence, determinants and relations to mental health. *BMC Psychiatry, 17*(1). <https://doi.org/10.1186/s12888-017-1262-x>
- Bodden, D. H. M., Bögels, S. M., & Muris, P. (2009). The diagnostic utility of the screen for child anxiety related emotional disorders-71 (SCARED-71). *Behaviour Research and Therapy, 47*(5), 418–425. <https://doi.org/10.1016/j.brat.2009.01.015>
- Boland, A., Cherry, M. G., & Dickson, R. (2014). *Doing a systematic review: a student's guide* (1st ed.). SAGE Publications Ltd.
- Borenstein, M, Hedges, L., Higgins, J., & Rothesteing, H. (2013). *Comprehensive meta-analysis: Version 3*. Biostat. <https://www.meta-analysis.com>
- Borenstein, Michael., Hedges, L. V., Higgins, J. P. T., & Rothstein, H. R. (2010). A basic introduction to fixed-effect and random-effects models for meta-analysis. *Research Synthesis Methods, 1*(2), 97–111. <https://doi.org/10.1002/jrsm.12>
- \*Bossaert, G., Colpin, H., Pijl, S. J., & Petry, K. (2012). Loneliness among students with special educational needs in mainstream seventh grade. *Research in Developmental Disabilities, 33*(6), 1888–1897. <https://doi.org/10.1016/j.ridd.2012.05.010>
- \*Bottema-Beutel, K., Malloy, C., Cuda, J., Kim, S. Y., & MacEvoy, J. P. (2019). Friendship

- expectations may be similar for mental age-matched children with autism spectrum disorder and typically developing children. *Journal of Autism and Developmental Disorders*, 49(10), 4346–4354. <https://doi.org/10.1007/s10803-019-04141-7>
- Bronfenbrenner, U. (1977). Toward an experimental ecology of human development. *American Psychologist*, 32(7), 513–531. <http://content.apa.org/journals/amp/32/7/513>
- \*Brooks, W. T. (2014). Gender differences in social skills, peer relationships, and emotional correlates in adults with high functioning autism spectrum disorders. [The Ohio State University]. In *ProQuest Dissertations and Theses* (Vol. 76). <https://search.proquest.com/dissertations-theses/gender-differences-social-skills-peer/docview/1699717702/se-2?accountid=13828>
- Brugha, T. S., Doos, L., Tempier, A., Einfeld, S., & Howlin, P. (2015). Outcome measures in intervention trials for adults with autism spectrum disorders; A systematic review of assessments of core autism features and associated emotional and behavioural problems. *International Journal of Methods in Psychiatric Research*, 24(2), 99–115. <https://doi.org/10.1002/mpr.1466>
- Byrt, T. (1996). How good is that agreement? *Epidemiology (Cambridge, Mass.)*, 7(5), 561. <http://www.ncbi.nlm.nih.gov/pubmed/8862998>
- Cacioppo, J. T., Hawkley, L. C., Ernst, J. M., Burleson, M., Berntson, G. G., Nouriani, B., & Spiegel, D. (2006). Loneliness within a nomological net: An evolutionary perspective. *Journal of Research in Personality*, 40(6), 1054–1085. <https://doi.org/10.1016/j.jrp.2005.11.007>
- Cacioppo, J. T., Hawkley, L. C., & Thisted, R. A. (2010). Perceived social isolation makes me sad: 5-year cross-lagged analyses of loneliness and depressive symptomatology in the Chicago health, aging, and social relations study. *Psychology and Aging*, 25(2), 453–463. <https://doi.org/10.1037/a0017216>
- Card, N. (2015). *Applied Meta-Analysis for Social Science Research* (S. Ahn, B. Bushman, & J. Worley (eds.); 1st ed.). Guilford Press. <https://www.routledge.com/Applied-Meta-Analysis-for-Social-Science-Research/Card/p/book/9781462525003>

- Cassidy, S., Bradley, L., Shaw, R., & Baron-Cohen, S. (2018). Risk markers for suicidality in autistic adults. *Molecular Autism*, 9(1), 1–14. <https://doi.org/10.1186/s13229-018-0226-4>
- \*Chamberlain, B., Kasari, C., & Rotheram-Fuller, E. (2007). Involvement or isolation? The social networks of children with autism in regular classrooms. *Journal of Autism and Developmental Disorders*, 37(2), 230–242. <https://doi.org/10.1007/s10803-006-0164-4>
- \*Chang, Y.-C., Chen, C.-H., Huang, P.-C., & Lin, L.-Y. (2019). Understanding the characteristics of friendship quality, activity participation, and emotional well-being in Taiwanese adolescents with autism spectrum disorder. *Scandinavian Journal of Occupational Therapy*, 26(6), 452–462. <https://doi.org/10.1080/11038128.2018.1449887>
- Che, H.-H., Lu, M.-L., Chen, H.-C., Chang, S.-W., & Lee, Y.-J. (2006). Validation of the Chinese version of the Beck Anxiety Inventory. *Taipei Medical University*, 10(4), 447–454. [https://doi.org/10.6320/FJM.2006.10\(4\).05](https://doi.org/10.6320/FJM.2006.10(4).05)
- Chevallier, C., Kohls, G., Troiani, V., Brodtkin, E. S., & Schultz, R. T. (2012). The social motivation theory of autism. In *Trends in Cognitive Sciences* (Vol. 16, Issue 4, pp. 231–239). Elsevier Ltd. <https://doi.org/10.1016/j.tics.2012.02.007>
- \*Chiang, I.-T. (2003). Effects of a therapeutic recreation intervention within a technology-based physical activity context on the social interaction of male youth with autism spectrum disorders [Indiana University]. In *ProQuest Dissertations and Theses*. <https://search.proquest.com/dissertations-theses/effects-therapeutic-recreation-intervention/docview/305332304/se-2?accountid=13828>
- Clarke, G., Lewinsohn, P., Hyman, H., & Seeley, J. (1992). A self- and parent-report measure of adolescent depression: The Child Behavior Checklist Depression scale (CBCL-D). *Behavioral Assessment*, 14(3), 443–463. <https://psycnet.apa.org/record/1993-24114-001>
- Cohen, J. (1992). A power primer. *Psychological Bulletin*, 112, 155–159. <https://doi.org/10.1037/0033-2909.112.1.155>

- Connor, K. M., Davidson, J. R. T., Erik Churchill, L., Sherwood, A., Foa, E., & Weisler, R. H. (2000). Psychometric properties of the social phobia inventory (SPIN). New self-rating scale. *British Journal of Psychiatry*, *176*(6), 379–386.  
<https://doi.org/10.1192/bjp.176.4.379>
- Constantino, J. (2012). *Social Responsiveness Scale, Second Edition (SRS-2)*. Western Psychological Services.  
<https://www.pearsonclinical.co.uk/Psychology/ChildMentalHealth/ChildAutisticSpectrumDisorders/srs-2/social-responsiveness-scale-second-edition.aspx>
- Cox, N. J. (2008). Speaking Stata: Correlation with confidence, or Fisher's z revisited. In *Stata Journal* (Vol. 8, Issue 3, pp. 413–439). DPC Nederland.  
<https://doi.org/10.1177/1536867x0800800307>
- Danneel, S., Bijttebier, P., Bastin, M., Colpin, H., Van Den Noortgate, W., Karla, •, Leeuwen, V., Verschueren, K., & Goossens, • Luc. (2019). Loneliness, social anxiety, and depressive symptoms in adolescence: Examining their distinctiveness through factor analysis. *Journal of Child and Family Studies*, *28*, 1326–1336.  
<https://doi.org/10.1007/s10826-019-01354-3>
- \*De Gennaro, L. M. (2016). Loneliness in adolescents with high-functioning Autism Spectrum Disorder. [ProQuest Information & Learning]. In *Dissertation Abstracts International: Section B: The Sciences and Engineering* (Vol. 77).  
<http://ovidsp.ovid.com/ovidweb.cgi?T=JS&PAGE=reference&D=psyc13&NEWS=N&AN=2016-37853-094>
- De Jong-Gierveld, J., & Kamphuls, F. (1985). The development of a rasch-type loneliness scale. *Applied Psychological Measurement*, *9*(3), 289–299.  
<https://doi.org/10.1177/014662168500900307>
- \*Deckers, A., Muris, P., & Roelofs, J. (2017). Being on your own or feeling lonely? Loneliness and other social variables in youths with autism spectrum disorders. *Child Psychiatry and Human Development*, *48*(5), 828–839. <https://doi.org/10.1007/s10578-016-0707-7>

- Deckers, Anne, Muris, P., Roelofs, J., & Arntz, A. (2016). A group-administered social skills training for 8- to 12- year-old, high-functioning children with autism spectrum disorders: An evaluation of its effectiveness in a naturalistic outpatient treatment setting. *Journal of Autism and Developmental Disorders*, *46*(11), 3493–3504.  
<https://doi.org/10.1007/s10803-016-2887-1>
- Deckers, Anne, Roelofs, J., Muris, P., & Rinck, M. (2014). Desire for social interaction in children with autism spectrum disorders. *Research in Autism Spectrum Disorders*, *8*, 449–453. <https://doi.org/10.1016/j.rasd.2013.12.019>
- DiTommaso, E., & Spinner, B. (1997). Social and emotional loneliness: A reexamination of weiss' typology of loneliness. *Personality and Individual Differences*, *22*(3), 417–427.  
[https://doi.org/10.1016/S0191-8869\(96\)00204-8](https://doi.org/10.1016/S0191-8869(96)00204-8)
- Duval, S., & Tweedie, R. (2000). Trim and fill: A simple funnel-plot-based method of testing and adjusting for publication bias in meta-analysis. *Biometrics*, *56*(2), 455–463.  
<https://doi.org/10.1111/j.0006-341X.2000.00455.x>
- Egger, M., Smith, G. D., Schneider, M., & Minder, C. (1997). Bias in meta-analysis detected by a simple, graphical test. *British Medical Journal*, *315*(7109), 629–634.  
<https://doi.org/10.1136/bmj.315.7109.629>
- Ellis, P. D. (2010). *The Essential Guide to Effect Sizes*. Cambridge University Press.  
<https://doi.org/10.1017/CBO9780511761676>
- Erzen, E., & Çikrikci, Ö. (2018). The effect of loneliness on depression: A meta-analysis. In *International Journal of Social Psychiatry* (Vol. 64, Issue 5, pp. 427–435). SAGE Publications Ltd. <https://doi.org/10.1177/0020764018776349>
- Evans, B. (2013). How autism became autism: The radical transformation of a central concept of child development in Britain. In *History of the Human Sciences* (Vol. 26, Issue 3, pp. 3–31). SAGE Publications. <https://doi.org/10.1177/0952695113484320>
- Flett, G. L., Goldstein, A. L., Pechenkov, I. G., Nepon, T., & Wekerle, C. (2016). Antecedents, correlates, and consequences of feeling like you don't matter: Associations with maltreatment, loneliness, social anxiety, and the five-factor model.

*Personality and Individual Differences*, 92, 52–56.

<https://doi.org/10.1016/j.paid.2015.12.014>

Gillespie-Lynch, K., Kapp, S. K., Shane-Simpson, C., Smith, D. S., & Hutman, T. (2014).

Intersections Between the Autism Spectrum and the Internet: Perceived Benefits and Preferred Functions of Computer-Mediated Communication. *Intellectual and Developmental Disabilities*, 52(6), 456–469. <https://doi.org/10.1352/1934-9556-52.6.456>

Glod, M., Riby, D. M., Honey, E., & Rodgers, J. (2015). Psychological Correlates of Sensory Processing Patterns in Individuals with Autism Spectrum Disorder: A Systematic Review. *Review Journal of Autism and Developmental Disorders*, 2, 199–221.

<https://doi.org/10.1007/s40489-015-0047-8>

Gotham, K., Risi, S., Pickles, A., & Lord, C. (2006). The Autism Diagnostic Observation Schedule (ADOS). In *Journal of Autism and Developmental Disorders*. Springer Nature.

[https://www.research.manchester.ac.uk/portal/en/publications/the-autism-diagnostic-observation-schedule-ados\(31646979-0428-4614-b727-e0052e1497ed\)/export.html](https://www.research.manchester.ac.uk/portal/en/publications/the-autism-diagnostic-observation-schedule-ados(31646979-0428-4614-b727-e0052e1497ed)/export.html)

Grills, A. E., & Ollendick, T. H. (2003). Multiple informant agreement and the anxiety disorders interview schedule for parents and children. *Journal of the American Academy of Child and Adolescent Psychiatry*, 42(1), 30–40.

<https://doi.org/10.1097/00004583-200301000-00008>

\*Han, G. T., Tomarken, A. J., & Gotham, K. O. (2019). Social and nonsocial reward moderate the relation between autism symptoms and loneliness in adults with ASD, depression, and controls. *Autism Research*, 12(6), 884–896.

<https://doi.org/10.1002/aur.2088>

Hawkey, L. C., & Cacioppo, J. T. (2010). Loneliness matters: A theoretical and empirical review of consequences and mechanisms. *Annals of Behavioral Medicine*, 40(2), 218–227. <https://doi.org/10.1007/s12160-010-9210-8>

Hays, R. D., & Dimatteo, M. R. (1987). A short-form measure of loneliness. *Journal of Personality Assessment*, 51(1), 69–81. [https://doi.org/10.1207/s15327752jpa5101\\_6](https://doi.org/10.1207/s15327752jpa5101_6)



- \*Hedley, D., Uljarević, M., Foley, K.-R., Richdale, A., & Trollor, J. (2018). Risk and protective factors underlying depression and suicidal ideation in autism spectrum disorder. *Depression and Anxiety, 35*(7), 648–657. <https://doi.org/10.1002/da.22759>
- \*Hedley, D., Uljarević, M., Wilmot, M., Richdale, A., & Dissanayake, C. (2018). Understanding depression and thoughts of self-harm in autism: A potential mechanism involving loneliness. *Research in Autism Spectrum Disorders, 46*, 1–7. <https://doi.org/10.1016/j.rasd.2017.11.003>
- Heimberg, R. G., Horner, # K J, Juster, H. R., Safren, S. A., Brown, E. J., Schneier, F. R., & Liebowitz, □□□ M R. (1999). Psychometric properties of the Liebowitz Social Anxiety Scale. *Psychological Medicine, 29*, 199–212.
- Heinrich, L. M., & Gullone, E. (2006). The clinical significance of loneliness: A literature review. In *Clinical Psychology Review* (Vol. 26, Issue 6, pp. 695–718). Pergamon. <https://doi.org/10.1016/j.cpr.2006.04.002>
- Hickey, A., Crabtree, J., & Stott, J. (2018). ‘Suddenly the first fifty years of my life made sense’: Experiences of older people with autism. *Autism, 22*(3), 357–367. <https://doi.org/10.1177/1362361316680914>
- Higgins, J. P. T., Thompson, S. G., Deeks, J. J., & Altman, D. G. (2003). Measuring inconsistency in meta-analyses. In *British Medical Journal* (Vol. 327, Issue 7414, pp. 557–560). BMJ Publishing Group. <https://doi.org/10.1136/bmj.327.7414.557>
- Hoekstra, R. A., Vinkhuyzen, A. A. E., Wheelwright, S., Bartels, M., Boomsma, D. I., Baron-Cohen, S., Posthuma, D., & Van Der Sluis, S. (2011). The construction and validation of an abridged version of the autism-spectrum quotient (AQ-short). *Journal of Autism and Developmental Disorders, 41*(5), 589–596. <https://doi.org/10.1007/s10803-010-1073-0>
- Hollocks, M. J., Lerh, J. W., Magiati, I., Meiser-Stedman, R., & Brugha, T. S. (2019). Anxiety and depression in adults with autism spectrum disorder: A systematic review and meta-analysis. *Psychological Medicine, 49*(4), 559–572. <https://doi.org/10.1017/S0033291718002283>

- Howlin, P., Goode, S., Hutton, J., & Rutter, M. (2004). Adult outcome for children with autism. *Journal of Child Psychology and Psychiatry and Allied Disciplines*, 45(2), 212–229. <https://doi.org/10.1111/j.1469-7610.2004.00215.x>
- Hoza, B., Bukowski, W. M., & Beery, S. (2000). Assessing peer network and dyadic loneliness. *Journal of Clinical Child and Adolescent Psychology*, 29(1), 119–128. [https://doi.org/10.1207/S15374424jccp2901\\_12](https://doi.org/10.1207/S15374424jccp2901_12)
- Hudson, C. C., Hall, L., & Harkness, K. L. (2019). Prevalence of Depressive Disorders in Individuals with Autism Spectrum Disorder: a Meta-Analysis. *Journal of Abnormal Child Psychology*, 47(1), 165–175. <https://doi.org/10.1007/s10802-018-0402-1>
- Hughes, M. E., Waite, L. J., Hawkey, L. C., & Cacioppo, J. T. (2004). A short scale for measuring loneliness in large surveys: Results from two population-based studies. *Research on Aging*, 26(6), 655–672. <https://doi.org/10.1177/0164027504268574>
- Ioannidis, J. P. A. (2008). Why most discovered true associations are inflated. *Epidemiology*, 19(5), 640–648. <https://doi.org/10.1097/EDE.0b013e31818131e7>
- Israel, H., & Richter, R. R. (2011). A Guide to Understanding Meta-Analysis. *Journal of Orthopaedic & Sports Physical Therapy*, 49(7), 496–504. <https://doi.org/10.2519/jospt.2011.3333>
- \*Jackson, S. L. J., Hart, L., Brown, J. T., & Volkmar, F. R. (2018). Brief report: Self-reported academic, social, and mental health experiences of post-secondary students with autism spectrum disorder. *Journal of Autism and Developmental Disorders*, 48(3), 643–650. <https://doi.org/10.1007/s10803-017-3315-x>
- Jaswal, V. K., & Akhtar, N. (2018). Being vs. appearing socially uninterested: Challenging assumptions about social motivation in autism. *Behavioral and Brain Sciences*, 42, 1–84. <https://doi.org/10.1017/S0140525X18001826>
- Joshi, G., Wozniak, J., Petty, C., Martelon, M. K., Fried, R., Bolfek, A., Kotte, A., Stevens, J., Furtak, S. L., Bourgeois, M., Caruso, J., Caron, A., & Biederman, J. (2013). Psychiatric comorbidity and functioning in a clinically referred population of adults with autism spectrum disorders: A comparative study. *Journal of Autism and Developmental*

- Disorders*, 43(6), 1314–1325. <https://doi.org/10.1007/s10803-012-1679-5>
- \*Kalyva, E. (2010). Multirater congruence on the social skills assessment of children with asperger syndrome: Self, mother, father, and teacher ratings. *Journal of Autism and Developmental Disorders*, 40(10), 1202–1208. <https://doi.org/10.1007/s10803-010-0978-y>
- Kanner, L. (1943). Autistic disturbances of affective contact. *Nervous Child*, 2, 217–250. <https://psycnet.apa.org/record/1943-03624-001>
- Kasari, C., & Sterling, L. (2013). Loneliness and Social Isolation in Children with Autism Spectrum Disorders. In *The Handbook of Solitude* (pp. 409–426). Wiley. <https://doi.org/10.1002/9781118427378.ch23>
- Kaufman, A., & Kaufman, N. (2004). *Kaufman Brief Intelligence Test, Second Edition (KBIT-2)*. Pearson. [https://www.pearsonclinical.co.uk/Education/Assessments/GeneralAbility/KaufmanBriefIntelligenceTestSecondEdition\(KBIT-2\)/KaufmanBriefIntelligenceTestSecondEdition\(KBIT-2\).aspx](https://www.pearsonclinical.co.uk/Education/Assessments/GeneralAbility/KaufmanBriefIntelligenceTestSecondEdition(KBIT-2)/KaufmanBriefIntelligenceTestSecondEdition(KBIT-2).aspx)
- Kellogg, C., & Morton, N. (1999). *Revised Beta Examination (Beta III)*. The Psychological Corporation. <https://www.pearsonclinical.co.uk/Psychology/AdultCognitionNeuropsychologyandLanguage/AdultGeneralAbilities/BetaIII/BetaIII.aspx>
- Kenny, L., Hattersley, C., Molins, B., Buckley, C., Povey, C., & Pellicano, E. (2016). Which terms should be used to describe autism? Perspectives from the UK autism community. *Autism*, 20, 442–462. <https://doi.org/10.1177/1362361315588200>
- Kopp, S., & Gillberg, C. (2011). The Autism Spectrum Screening Questionnaire (ASSQ)-Revised Extended Version (ASSQ-REV): An instrument for better capturing the autism phenotype in girls? A preliminary study involving 191 clinical cases and community controls. *Research in Developmental Disabilities*, 32(6), 2875–2888. <https://doi.org/10.1016/j.ridd.2011.05.017>
- Kovacs, M. (1992). *Children's depression inventory manual*.

- Kroenke, K., Spitzer, R. L., & Williams, J. B. W. (2001). The PHQ-9: Validity of a brief depression severity measure. *Journal of General Internal Medicine*, *16*(9), 606–613.  
<https://doi.org/10.1046/j.1525-1497.2001.016009606.x>
- Kroenke, K., Spitzer, R. L., Williams, J. B. W., & Löwe, B. (2009). An ultra-brief screening scale for anxiety and depression: The PHQ-4. *Psychosomatics*, *50*(6), 613–621.  
<https://doi.org/10.1176/appi.psy.50.6.613>
- \*La Buissonniere Ariza, V., Schneider, S. C., Cepeda, S. L., Wood, J. J., Kendall, P. C., Small, B. J., Wood, K. S., Kerns, C., Saxena, K., & Storch, E. A. (2021). Predictors of suicidal thoughts in children with autism spectrum disorder and anxiety or obsessive-compulsive disorder: The unique contribution of externalizing behaviors. *Child Psychiatry and Human Development*, 1–14.  
<https://doi.org/https://dx.doi.org/10.1007/s10578-020-01114-1>
- La Greca, A. M., & Lopez, N. (1998). Social anxiety among adolescents: Linkages with peer relations and friendships. *Journal of Abnormal Child Psychology*, *26*(2), 83–94.  
<https://doi.org/10.1023/A:1022684520514>
- \*Lasgaard, M., Nielsen, A., Eriksen, M. E., & Goossens, L. (2010). Loneliness and social support in adolescent boys with autism spectrum disorders. *Journal of Autism and Developmental Disorders*, *40*(2), 218–226. <https://doi.org/10.1007/s10803-009-0851-z>
- Lasgaard, Mathias. (2007). Reliability and validity of the Danish version of the UCLA loneliness scale. *Personality and Individual Differences*, *42*(7), 1359–1366.  
<https://doi.org/10.1016/j.paid.2006.10.013>
- Leigh-Hunt, N., Bagguley, D., Bash, K., Turner, V., Turnbull, S., Valtorta, N., & Caan, W. (2017). An overview of systematic reviews on the public health consequences of social isolation and loneliness. In *Public Health* (Vol. 152, pp. 157–171). Elsevier B.V.  
<https://doi.org/10.1016/j.puhe.2017.07.035>
- Liberati, A., Altman, D. G., Tetzlaff, J., Mulrow, C., Gøtzsche, P. C., Ioannidis, J. P. A., Clarke, M., Devereaux, P. J., Kleijnen, J., & Moher, D. (2009). The PRISMA statement for reporting systematic reviews and meta-analyses of studies that evaluate healthcare

interventions: explanation and elaboration. *BMJ (Clinical Research Ed.)*, 339.

<https://doi.org/10.1136/BMJ.B2700>

- \*Lieb, R. W., & Bohnert, A. M. (2017). Relations between executive functions, social impairment, and friendship quality on adjustment among high functioning youth with autism spectrum disorder. *Journal of Autism and Developmental Disorders*, 47(9), 2861–2872. <https://doi.org/10.1007/s10803-017-3205-2>
- \*Lin, L.-Y., & Huang, P.-C. (2019). Quality of life and its related factors for adults with autism spectrum disorder. *Disability and Rehabilitation*, 41(8), 896–903. <https://doi.org/10.1080/09638288.2017.1414887>
- \*Locke, J., Ishijima, E. H., Kasari, C., & London, N. (2010). Loneliness, friendship quality and the social networks of adolescents with high-functioning autism in an inclusive school setting. *Journal of Research in Special Educational Needs*, 10(2), 74–81. <https://doi.org/10.1111/j.1471-3802.2010.01148.x>
- Loomes, R., Hull, L., & Mandy, W. P. L. (2017). What is the male-to-female ratio in autism spectrum disorder? A systematic review and meta-analysis. In *Journal of the American Academy of Child and Adolescent Psychiatry* (Vol. 56, Issue 6, pp. 466–474). Elsevier Inc. <https://doi.org/10.1016/j.jaac.2017.03.013>
- Lovibond, P. F., & Lovibond, S. H. (1995). The structure of negative emotional states: Comparison of the Depression Anxiety Stress Scales (DASS) with the Beck Depression and Anxiety Inventories. *Behaviour Research and Therapy*, 33, 335–343. [https://doi.org/10.1016/0005-7967\(94\)00075-U](https://doi.org/10.1016/0005-7967(94)00075-U)
- \*Maddox, B. B., Miyazaki, Y., & White, S. W. (2017). Long-term effects of CBT on social impairment in adolescents with ASD. *Journal of Autism and Developmental Disorders*, 47(12), 3872–3882. <https://doi.org/10.1007/s10803-016-2779-4>
- Maes, M., Qualter, P., Vanhalst, J., Van den Noortgate, W., & Goossens, L. (2019). Gender differences in loneliness across the lifespan: A meta-analysis. *European Journal of Personality*, 33(6), 642–654. <https://doi.org/10.1002/per.2220>
- Magnuson, K. M., & Constantino, J. N. (2011). Characterization of depression in children

with autism spectrum disorders. In *Journal of Developmental and Behavioral Pediatrics* (Vol. 32, Issue 4, pp. 332–340). Lippincott Williams and Wilkins.

<https://doi.org/10.1097/DBP.0b013e318213f56c>

\*Mahjouri, S. (2011). A cross-sectional analysis of social engagement, isolation and loneliness for children and adolescents with autism. [ProQuest Information & Learning]. In *ProQuest Dissertations and Theses* (Issue 11).

<https://search.proquest.com/dissertations-theses/cross-sectional-analysis-social-engagement/docview/1033014349/se-2?accountid=13828>

March, J. S., Parker, J. D., Sullivan, K., Stallings, P., & Conners, C. K. (1997). The multidimensional anxiety scale for children (MASC): Factor structure, reliability, and validity. *Journal of the American Academy of Child and Adolescent Psychiatry*, 36(4), 554–565. <https://doi.org/10.1097/00004583-199704000-00019>

Marcoen, A., Goossens, L., & Caes, P. (1987). Loneliness in pre-through late adolescence: Exploring the contributions of a multidimensional approach. *Journal of Youth and Adolescence*, 16(6), 561–577. <https://doi.org/10.1007/BF02138821>

Martín-María, N., Caballero, F. F., Miret, M., Tyrovolas, S., Haro, J. M., Ayuso-Mateos, J. L., & Chatterji, S. (2020). Differential impact of transient and chronic loneliness on health status. A longitudinal study. *Psychology and Health*, 35(2), 177–195. <https://doi.org/10.1080/08870446.2019.1632312>

Masi, C. M., Chen, H. Y., Hawkey, L. C., & Cacioppo, J. T. (2011). A meta-analysis of interventions to reduce loneliness. In *Personality and Social Psychology Review* (Vol. 15, Issue 3, pp. 219–266). SAGE PublicationsSage CA: Los Angeles, CA. <https://doi.org/10.1177/1088868310377394>

Matson, J. L., Rotatori, A. F., & Helsel, W. J. (1983). Development of a rating scale to measure social skills in children: The matson evaluation of social skills with youngsters (MESSY). *Behaviour Research and Therapy*, 21(4), 335–340. [https://doi.org/10.1016/0005-7967\(83\)90001-3](https://doi.org/10.1016/0005-7967(83)90001-3)

Matthews, T., Danese, A., Wertz, J., Odgers, C. L., Ambler, A., Moffitt, T. E., & Arseneault,

- L. (2016). Social isolation, loneliness and depression in young adulthood: a behavioural genetic analysis. *Social Psychiatry and Psychiatric Epidemiology*, 51(3), 339–348.  
<https://doi.org/10.1007/s00127-016-1178-7>
- \*Mazurek, M. O. (2014). Loneliness, friendship, and well-being in adults with autism spectrum disorders. *Autism*, 18(3), 223–232.  
<https://doi.org/10.1177/1362361312474121>
- \*Merkler, E. E. (2007). The experience of isolation and loneliness in young adults with high-functioning autism. *Dissertation Abstracts International: Section B: The Sciences and Engineering*, 68(3-B), 1936.  
<http://ovidsp.ovid.com/ovidweb.cgi?T=JS&PAGE=reference&D=psyc5&NEWS=N&AN=2007-99018-265>
- Milton, D., & Sims, T. (2016). How is a sense of well-being and belonging constructed in the accounts of autistic adults? *Disability & Society*, 31, 520–534.  
<https://doi.org/10.1080/09687599.2016.1186529>
- Moretta, T., & Buodo, G. (2020). Problematic Internet Use and Loneliness: How Complex Is the Relationship? A Short Literature Review. *Current Addiction Reports*, 7(2), 125–136. <https://doi.org/10.1007/S40429-020-00305-Z>
- National Academy of Sciences. (2015). *Prevalence of autism spectrum disorder: Mental disorders and disabilities among low-income children*.  
<https://www.ncbi.nlm.nih.gov/books/NBK332896/>
- National Autistic Society. (2018, April 25). *Hidden Crisis: Autism and Loneliness*.  
<https://www.autism.org.uk/get-involved/media-centre/news/2018-04-25-hidden-crisis-autism-and-loneliness.aspx>
- NHS Centre for Reviews and Dissemination. (2009). *Systematic reviews : CRD's guidance for undertaking reviews in health care*. NHS Centre for Reviews and Dissemination.
- \*Nomura, K., Beppu, S., & Tsujii, M. (2012). Loneliness in children with high functioning pervasive developmental disorders. *Japanese Journal of Special Education*, 49(6), 645–656. <https://doi.org/http://dx.doi.org/10.6033/tokkyou.49.645>

- Nuyen, J., Tuithof, M., de Graaf, R., van Dorsselaer, S., Kleinjan, M., & Have, M. ten. (2020). The bidirectional relationship between loneliness and common mental disorders in adults: findings from a longitudinal population-based cohort study. *Social Psychiatry and Psychiatric Epidemiology*, 55(10), 1297–1310. <https://doi.org/10.1007/s00127-019-01778-8>
- Office for National Statistics. (2018, December 5). *Recommended national indicators of loneliness*. <https://www.ons.gov.uk/peoplepopulationandcommunity/wellbeing/compendium/nationalmeasurementofloneliness/2018/recommendednationalindicatorsof Loneliness>
- Offord, D. R., & Kraemer, H. C. (2000). Risk factors and prevention. *Evidence-Based Mental Health*, 3, 70–71. <https://doi.org/10.1136/ebmh.3.3.70>
- Orsmond, G. I., Krauss, M. W., & Seltzer, M. M. (2004). Peer relationships and social and recreational activities among adolescents and adults with autism. In *Journal of Autism and Developmental Disorders* (Vol. 34, Issue 3, pp. 245–256). J Autism Dev Disord. <https://doi.org/10.1023/B:JADD.0000029547.96610.df>
- Pak, E. P. (2019). Self-Perceptions of Friendship Quality and Loneliness Predicting Social Adaptivity of Children with HFASD [University of California, Los Angeles]. In *ProQuest Dissertations and Theses*. <https://search.proquest.com/dissertations-theses/self-perceptions-friendship-quality-loneliness/docview/2301477854/se-2?accountid=13828>
- Pallathra, A. A., Cordero, L., Wong, K., & Brodtkin, E. S. (2019). Psychosocial Interventions Targeting Social Functioning in Adults on the Autism Spectrum: a Literature Review. *Current Psychiatry Reports*, 21(5), 1–11. <https://doi.org/10.1007/s11920-019-0989-0>
- Park, S., & Beretvas, S. N. (2019). Synthesizing effects for multiple outcomes per study using robust variance estimation versus the three-level model. *Behavior Research Methods*, 51(1), 152–171. <https://doi.org/10.3758/s13428-018-1156-y>
- Peplau, L., & Perlman, D. (1982). *Loneliness: a sourcebook of current theory, research, and therapy*. (L. Peplau & D. Perlman (eds.)). Wiley. <https://trove.nla.gov.au/work/14222510>
- Poquérousse, J., Pastore, L., Dellantonio, S., & Esposito, G. (2018). Alexithymia and autism



- spectrum disorder: A complex relationship. *Frontiers in Psychology*, 9.  
<https://doi.org/10.3389/fpsyg.2018.01196>
- Radloff, L. S. (1977). The CES-D scale: A self-report depression scale for research in the general population. *Applied Psychological Measurement*, 1(3), 385–401.  
<https://doi.org/10.1177/014662167700100306>
- Richardson, T., Elliott, P., & Roberts, R. (2017). Relationship between loneliness and mental health in students. *Journal of Public Mental Health*, 16(2), 48–54.  
<https://doi.org/10.1108/JPMH-03-2016-0013>
- Rodgers, J., Farquhar, K., Mason, D., Brice, S., Wigham, S., Ingham, B., Freeston, M., & Parr, J. R. (2020). Development and initial evaluation of the anxiety scale for autism-adults. *Autism in Adulthood*, 2(1), 24–33. <https://doi.org/10.1089/aut.2019.0044>
- Rosen, T. E., Mazefsky, C. A., Vasa, R. A., & Lerner, M. D. (2018). Co-occurring psychiatric conditions in autism spectrum disorder. In *International Review of Psychiatry* (Vol. 30, Issue 1, pp. 40–61). Taylor and Francis Ltd.  
<https://doi.org/10.1080/09540261.2018.1450229>
- Rosenthal, R. (1979). The file drawer problem and tolerance for null results. *Psychological Bulletin*, 86(3), 638–641. <https://doi.org/10.1037/0033-2909.86.3.638>
- Rubio-Aparicio, M., Sánchez-Meca, J., López-López, J. A., Botella, J., & Marín-Martínez, F. (2017). Analysis of categorical moderators in mixed-effects meta-analysis: Consequences of using pooled versus separate estimates of the residual between-studies variances. *British Journal of Mathematical and Statistical Psychology*, 70(3), 439–456. <https://doi.org/10.1111/bmsp.12092>
- Russell, D. W. (1996). UCLA Loneliness Scale (Version 3): Reliability, validity, and factor structure. *Journal of Personality Assessment*, 66(1), 20–40.  
[https://doi.org/10.1207/s15327752jpa6601\\_2](https://doi.org/10.1207/s15327752jpa6601_2)
- Rutter, M., LeCouteur, A., & Lord, A. (2008). *Autism Diagnostic Interview – Revised (ADI-R)*. Western Psychological Services. <https://www.carautismroadmap.org/individual-test-summaries-and-review-autism-diagnostic-interview-revised-adi-r/>

- \*Schiltz, H. K., McVey, A. J., Dolan Wozniak, B., Haendel, A. D., Stanley, R., Arias, A., Gordon, N., & Van Hecke, A. V. (2020). The role of loneliness as a mediator between autism features and mental health among autistic young adults. *Autism*, *25*(2), 545–555. <https://doi.org/10.1177/1362361320967789>
- Schopler, E., Van Bourgondien, M., Wellman, G., & Love, S. (2010). *Childhood Autism Rating Scale - Second Edition (CARS-2)*. Western Psychological Services. [https://www.pearsonclinical.co.uk/Psychology/ChildMentalHealth/ChildAutisticSpectrumDisorders/ChildhoodAutismRatingScale-SecondEdition\(CARS2\)/ChildhoodAutismRatingScale-SecondEdition\(CARS2\).aspx](https://www.pearsonclinical.co.uk/Psychology/ChildMentalHealth/ChildAutisticSpectrumDisorders/ChildhoodAutismRatingScale-SecondEdition(CARS2)/ChildhoodAutismRatingScale-SecondEdition(CARS2).aspx)
- Schroeder, J. H., Cappadocia, M. C., Bebko, J. M., Pepler, D. J., & Weiss, J. A. (2014). Shedding light on a pervasive problem: A review of research on bullying experiences among children with autism spectrum disorders. *Journal of Autism and Developmental Disorders*, *44*(7), 1520–1534. <https://doi.org/10.1007/s10803-013-2011-8>
- Schuck, P. (2004). Assessing reproducibility for interval data in health-related quality of life questionnaires: Which coefficient should be used? *Quality of Life Research*, *13*(3), 571–585. <https://doi.org/10.1023/B:QURE.0000021318.92272.2a>
- Scott, F. J., Baron-Cohen, S., Bolton, P., & Brayne, C. (2002). The CAST (childhood asperger syndrome test): Preliminary development of a UK screen for mainstream primary-school-age children. *Autism*, *6*(1), 9–31. <https://doi.org/10.1177/1362361302006001003>
- Sedgewick, F., Hill, V., Yates, R., Pickering, L., & Pellicano, E. (2016). Gender differences in the social motivation and friendship experiences of autistic and non-autistic adolescents. *Journal of Autism and Developmental Disorders*, *46*(4), 1297–1306. <https://doi.org/10.1007/s10803-015-2669-1>
- Sedgewick, F., Leppanen, J., & Tchanturia, K. (2020). Gender differences in mental health prevalence in autism. *Advances in Autism*. <https://doi.org/10.1108/AIA-01-2020-0007>
- Shattuck, P. T., Orsmond, G. I., Wagner, M., & Cooper, B. P. (2011). Participation in social activities among adolescents with an autism spectrum disorder. *PLoS ONE*, *6*(11),

e27176. <https://doi.org/10.1371/journal.pone.0027176>

Shiovitz-Ezra, S., & Ayalon, L. (2010). Situational versus chronic loneliness as risk factors for all-cause mortality. *International Psychogeriatrics*, 22(3), 455–462.

<https://doi.org/10.1017/S1041610209991426>

Silverman, W. K., & Albano, A. M. (1996). *The anxiety disorders interview schedule for children and parents- DSM-IV version*. . Graywind.

[https://www.scirp.org/\(S\(351jmbntvnsjt1aadkposzje\)\)/reference/ReferencesPapers.aspx?ReferenceID=720677](https://www.scirp.org/(S(351jmbntvnsjt1aadkposzje))/reference/ReferencesPapers.aspx?ReferenceID=720677)

Spain, D., & Blainey, S. H. (2015). Group social skills interventions for adults with high-functioning autism spectrum disorders: A systematic review. *Autism*, 19(7), 874–886.

<https://doi.org/http://dx.doi.org/10.1177/1362361315587659>

Spain, D., Sin, J., Linder, K. B., McMahon, J., & Happé, F. (2018). Social anxiety in autism spectrum disorder: A systematic review. *Research in Autism Spectrum Disorders*, 52, 51–68.

<https://doi.org/10.1016/J.RASD.2018.04.007>

Spitzer, R. L., Kroenke, K., & Williams, J. B. W. (1999). Validation and utility of a self-report version of PRIME-MD: The PHQ primary care study. *Journal of the American Medical Association*, 282(18), 1737–1744.

<https://doi.org/10.1001/jama.282.18.1737>

Sterne, J. A. C., & Egger, M. (2005). Regression Methods to Detect Publication and Other Bias in Meta-Analysis. In *Publication Bias in Meta-Analysis: Prevention, Assessment and Adjustments* (pp. 99–110). John Wiley & Sons, Ltd.

<https://doi.org/10.1002/0470870168.ch6>

\*Sundberg, M. (2018). Online gaming, loneliness and friendships among adolescents and adults with ASD. *Computers in Human Behavior*, 79, 105–110.

<https://doi.org/10.1016/j.chb.2017.10.020>

\*Syu, Y.-C., & Lin, L.-Y. (2018). Sensory Overresponsivity, Loneliness, and Anxiety in Taiwanese Adults with Autism Spectrum Disorder. *Occupational Therapy International*, 1–7.

<https://doi.org/10.1155/2018/9165978>

Teoh, S. L., Letchumanan, V., & Lee, L. H. (2021). Can mindfulness help to alleviate

- loneliness? A systematic review and meta-analysis. In *Frontiers in Psychology* (Vol. 12, p. 402). Frontiers Media S.A. <https://doi.org/10.3389/fpsyg.2021.633319>
- The Research Units on Pediatric Psychopharmacology Anxiety Study Group. (2002). The pediatric anxiety rating scale (PARS): Development and psychometric properties. *Journal of the American Academy of Child and Adolescent Psychiatry*, 41(9), 1061–1069. <https://doi.org/10.1097/00004583-200209000-00006>
- Thomas, B. H., Ciliska, D., Dobbins, M., & Micucci, S. (2004). A Process for Systematically Reviewing the Literature: Providing the Research Evidence for Public Health Nursing Interventions. *Worldviews on Evidence-Based Nursing*, 1, 176–184. <https://doi.org/10.1111/j.1524-475X.2004.04006.x>
- Thurm, A., Farmer, C., Salzman, E., Lord, C., & Bishop, S. (2019). State of the field: Differentiating intellectual disability from autism spectrum disorder. In *Frontiers in Psychiatry* (Vol. 10). Frontiers Media S.A. <https://doi.org/10.3389/fpsyg.2019.00526>
- Thurston, R. C., & Kubzansky, L. D. (2009). Women, loneliness, and incident coronary heart disease. *Psychosomatic Medicine*, 71(8), 836–842. <https://doi.org/10.1097/PSY.0b013e3181b40efc>
- Tiwari, S. C. (2013). Loneliness: A disease? In *Indian Journal of Psychiatry* (Vol. 55, Issue 4, pp. 320–322). Wolters Kluwer -- Medknow Publications. <https://doi.org/10.4103/0019-5545.120536>
- Vandenbroucke, J. P., von Elm, E., Altman, D. G., Gøtzsche, P. C., Mulrow, C. D., & Pocock, S. J. (2007). Strengthening the Reporting of Observational Studies in Epidemiology (STROBE): Explanation and Elaboration. *PLoS Medicine*, 4(10), 805–835. <https://doi.org/10.1371/journal.pmed.0040297>
- Vasa, R. A., & Mazurek, M. O. (2015). An update on anxiety in youth with autism spectrum disorders. In *Current Opinion in Psychiatry* (Vol. 28, Issue 2, pp. 83–90). Lippincott Williams and Wilkins. <https://doi.org/10.1097/YCO.0000000000000133>
- Victor, C. R., & Yang, K. (2012). The prevalence of loneliness among adults: A case study of the United Kingdom. *Journal of Psychology: Interdisciplinary and Applied*, 146(1–2),

85–104. <https://doi.org/10.1080/00223980.2011.613875>

Volkmar, F., Chawarska, K., & Klin, A. (2005). Autism in infancy and early childhood. *Annual Review of Psychology*, *56*, 315–336.

<https://doi.org/10.1146/annurev.psych.56.091103.070159>

Vorst, H. C. M., & Bermond, B. (2001). Validity and reliability of the Bermond-Vorst alexithymia questionnaire. *Personality and Individual Differences*, *30*(3), 413–434.

[https://doi.org/10.1016/S0191-8869\(00\)00033-7](https://doi.org/10.1016/S0191-8869(00)00033-7)

Wang, J., Mann, F., Lloyd-Evans, B., Ma, R., & Johnson, S. (2018). Associations between loneliness and perceived social support and outcomes of mental health problems: A systematic review. *BMC Psychiatry*, *18*(1), 1–16. <https://doi.org/10.1186/s12888-018-1736-5>

Ward, A., Arola, N., Bohnert, A., & Lieb, R. (2017). Social-emotional adjustment and pet ownership among adolescents with autism spectrum disorder. *Journal of Communication Disorders*, *65*, 35–42. <https://doi.org/10.1016/j.jcomdis.2017.01.002>

<https://doi.org/10.1016/j.jcomdis.2017.01.002>

Wechsler, D. (2008). Wechsler Intelligence Scale for Children, Fourth Edition (WISC-IV). In *Pearson*. Springer US. <https://doi.org/10.1007/978-0-387-79061-9>

Wechsler, D. (2011). Wechsler Adult Intelligence Scale - Fourth Edition (WAIS-IV). In *Pearson*.

[https://www.pearsonclinical.co.uk/Psychology/AdultCognitionNeuropsychologyandLanguage/AdultGeneralAbilities/WechslerAdultIntelligenceScale-FourthUKEdition\(WAIS-IVUK\)/WechslerAdultIntelligenceScale-FourthUKEdition\(WAIS-IVUK\).aspx](https://www.pearsonclinical.co.uk/Psychology/AdultCognitionNeuropsychologyandLanguage/AdultGeneralAbilities/WechslerAdultIntelligenceScale-FourthUKEdition(WAIS-IVUK)/WechslerAdultIntelligenceScale-FourthUKEdition(WAIS-IVUK).aspx)

Weiss, R. S. (1973). *Loneliness: The experience of emotional and social isolation*. The MIT Press. <https://psycnet.apa.org/record/1974-22306-000>

\*Wendler, D. (2019). Improv theater as a social cognition intervention for autism.

*Dissertation Abstracts International: Section B: The Sciences and Engineering*, *80*.

<http://ovidsp.ovid.com/ovidweb.cgi?T=JS&PAGE=reference&D=psyc16&NEWS=N&AN=2019-41141-135>

\*White, S. W., & Roberson-Nay, R. (2009). Anxiety, social deficits, and loneliness in youth

- with autism spectrum disorders. *Journal of Autism and Developmental Disorders*, 39(7), 1006–1013. <https://doi.org/10.1007/s10803-009-0713-8>
- \*Whitehouse, A. J. O., Durkin, K., Jaquet, E., & Ziatas, K. (2009). Friendship, loneliness and depression in adolescents with Asperger's Syndrome. *Journal of Adolescence*, 32(2), 309–322. <https://doi.org/10.1016/j.adolescence.2008.03.004>
- Wigham, S., Barton, S., Parr, J. R., & Rodgers, J. (2017). A systematic review of the rates of depression in children and adults with high-functioning autism spectrum disorder. *Journal of Mental Health Research in Intellectual Disabilities*, 10(4), 267–287. <https://doi.org/10.1080/19315864.2017.1299267>
- \*Wood, H. (2014). Social anxiety and self-perceptions of social performance in adolescents and young adults with high functioning autism spectrum disorders [University of Bath (United Kingdom)]. In *PQDT - UK & Ireland*. <https://search.proquest.com/dissertations-theses/doctorate-clinical-psychology-main-research/docview/1784057225/se-2?accountid=13828>
- \*Wright, M. F. (2017). Parental mediation, cyber victimization, adjustment difficulties, and adolescents with autism spectrum disorder. *Cyberpsychology*, 11(1), 1–12. <https://doi.org/10.5817/CP2017-1-6>
- \*Yeung, A. W. (2009). The perception of friendships for children with Asperger's disorder and its relationship with loneliness and depression. *Dissertation Abstracts International: Section B: The Sciences and Engineering*, 70(6-B). <http://ovidsp.ovid.com/ovidweb.cgi?T=JS&PAGE=reference&D=psyc6&NEWS=N&AN=2009-99240-417>

## Appendices

### Appendix A

*Prospero Protocol Accepted on 09.09.2020*

#### Citation

Rebecca Hymas, Elizabeth Milne, Johanna Badcock. Loneliness and its association with anxiety and depression in autistic people: a systematic review. PROSPERO 2020 CRD42020205493 Available from:

[https://www.crd.york.ac.uk/prospero/display\\_record.php?ID=CRD42020205493](https://www.crd.york.ac.uk/prospero/display_record.php?ID=CRD42020205493)

#### Review question

How common is loneliness amongst autistic people, as compared to neurotypical people?

Is there an association between loneliness and depression and/or anxiety among autistic people? If so, is there any evidence for mediators or moderators of this association?

What is the current quality of evidence in answering these questions?

If a meta-analysis is undertaken, the following research questions shall be addressed:

What is the combined size of effect in the difference between rates of loneliness among autistic people, in comparison to neurotypical people?

What is the strength of the association between specific measures of anxiety and/or depression and loneliness in autistic people?

#### Searches

Published and unpublished literature will be examined through searching of reference lists of relevant articles or reviews; hand-searching of relevant journals, and an author search on known authors who have conducted research on the review topic. The following databases will be searched: Scopus; PsycINFO; MEDLINE (via Ovid); PQDT Global. No date restrictions will be applied to the search.

Eligible studies will be identified using combinations of search terms relating to Autism, loneliness, depression and anxiety. An example of the key search terms is provided below. These will be expanded using relevant MeSH terms and mapping to subject headings in each database.

Lonel\* OR "Social\* isolat\*" AND Autis\* OR ASD OR ASC OR Asperger\* OR "pervasive development\* disorder\*" OR PDD

For the search on mental health, an additional search strategy will include the following search terms:

[Search terms as above] AND Depression/Anxiety: Depress\*OR "low mood" OR "negative affect" OR

"affective disorder\*" OR "mood disorder" OR "dysthymi\*" OR anxi\*

### Types of study to be included

It is expected that most included studies will have used observational designs. Qualitative studies, case study or case-series designs will be excluded from this review.

### Condition or domain being studied

DSM-5 (APA, 2013) states that ASD is a neurodevelopmental disorder, characterised by persistent deficits in social communication and interaction, and a restricted and repetitive pattern of behaviour, interests or activities present from childhood. People with a confirmed or self-reported diagnosis of Autism Spectrum Disorder (ASD) according to DSM or ICD criteria will be included.

Studies measuring subjective loneliness (as measured by specified loneliness measures) will be included. For the purposes of the review, loneliness will be defined as a subjective discrepancy between one's desired and achieved levels (including the number and/or quality) of social relationships (Peplau & Perlman, 1982). Studies of social isolation or social network size will not be included, unless measures used reflect the aforementioned loneliness definition. If data allow, the influence of the type of loneliness measure used on the outcomes of interest will be examined.

Anxiety and depression refer to psychological constructs of internal states. Studies reporting anxiety and depression as diagnoses or as self-reported symptom severity questionnaire scores will be included.

### Participants/population

People who have been diagnosed with Autism Spectrum Disorder, including Asperger's and Pervasive Developmental Disorder made according to DSM or ICD criteria using a 'gold standard' diagnostic tool (i.e., an ADOS or ADI-R) or people who have self-reported a diagnosis of ASD, established through meeting a predefined clinical cut-off on a validated instrument such as the Broad Autism Phenotype Questionnaire (Hurley et al., 2007) . No age restriction will be applied. Where the process for diagnosis is ambiguous, an inclusive approach will be taken and considered when appraising study quality. If data allow, the impact of ASD diagnostic tools on prevalence estimate will be explored in a sensitivity analysis.

Studies including participants with co-occurring intellectual disability (ID; indicated by an IQ of less than 70 and deficits in adaptive functioning) will be included. If data allow, the impact of differences with regards to ID diagnosis will be explored due to



the potentially different experience of mental health and loneliness within this population, compared to autistic people without ID (Matson & Shoemaker, 2009).

### Intervention(s), exposure(s)

For the first review question, studies will be included which:

Measure loneliness using a validated measure and report the percentage of participants meeting a pre-defined cut-off score or average score obtained by an Autistic sample, in comparison to a neurotypical sample(s).

Studies reporting an intervention (e.g., aimed at reducing loneliness) will only be included if they provide a baseline score of loneliness prior to intervention. If available, scores will be used from a control group rather than the intervention group.

With regards to the second review question, studies will be included which:

Measure symptoms of loneliness, depression and/or anxiety using a validated measure.

Use a correlational design (e.g., correlation, regression, mediation or moderation) to measure and report the association between depression and/or anxiety with loneliness.

Additional criteria for meta-analysis:

Prevalence review: studies must report an appropriate effect size of prevalence of loneliness (above a specified cut-off) or report the difference in average loneliness scores between an ASD sample and comparison control sample.

Anxiety/Depression review: reported an appropriate effect size for anxiety/depression correlates associated with loneliness, and corresponding 95% confidence intervals.

If an effect size is not reported or calculatable, study authors will be contacted to provide this.

### Comparator(s)/control

For the first review question:

People without ASD

For the second review question, no comparison or control group is required.

### Context

Studies recruiting participants from clinical or non-clinical settings will be eligible for inclusion. Studies will be excluded if they report only mean loneliness scores for a group of people, but with no control group provided or where no dichotomous distinction is made within groups (i.e., lonely vs not lonely).

### Main outcome(s)

Primary outcomes for review question 1:

% of loneliness above a specified cut-off among people with ASD or the average score obtained by people with ASD in comparison to a non-ASD control group.

Primary outcomes for review question 2:

The identification of anxiety and depression constructs and the effect sizes for their correlation with loneliness.

Secondary outcomes:

What is the quality of the evidence in studies reporting the prevalence of loneliness in people with ASD, in comparison to NT controls.

What is the quality of the evidence in studies reporting associations between loneliness and depression/anxiety in people with ASD.

### Measures of effect

It is anticipated that group differences in loneliness prevalence will be reported as percentages or cohen's d and correlation coefficients will be recorded as r. Other effect measures may be reported in studies included in this review.

### Additional outcome(s)

None

### Data extraction (selection and coding)

For transparency, two searches will be conducted to enable PRISMA flow-charts to detail the exact numbers of retrieved articles using the aforementioned search terms relevant to the two review questions. This provides information on the number of identified, excluded and included studies, as well as explanations for exclusions.

For each search, study titles and abstracts will be screened for relevance, and full copies of manuscripts for studies likely to meet selection criteria will be obtained and reviewed to identify any available sister papers. Final included studies will be reviewed independently by the main reviewer, with a subset (20%) reviewed by a second reviewer. Disagreements will be resolved through consensus or a third independent reviewer.

Data to be extracted:

For articles remaining after full-text screening, extraction will be done through copying and pasting relevant information onto an excel spreadsheet to minimise the risk of errors occurring. The data extraction tool will initially be piloted on a subset of studies and amended as required. It will include study details, sample characteristics, measurement tools (including loneliness measure used and threshold criterion used, if any), and results.

Authors will be contacted in studies where usable but unpublished data is thought to exist.

### Risk of bias (quality) assessment

The quality and risk of bias for each study will be determined through the use of two quality appraisal tools adapted for use in this review. The EPHPP Quality Assessment Tool for Quantitative Studies (Thomas et al.,

2004) will be used to appraise studies on the basis of selection bias, potential confounders, data collection/analysis methods and withdrawal and dropout rates. Due to the nature of this review only appraising observational or pre-intervention data, some categories may be removed from the EPHPP or studies will be rated as 'Not Applicable' in relation to them.

Questions will also be included from the quality evaluation grid developed by Glod et al., (2015). These include whether the study was sufficiently powered, if ASD diagnosis (and subtype) was confirmed for the study, whether cognitive functioning was assessed or reported, and whether the measures used were appropriate and validated for ASD populations.

In line with the EPHPP tool, criteria will be rated as: Strong, Moderate, Weak or Not Applicable. The overall quality of the studies will consist of a rating of 'Strong' if no weak ratings are reported, 'Moderate' if one weak rating is reported, and 'Weak' if two or more weak ratings are reported.

### Strategy for data synthesis

For the first review question, it is expected that a meta-analysis will be conducted. Quantitative data will be synthesized using meta-analysis software such as Meta Essentials or Comprehensive Meta-Analysis (CMA). Meta-analysis results will be assessed visually through Forrest Plots. If 10 or more studies are included in the review, a funnel plot will be used to determine the relationship between study size and effect power of studies. Heterogeneity will be assessed using the Q-statistics and  $I^2$  statistic.

For the second review question, studies will be combined based on the psychological construct that they measure i.e., anxiety or depression. A table will be used to summarise findings, demonstrating the overall quality of evidence from included studies, and pooled estimates of effect. The strengths and weaknesses of the evidence will be reported, and the relationships between the studies, including discrepancies, will be discussed.

### Analysis of subgroups or subsets

If appropriate data are obtained, data on gender (i.e., male and female) and age (i.e., adults and children) will be entered as variables in any meta-analyses and in the narrative write-up due to the potential differences in experiences of mental health and loneliness at different developmental stages/ages as well as in males and females. Adults will be defined as being aged 18 years or older. For studies to be included in the 'child' category, average age of the sample must be less than 18 years old, and similarly for the 'adult' category, average sample age must be over 18.

### Contact details for further information

Rebecca Hymas

rhymas1@sheffield.ac.uk

#### Organisational affiliation of the review

The University of Sheffield

#### Review team members and their organisational affiliations

Miss Rebecca Hymas. The University of Sheffield

Professor Elizabeth Milne. The University of Sheffield

Professor Johanna Badcock. The University of Western Australia

#### Type and method of review

Prospective meta-analysis (PMA), Systematic review

#### Anticipated or actual start date

31 May 2020

#### Anticipated completion date

31 May 2021

#### Funding sources/sponsors

None

#### Conflicts of interest

#### Language

English

#### Country

England

#### Stage of review

Review Ongoing

#### Subject index terms status

Subject indexing assigned by CRD

#### Subject index terms

Anxiety; Anxiety Disorders; Autistic Disorder; Depression; Humans; Loneliness

#### Date of registration in PROSPERO

09 September 2020

#### Date of first submission

21 August 2020

Stage of review at time of this submission

<b>Stage</b>	<b>Started</b>	<b>Completed</b>
Preliminary searches	Yes	No
Piloting of the study selection process	No	No
Formal screening of search results against eligibility criteria	No	No
Data extraction	No	No
Risk of bias (quality) assessment	No	No
Data analysis	No	No

## Appendix B

**Table B1**

*Calculating Overall Ratings of Component Ratings*

Component	Rating		
	Weak	Moderate	Strong
<b>A) Selection Bias</b>	The selected individuals are not likely to be representative of the target population (Q1 is 3); <b>or</b> there is less than 60% participation (Q2 is 3) <b>or</b> selection is not described (Q1 is 4); and the level of participation is not described (Q2 is 5).	The selected individuals are at least somewhat likely to be representative of the target population (Q1 is 1 or 2); <b>and</b> there is 60 - 79% participation (Q2 is 2). 'Moderate' may also be assigned if Q1 is 1 or 2 and Q2 is 5 (can't tell).	The selected individuals are very likely to be representative of the target population (Q1 is 1) <b>and</b> there is greater than 80% participation (Q2 is 1).
<b>B) Study Design</b>	Will be assigned to those that used any other method or did not state the method used.	Will be assigned to those that described a cohort analytic study, a case control study, a cohort design, or an interrupted time series.	Will be assigned to those articles that described RCTs and CCTs.
<b>C) Confounders</b>	Will be assigned when less than 60% of relevant confounders were controlled (Q1 is 1) <b>and</b> (Q2 is 3) <b>or</b> control of confounders was not described (Q1 is 3) <b>and</b> (Q2 is 4).	Will be given to those studies that controlled for 60 – 79% of relevant confounders (Q1 is 1) <b>and</b> (Q2 is 2).	Will be assigned to those articles that controlled for at least 80% of relevant confounders (Q1 is 2); <b>or</b> (Q2 is 1).
<b>D) Data Collection</b>	The data collection tools have not been shown to be valid (Q1 is 3) <b>or</b> both reliability and validity are not described (Q1 is 4 and Q2 is 3).	The data collection tools have been shown to be valid in NT sample (Q1 is 1 or 2); <b>and</b> the data collection tools have not been shown to be reliable (Q2 is 2) <b>or</b> reliability is not described (Q2 is 3).	The data collection tools have been shown to be valid in ASD sample and NT sample (Q1 is 1); <b>and</b> the data collection tools have been shown to be reliable (Q2 is 1).
<b>E) Attrition</b>	Will be assigned when a completion rate is less than 60% (Q2 is 3) or if the	Will be assigned when the completion rate is 60 – 79% (Q2 is 2) <b>OR</b> Q2 is 5	will be assigned when the completion rate is 80% or greater (Q2 is 1).

	withdrawals and drop-outs were not described (Q2 is 4).	(N/A).	
<b>F) ASD Diagnosis</b>	Will be assigned if ASD diagnoses have not been confirmed for this study or diagnoses were self-reported only or confirmed for the study but article does not provide detail on how.	Will be assigned when diagnoses have been confirmed for this study via self-report or other report and a screening tool has been used (e.g., AQ, SRS), but diagnosis not been confirmed by use of a gold-standard tool.	Will be assigned when diagnoses have been confirmed for this study by use of a 'gold-standard' diagnostic tool (i.e. ADOS or ADI-R).
<b>G) Cognitive Functioning</b>	Will be assigned if level of cognitive functioning is not reported.	Level of cognitive functioning is reported but is based on previous (non-recent) assessment or on method other than standardised instrument (e.g. position in school system) or cognitive function was assessed but very broadly reported (e.g. 'all participants had FSIQs over 75 as assessed by....' or 'MA less than 6 months').	Level of cognitive functioning is reported and based on assessment using a standardised instrument and was assessed either for the study or within the preceding 3 months.

## Appendix C

**Table C1**

*Agreement between Raters for the Quality Appraisal Domains*

Domain	% Agreement	Weighted Kappa	SE	CI	Rating
Global	75	0.70	0.17	0.29-0.97	Good
Selection Bias	83.3	0.46	0.32	-0.20-1.00	Fair
Confounders	87.5	0.67	0.24	0.28-1.00	Good
Data Collection	83.3	0.60	0.24	0.12-1.00	Fair
Attrition	91.67	0.90	0.15	0.56-1.00	Very Good
ASD Diagnosis	75	0.62	0.19	0.19-0.94	Good
Cognitive Functioning	75	0.58	0.23	0.08-0.99	Fair

Note. SE=Standard Error; CI=Confidence Interval. Kappa values could not be calculated for study design, however there was high agreement between raters across studies (91.67%). The Byrt (1996) criteria were used to interpret the weighted kappa values as follows: none <0.01, poor=0.01-0.20; slight=0.21-0.40; fair=0.41-0.60; good=0.61-0.80; very good=0.81-0.92; and excellent=0.93-1.00. The weighted kappa allows consideration of the closeness of agreement between raters (i.e., a disagreement of 'strong' vs 'moderate' is closer than 'strong' vs 'weak') and may not correspond to the % of exact agreement.



## Appendix D

### Quality Appraisal Tables

**Table D1**

*Quality Appraisal Ratings across Studies Measuring Loneliness Rates between ASD and NT Samples*

Study	Component Rating Quality							Global Quality Rating
	Management of Selection Bias	Study Design	Control of Confounders	Data Collection	Management of Attrition	ASD Diagnosis Confirmation	Cognitive Functioning Assessment	
Bauminger and Kasari (2000)	Moderate	Moderate	Strong	Moderate	Weak	Strong	Strong	Moderate
Bauminger et al. (2003)	Moderate	Moderate	Strong	Strong	Weak	Strong	Moderate	Moderate
Bossaert et al. (2012)	Moderate	Moderate	Strong	Moderate	Weak	Weak	Weak	Weak
Bottema-Beutel et al. (2019)	Moderate	Moderate	Moderate	Moderate	Strong	Moderate	Strong	Strong
Brooks (2014)	Moderate	Moderate	Strong	Moderate	Weak	Strong	Strong	Moderate
Chamberlain et al. (2007)	Moderate	Moderate	Moderate	Moderate	Weak	Moderate	Moderate	Moderate
Chang et al. (2019)	Moderate	Moderate	Strong	Moderate	Weak	Moderate	Moderate	Moderate
Chiang (2003)	Moderate	Moderate	Moderate	Moderate	Weak	Weak	Moderate	Weak
De Gennaro (2016)	Moderate	Moderate	Moderate	Moderate	Strong	Moderate	Weak	Moderate
Deckers et al. (2017)	Weak	Moderate	Weak	Moderate	Moderate	Moderate	Weak	Weak
Han et al. (2019)	Moderate	Moderate	Strong	Moderate	Weak	Strong	Moderate	Moderate
Kalyva (2010)	Moderate	Moderate	Strong	Moderate	Strong	Moderate	Strong	Strong

Lasgaard et al. (2010)	Weak	Moderate	Moderate	Moderate	Moderate	Moderate	Weak	Weak
Lin and Huang (2019)	Moderate	Moderate	Moderate	Moderate	Weak	Moderate	Moderate	Moderate
Locke et al. (2010)	Moderate	Moderate	Weak	Moderate	Weak	Moderate	Weak	Weak
Merkler (2007)	Moderate	Moderate	Moderate	Moderate	Weak	Weak	Strong	Weak
Nomura et al., (2012)	Moderate	Moderate	Weak	Weak	Weak	Weak	Moderate	Weak
Sundberg (2018)	Moderate	Moderate	Weak	Moderate	Weak	Weak	Weak	Weak
Whitehouse et al. (2009)	Moderate	Moderate	Moderate	Moderate	Strong	Moderate	Weak	Moderate
Yeung (2009)	Moderate	Moderate	Moderate	Moderate	Weak	Weak	Weak	Weak

**Table D2***Quality Appraisal Ratings across Studies Measuring Loneliness and Anxiety/Depression*

Study	Component Rating Quality						Global Quality Rating
	Management of Selection Bias	Study Design	Data Collection	Management of Attrition	ASD Diagnosis Confirmation	Cognitive Functioning Assessment	
Chang et al. (2019)	Moderate	Moderate	Moderate	Weak	Moderate	Moderate	Moderate
Deckers et al. (2017)	Weak	Moderate	Moderate	Moderate	Moderate	Weak	Weak
Han et al. (2019)	Moderate	Moderate	Moderate	Weak	Strong	Moderate	Moderate
Hedley , Uljarević, Foley, et al. (2018)	Moderate	Moderate	Moderate	Strong	Moderate	Weak	Moderate
Hedley, Uljarević, Wilmot, et al. (2018)	Moderate	Moderate	Moderate	Strong	Moderate	Weak	Moderate
Jackson et al. (2018)	Moderate	Moderate	Moderate	Weak	Moderate	Moderate	Moderate
La Buissonniere Ariza et al. (2021)	Weak	Moderate	Moderate	Strong	Strong	Strong	Moderate
Lieb and Bohnert (2017)	Moderate	Moderate	Moderate	Weak	Moderate	Moderate	Moderate
Maddox et al. (2017)	Weak	Strong	Strong	Strong	Strong	Strong	Moderate
Mahjouri (2011)	Moderate	Moderate	Moderate	Moderate	Strong	Strong	Strong
Mazurek (2014)	Moderate	Moderate	Moderate	Weak	Moderate	Weak	Weak
Schiltz et al. (2020)	Moderate	Strong	Moderate	Weak	Strong	Strong	Moderate
Syu and Lin (2018)	Moderate	Moderate	Moderate	Weak	Moderate	Moderate	Moderate
Wendler (2019)	Moderate	Moderate	Moderate	Moderate	Moderate	Weak	Moderate
White and Roberson-Nay (2009)	Moderate	Moderate	Moderate	Weak	Strong	Moderate	Moderate

Wood (2014)	Moderate	Moderate	Moderate	Strong	Weak	Weak	Weak
Wright (2017)	Moderate	Moderate	Moderate	Strong	Weak	Weak	Moderate
Yeung (2009)	Moderate	Moderate	Moderate	Weak	Weak	Weak	Weak

## **Section 2: Empirical Study**

### **Social identity and mental health in autistic adults: An exploratory study**

## Abstract

**Objectives:** Social identity can be defined as our felt belongingness to groups. In the general population, social identity with multiple groups has been associated with better mental health. This study aimed to establish whether social identification with groups differs between autistic and neurotypical adults and whether it predicts mental health in both samples.

**Design:** A quantitative, cross-sectional design was employed.

**Methods:** Autistic (N=199) and neurotypical (N=174) adults completed an online survey including questions related to demographics, group memberships, social identification and mental health (anxiety, depression and stress). Hierarchical multiple regression was used to establish whether associations exist between social identity (i.e., number of important groups and number of positive groups) and mental health for both samples, controlling for relevant confounders (including loneliness, self-esteem, and Covid-19 variables). Due to multicollinearity, only the 'number of positive groups' was used to represent social identification in regression analyses.

**Results:** Autistic individuals reported belonging to fewer overall groups, fewer important groups and fewer positive groups, compared with neurotypical individuals. In neurotypical individuals, having a fewer number of positive groups explained unique variance in anxiety (although not depression or stress), after controlling for confounding variables. This was partially mediated by self-esteem. No variance in anxiety, depression or stress was explained by social identification in the autistic sample.

**Conclusions:** In contrast to the general population, social identification may not be an important predictor of wellbeing in autistic adults. These findings should be interpreted with caution and should not preclude future research into social identity in autism.

### **Practitioner Points**

- Autistic adults report being members of fewer overall groups, fewer positive groups and fewer important groups in comparison to neurotypical adults.
- Promoting the number of groups one feels positive about belonging to may improve self-esteem and reduce anxiety within neurotypical populations, however longitudinal research is required to establish the causal direction and mechanisms of these associations.
- Further research should explore the meaning of social identity for autistic individuals and establish whether alternative conceptualisations or measures of social identity are more relevant to the mental health of autistic populations, compared with those currently used in neurotypical populations.

*Key Words:* Autism, Social Identity, Multiple-Group Membership, Anxiety, Depression, Stress

## Introduction

### Social Identity

The capacity to develop enduring and meaningful social connections is an essential part of the human experience (Herrmann et al., 2007). Indeed, a person's sense of who they are is, in part, determined through the group memberships they ascribe themselves (Tajfel, 1974). A group can be defined as two or more individuals who are connected to one another by and within social relationships (Forsyth & Burnette, 2010). Research suggests that being a member of multiple social groups contributes to greater physical and mental wellbeing compared with having fewer or no group memberships; this is known as the 'Social Cure Effect' (Jetten et al., 2014). Moreover, there appears to be an additive effect, with greater ascribed numbers of social groups conferring greater mental wellbeing (Iyer et al., 2009).

The beneficial effects of multiple-group memberships, however, may be contingent on factors beyond just their number (Sønderlund et al., 2017). For example, the emotional significance attached to social groups likely influences the extent to which beneficial psychological outcomes can be attained (Roccas & Brewer, 2002). This is known as *social identity*; whereby a social group is internalised as a salient part of one's self-concept (Tajfel & Turner, 1979). There has been debate about how best to theoretically describe and empirically measure social identity (Postmes et al., 2013), however it is commonly defined as a multidimensional concept, incorporating cognitive (knowledge of group-membership), emotional (perceived importance of group-membership) and evaluative (perceived valence of group-membership) components (Jackson, 2002).

When a person ascribes themselves as belonging to a particular group, a process of social categorisation, identification and comparison occurs. When one can relate to the self as being interchangeable with other members of the groups to which they belong, a process of self-categorisation occurs (Turner & Oakes, 1986). Such processes aid 'ingroup/outgroup' mentality; the tendency to exaggerate the similarities between 'ingroup' members and inflate the differences of 'outgroup' members (Stets & Burke, 2000). Favourable intergroup



comparisons are understood to maintain or augment one's self-esteem and self-concept (Abdelal et al., 2009).

### **Social Identity and Mental health**

Research has evidenced associations between social identity and mental health. Higher social identification with valued group(s) predicts fewer depression symptoms, which has been consistently evidenced in numerous social groups and across diverse populations (Cruwys et al., 2014). Meuret and colleagues (2016) showed beneficial effects of a cognitive therapy group targeting social anxiety by significantly increasing feelings of identification with other 'social anxiety sufferers'. Haslam and colleagues (2016) delivered an intervention strengthening social group relationships in socially isolated and distressed adults. The program increased participants' identification with salient groups, which subsequently influenced significant short and long-term improvements in symptoms of depression, anxiety, stress, and loneliness.

Evidently, the number of group memberships and one's social identification with groups can have implications for mental health. Existing research combining both number *and* social identification with groups (i.e., number of social identities) suggests that having a greater number of social identities protects against depression and relapse during stressful circumstances (Cruwys et al., 2013). However, most research to date has focused on social identification with only one group membership e.g., one's family (Sani et al., 2012) or ethnic group (Schmitt et al., 2003) which are groups chosen by the researcher. Asking people to rate predetermined memberships could increase the salience and reported identification to such groups (Haslam et al., 1999), thus biasing responses. Measures that allow for the spontaneous self-generation of one's multiple-group memberships reduces potential priming effects. One study that has explored self-generated multiple-group memberships in relation to mental wellbeing found that the number of groups, number of important groups and number of groups one felt positive about belonging to were significantly associated with life

satisfaction, and important groups was additionally associated with less depression and anxiety (Cruwys et al., 2016).

The mechanisms through which multiple social identities influence mental wellbeing are likely to be multi-dimensional. A sense of self which is invested in several social-groups may buffer against the negative impact of loss or change, as people have more sources of support to draw upon (Haslam et al., 2008). It has also been theorised that self-esteem and loneliness may mediate the association between social identity and enhanced wellbeing (Cruwys et al., 2015; Jetten et al., 2015; McIntyre et al., 2018).

### **Autism and Social Identity**

Autism Spectrum Disorder (ASD) is a life-long neurodevelopmental condition characterised by pervasive socio-communicative and interaction difficulties, and restricted and/or repetitive behaviours or interests (American Psychiatric Association; 2013). Autistic<sup>1</sup> individuals are disproportionately affected by mental health difficulties, compared to neurotypical individuals (Croen et al., 2015). The reasons for this are not well understood, and research within this domain has largely focused on identifying neuropharmacological incongruities (Chrobak & Soltys, 2017). However, research has begun to focus on the psychosocial consequences of autism, something which has been deemed a research priority by the UK autism community (Pellicano et al., 2014).

To date, no research has explored the potential influence of multiple-group memberships or social identities on the mental health of autistic individuals, however some research has been conducted on dyadic friendships and perceived belongingness in general, or with regards to a specific group membership. For example, it has been shown that the number (although not quality) of friendships predicted self-esteem, depression and anxiety (Mazurek, 2014) and that there is a negative relationship between perceived group membership and depression symptoms in autistic samples (Hedley & Young, 2006).

---

<sup>1</sup> A large UK study by Kenny et al. (2016) found the term 'Autistic Adults' is preferred by the UK autistic community.

Furthermore, identifying with an autism identity has been shown to protect against anxiety and depression symptoms in a model which was fully mediated by personal and collective self-esteem (Cooper et al., 2017). However, autism identity is only one social identity that can be assimilated into an autistic adult's self-concept. What is still unknown are the multiple social identities that autistic people experience and whether this relates to their mental health.

Autistic individuals may experience the same social curative effect of belonging to multiple-social groups as neurotypical populations (Jetten et al., 2014). Conversely, being a member of, and identifying with multiple groups may be more difficult for autistic adults due to inherent socio-communicative difficulties and reciprocal social misinterpretation by neurotypical peers, which may increase their susceptibility to social adversity (Spain et al., 2018). Evidence for autistic individuals facing more barriers to forming and maintaining social relationships is elucidated by the extent to which they feel they need to employ techniques to mask their difficulties in social situations and 'fit-in' with the non-autistic world (Hull et al., 2017). This may lessen their ability to gauge their social group belongingness and derive psychosocial benefit from such groups (Milton & Sims, 2016). Indeed, autistic adults have been shown to experience lower felt positivity and identification with their gender groups compared to neurotypical adults (Cooper et al., 2018).

### **Clinical Implications**

Given the potential causal influence of social identity on mental wellbeing and the disproportionate prevalence of mental health difficulties in autistic adults, understanding social identity in autism and the relationship between social identities and mental health in this population is an important avenue of research. Within the context of mental health provision, exploring autistic adults' perception of their own social identities may allow both clinicians and autistic individuals greater insight into autistic individuals' social identities. On an individual level, this may enable more ownership being taken over social identity dynamics which can be drawn on therapeutically (Haslam et al., 2016). At a service-level,

given that social identity is deemed to be changeable and thus potentially targetable (Cruwys et al., 2014), interventions could be developed to increase social identities in autistic adults.

### **Current Study**

The primary aim of this exploratory study was to establish whether social identification with groups differs between autistic and neurotypical people and whether multiple-group membership and social identification to such groups predicts mental well-being. Given no research has explored multiple-group memberships or social identities in an autistic population, it is unknown whether the current ways of measuring this concept are suitable for an autistic population. Self-report questionnaires designed for neurotypical populations can often be demanding for autistic individuals who may have difficulty identifying and describing their feelings (Poquérusse et al., 2018). Pilot stages were therefore planned to enable autistic people to feedback on the concepts and wording of items to help inform the development of a larger scale survey. Social identity measures were developed based on the methodology of Cruwys et al. (2016).

Two research questions were addressed by the larger survey: 1) Is there a difference between self-reported number of groups, social identification with groups (i.e., number of important groups and number of groups felt to be positive to belong to- herein labelled as 'number of positive groups') in an autistic sample compared with a neurotypical sample? 2) Is there an association between number of groups, social identification with groups and mental wellbeing in the ASD sample? If so, do social identity measures explain unique variance in mental health (as measured by the Depression, Anxiety and Stress Scale 21-item version: DASS-21; Lovibond & Lovibond, 1995) when controlling for relevant demographic, Covid-19 and social-emotional variables. In an attempt to replicate previous work (Cruwys et al., 2016), this research question was also addressed in the NT sample.

It was hypothesised that:

1. The autistic sample would report membership of fewer groups, fewer important groups and fewer positive groups than the neurotypical sample.
2. The autistic sample would score higher on overall DASS-21 scores (and DASS-21 depression, anxiety, and stress scale scores) than the neurotypical sample.
3. The neurotypical sample would demonstrate negative associations between the number of groups, number of important groups and number of positive groups and the DASS-21 depression, anxiety and stress scale scores, after controlling for relevant confounding variables.

As this was the first time associations between social identity and mental health have been explored in autism, no specific hypotheses were generated for the ASD sample regarding this.

## **Method**

### **Design**

This exploratory cross-sectional study examined the relationship between multiple-group membership (number of groups), social identity (number of important groups and number of positive groups) and mental wellbeing (depression, anxiety and stress), and explored whether there were differences in these associations between autistic and neurotypical samples. The main online study was informed by pilot stages with autistic people, in line with an exploratory sequential design (Meissner et al., 2011). This study commenced in June 2019; several changes to the study design were necessary due to Covid-19 (See Appendix A). Variables found to relate to wellbeing in prior research were also measured to control for potential confounding i.e., demographic, Covid-19 and socio-emotional variables such as loneliness and self-esteem (Cooper et al., 2017; Thoits, 2013; Wang et al., 2018).

### **Procedure**

This study's topic area was discussed with approximately seven autistic service-users during a Clinical Group Meeting organised by Sheffield Adult Autism and

Neurodevelopmental Service. Feedback on the proposed research area was mixed; some service-users understood the concept and listed which groups they would ascribe themselves; however other service users did not appear to understand the notion of social identities and their connectedness with multiple social-groups. It was clear from this meeting that an initial part of the study to discuss the concepts would be an important first step in this field.

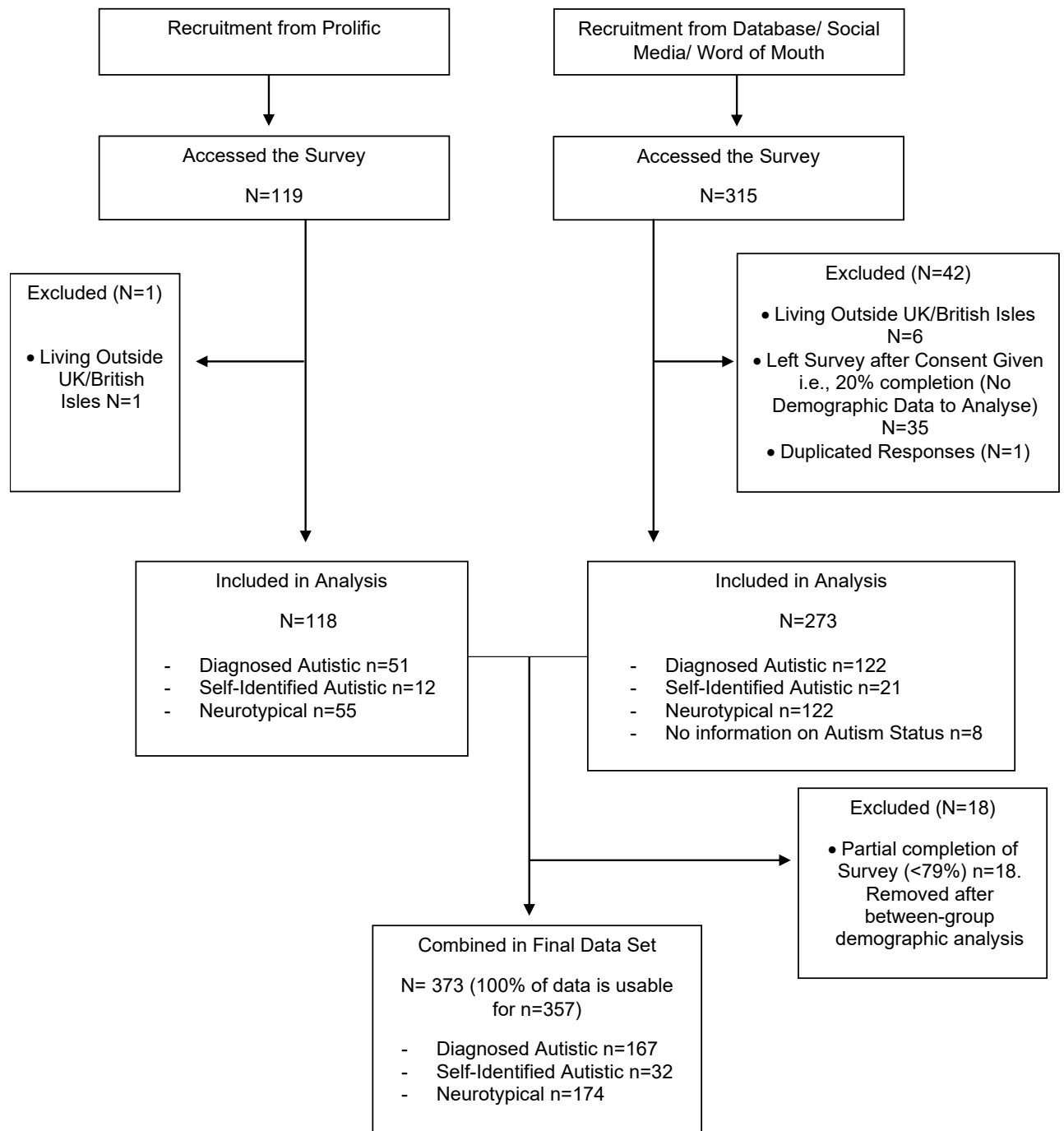
### ***Pilot Stage***

Ten autistic research volunteers from the Sheffield Autism Research Lab (ShARL) database were invited to give feedback (via telephone or email correspondence) on the study. Five people agreed to participate in the first pilot stage, which aimed to establish whether the concept of social identity was understandable and to see if the questions used to assess this required any amendments or clarification. Three people participated in the second pilot stage, which aimed to establish how the full online survey was experienced. Brief scripts were developed to guide questioning (Appendix B). Detailed notes on participant feedback were made and stored in line with university data protection policies. Several amendments were made to the wording and structure of the survey following piloting, as detailed in Appendix C.

### ***Online Survey***

Recruitment of participants for the online survey was delayed due to the changes that were required in response to Covid-19. Therefore, multiple recruitment channels were employed to optimise recruitment, including: an online paid participant recruitment platform *Prolific*; social media (including Facebook and Twitter); ShARL database; and UK autism support groups. An invitation email was sent to ShARL volunteers (Appendix D) and a poster aided advertisement through social media (Appendix E). Participants could choose to provide their email address to be entered into a prize draw to win one of two £25 Amazon vouchers. The online survey was hosted by Qualtrics. Participants recruited via *Prolific* were directed to the same survey, without the option to be entered into the prize draw, as they

were paid at a rate of £5 per hour, with an average completion time of 15-25 minutes, thus participants were typically paid <£2.50. The information, consent and debrief forms for each stage of the study are given in Appendices F-H. Figure 1 outlines the recruitment process.

**Figure 1***Participant Recruitment Flowchart***Participants**

To be eligible to participate, participants had to be aged  $\geq 18$  years and living in the UK or British Isles. Participants comprising the autistic sample had to identify as having a diagnosis of autism (i.e., ASD, Asperger's, Pervasive Developmental Disorder-Not



Otherwise Specified). Exclusion criteria included participants self-reporting a diagnosed learning disability.

### **Ethical Considerations**

Ethical approval was gained from the University of Sheffield research ethics committee prior to the commencement of this research (Appendix I). Participants were informed that the study would ask about personal social relationships and mental health, which may be especially distressing at a time of increased social isolation due to the impact of social restrictions. Participants were informed of their right to stop the survey at any time and were provided with the researcher's email contact. As part of the debrief procedure, participants were signposted to relevant support networks and websites (general and autism-specific) detailing guidance around coping with the uncertainty of Covid-19.

### **Measures**

See Appendices J-N for questionnaire measures, including demographics.

#### ***Demographics***

Participants were asked to provide information on sex at birth, gender identification, age, ethnicity, comorbid diagnoses, educational attainment, employment status, marital status and age at which ASD diagnosis was given (if applicable).

#### ***Autism Traits***

The 14-item Ritvo Autism Asperger Diagnostic Scale (RAADS-14; Eriksson et al., 2013) is an abridged version of the RAADS-Revised (Ritvo et al., 2011). It is a self-report instrument measuring autism traits, designed for adults with at least average intelligence. The psychometric properties of RAADS-14 have been shown to be satisfactory i.e., excellent internal consistency ( $\alpha=0.9$ ) and moderate-excellent validity for criteria, convergence and discriminatory power (a cut-off of  $\geq 14$  reached a sensitivity of 97% and a specificity between 46-64%) (Eriksson et al., 2013). This measure was used to provide descriptive information

about the sample rather than to support inclusion/exclusion criteria given its lack of diagnostic power.

### ***Social Identification with Groups***

This was measured through asking questions and using instructions/examples based on previous measures of social identification of multiple groups by Cruwys and colleagues (2016) which have demonstrated good internal consistency and good convergent and discriminant validity compared with other group identification measures (Haslam et al., 2008). The items of interest in this study were: number of groups participants felt they belonged to, number of groups participants felt were important to them and number of groups participants felt positive about belonging to. These were measured on a scale (1-10, where 1=not at all important/positive and 10=very important/positive). In line with Cruwys et al. (2016), groups were categorised as 'important' and 'positive' if participants rated a group as 8, 9 or 10 out of 10.

### ***Mental Health***

The Depression, Anxiety and Stress scale, 21-item version (DASS-21; Lovibond & Lovibond, 1995) is a self-report questionnaire measuring depression, anxiety and stress using a 4-point Likert scale to rate frequency and severity of emotional states within the past week. Scores were doubled to enable comparison with the original DASS measure. This measure shows good convergent and discriminant validity in line with the full version (DASS-Anxiety and HADS-Anxiety ( $r=0.66$ ), DASS-Depression and HADS-Depression ( $r=0.75$ ), DASS-Stress scale and the HADS scales ( $r=0.58$  and  $0.60$ ); Nieuwenhuijsen et al., 2003), and good reliability ( $\alpha= .88$  for the Depression scale,  $\alpha=.82$  for the Anxiety scale,  $\alpha=.90$  for the Stress scale, and  $\alpha=.93$  for the total scale; Henry & Crawford, 2005). It has also been validated for use in autistic samples (Park et al., 2020).

### ***Self-Esteem***

The Single-Item Self-Esteem Scale (SISE; Robins et al, 2001) is based on the Rosenberg-Self Esteem Scale (RSE; Rosenberg, 1965). This measure demonstrates high

validity and reliability (concurrent correlations between the SISE and the RSE had a median of .75; the mean reliability estimate for the SISE was also .75; Robins et al., 2001) and measures the following statement: "I have high self-esteem" on a 5-point Likert scale from 'Not very true of me' to 'Very true of me'.

### ***Loneliness***

The University of California, Los Angeles (UCLA; Hughes et al., 2004) three-item scale indirectly captures subjective feelings of loneliness. Scores range from 3-9, with higher scores indicating more frequent loneliness. This scale demonstrates adequate internal reliability ( $\alpha=.72$ ) and good convergent and discriminant validity in line with other loneliness measures i.e., the Revised-UCLA ( $r=.82$ ; Hughes et al., 2004).

### ***Covid-19 Variables***

This study was conducted during a pandemic which resulted in a UK-wide lockdown commencing on March 26<sup>th</sup> 2020. It is acknowledged that this likely impacted on the responses to survey questions relating to group-memberships, social identity, and mental health. A national UK longitudinal probability survey of adult mental health (assessed using the General Health Questionnaire-12) showed an increase in clinically significant mental distress from 18.9% in 2018-19 to 27.3% in April 2020. These increases were greatest for younger participants (18-34 year-olds), women, and people living with children (Pierce et al., 2020). Other factors associated with increased psychiatric disorders directly or indirectly resulting from Covid-19 include having- or previously having- Covid-19-related symptoms (Li & Wang, 2020), being worried about- or clinically vulnerable to- contracting Covid-19, perceived loneliness (Jia et al., 2020), and employment changes (Chandola et al., 2020). Questions relating to covid-19 symptoms/vulnerability, living situation, presence of children in the home and employment status changes were therefore included in the present study, to control for their potential effect during analyses.

The Work and Social Adjustment Scale (WASA; Mundt et al., 2002) was used to assess the degree of functional impairment participants felt resulted from the changes that

occurred due to Covid-19. It appraises five areas of life (work, home, social leisure, private leisure, and relationships) on a 0-8 scale, where 0 indicates no impairment and 8 indicates very severe impairment. This scale demonstrates good internal reliability ( $\alpha=.70-.94$ ) and retest reliability ( $\alpha=.73$ ), and adequate convergent and discriminant validity ( $r=.61-.76$ ), when correlated with the Yale-Brown Obsessive Compulsive Scale (Goodman et al., 1989) and the Hamilton Rating Scale for Depression (Hamilton, 1960; as cited in Mundt et al., 2002).

### **Analytic Approach**

The pilot stage was an information-gathering exercise; therefore, a sample size calculation was not required. In line with sample sizes for exploratory research (Braun & Clarke, 2006), it was estimated that 6-10 participants would enable a reasonable breadth of opinion on the study concepts and overall survey experience.

Survey data were analysed using the Statistical Package for the Social Sciences (SPSS, Version 26). Descriptive analyses were completed for demographic and outcome variables (means, ranges and standard deviations were calculated for continuous data; percentages were calculated for demographic data). To examine between-group differences for variables consisting of two categories or where data could be collapsed into two categories and where assumptions were met (i.e., expected cell frequencies exceeded five), chi-square tests for association were conducted. To assess for significant differences between mean scores on continuous data, Mann Whitney U tests were performed. Cronbach's alpha was reported to establish the internal consistency of the continuous scale questionnaire responses. Correlational and hierarchical multiple regression analyses were used to establish whether associations exist between the independent variables and the dependent variable for both samples, controlling for relevant confounders. Effect sizes for Spearman's Rho ( $r_s$ ), Chi-Square (Phi;  $\phi$ ) or Mann Whitney U (Cohen's  $d$ ) calculations were interpreted as: .10-.29=weak, .30-.49=moderate and  $\geq .50$ =strong (Cohen, 1992).

### **Power Calculations**

As this research is novel, it was not possible to predict what the effect sizes were likely to be. However, research on the relationship between multiple-group membership and depression have indicated a medium effect size in neurotypical participants ( $r=-0.32, p=0.005$ ; Chang et al., 2016). Furthermore, an evaluation across 20 studies looking at the effect size ( $r$ ) between various measures of wellbeing (including depression, anxiety and life satisfaction) and multiple-group memberships found this ranged from  $r=0.08-0.48$  with a pooled small-medium effect size of  $r=0.25$ , 95% CI [0.194, 0.302],  $Z = 8.67, p < 0.001$  (Chang et al., 2016). If we expect to see a medium effect within an autistic population, then 107 autistic participants would be required to detect a significance at  $p=.05$  with .80 power (Cohen, 1992), using a correlation or regression with up to eight independent variables. It was expected that some demographic, Covid-19 and socio-emotional variables may need to be controlled for in analyses. A total sample size of 214 (107 per group) would also account for between-group mean comparisons assuming a medium effect size, (with .80 power when  $p=.05$ ), whereby 64 participants (per group) is recommended (Cohen, 1992). A minimum sample size of 214 is also commensurate with the recommendation of 10-15 participants per variable when conducting multiple regression analysis (Field, 2017).

## **Results**

### **Data Screening**

Following exclusion of ineligible participant data, all data points ( $n=391$ ) were checked for missing, impossible, or outlying values. Participants' data were excluded from analyses if they failed to provide data on the number of- or social identification with- group memberships (i.e., completing <79% of items within the questionnaire;  $n=18$ ). These participants were compared to participants retained in the dataset ( $n=373$ ) for any significant demographic differences. Only age was deemed significant, with those removed from the dataset being significantly older, on average, than those remaining in the dataset ( $U=2337.50, z=-2.18, p<0.05$ ). No errors in the data were found, therefore outliers were

assumed to reflect participants' true scores and remained in the dataset. All but one of the continuous variables were deemed to significantly differ from a normal distribution as measured by the Kolmogorov-Smirnov and Shapiro-Wilk statistics (See Appendix O). These results were supported by visual inspection of histograms, Q-Q plots and Skewness and Kurtosis values. Parametric assumptions of normality were therefore violated and subsequent analyses on continuous variables were conducted through non-parametric tests.

Data from participants who self-identified as Autistic (n=32) were combined with those who reported an official diagnosis of ASD (n=167) due to the absence of any statistical differences between these groups on any variables of interest (see Appendix P).

### **Demographics**

The final sample size was N=373 adults (199 ASD and 174 NT). Sample demographics are detailed in Table 1. The majority of both samples reported their sex at birth as female and their ethnicity as White and were, on average, aged 33-35. The ASD sample received their diagnosis or self-identified as autistic aged 29.5 years, on average.

Where postcode data were provided by participants (ASD: N=176; NT: N=157), this was used as a proxy for socioeconomic status following conversion into an Index of Multiple Deprivation (IMD) decile score (1-10) which indicates level of deprivation from most to least deprived (Office for National Statistics, 2019). The majority of participants from both samples were from England (NT=86.2%, ASD=92%).

**Table 1***Sample Demographics*

	ASD <sup>2</sup> Participants (n=199)		NT Participants (n=174)		Differences Between Groups	
	N	%	N	%		
<b>Sex</b>						
Male	81	40.7	39	22.4	$\chi^2(1)=14.77,$ $p<.001, \phi=0.2$	
Female	116	58.3	135	77.6		
Prefer not to Answer	2	1	-	-		
<b>Gender</b>						
Male	75	37.7	39	22.4	N/A	
Female	98	49.2	134	77.0		
Transgender Male	2	1	-	-		
Gender Variant/ Non- Conforming	13	6.5	1	0.6		
Other	11	5.5	-	-		
<b>Ethnicity</b>						
White					N/A	
English/Welsh/Scottish/ Northern Irish	174	87.4	149	85.6		
White Irish	2	1	2	1.1		
Black African	-	-	1	0.6		
Black Caribbean	-	-	2	1.1		
Black British	-	-	2	1.1		
Mixed White and Black Caribbean	5	2.5	2	1.1		
Mixed White and Black African	2	1	-	-		
White and Asian	2	1	3	1.7		
Asian Indian	-	-	1	0.6		
Asian Pakistani	1	0.5	2	1.1		
Asian Bangladeshi	1	0.5	1	0.6		
Asian Chinese	-	-	1	0.6		
Other	12	6.0	8	4.6		
Has one or more additional Psychiatric, Physical or Neurodevelopmental Conditions	136	68.3	44	25.3		$\chi^2(1)=68.92,$ $p<.001, \phi=0.43$
<b>Highest Education Level</b>						
University (Undergraduate or Postgraduate Degree)	117	58.8	123	70.7		$\chi^2(1)=5.73, p=.02,$ $\phi=0.1$
Sixth Form College, Secondary School or less.	82	41.2	51	29.3		

<sup>2</sup> Of those who reported their preferred reference to their diagnosis, the majority of diagnosed participants stated 'ASD' (43%). Those who self-identified reported a preference for referring to this as 'Autism' (32%) or 'ASD' (27%). In this thesis, the autistic group will therefore be referred to as the 'ASD' sample and the neurotypical group will be referred to as the 'NT' sample.

<b>Current Employment Status</b>					
Employed (Part or Full-time)	103	51.8	134	77.0	$\chi^2(1)=25.56$ , $p<.001$ , $\phi=0.26$
Unemployed, Student or Unable to Work	96	48.2	40	23	
<b>Change in Employment since Lockdown</b>					
No change in Employment Status or gained employment	185	93	165	94.8	NS
Was Employed but now Unemployed	14	7	9	5.2	
Living Alone	49	24.6	25	14.4	$\chi^2(1)=6.14$ , $p=.01$ , $\phi=0.13$
Living with Children (<18 years)	35	17.6	41	23.6	NS
Had Covid-19 or Symptoms	30	15.1	20	11.5	NS
In Medium/High Covid-19 Risk Category	50	25.1	23	13.2	$\chi^2(1)=8.36$ , $p=.004$ , $\phi=0.15$
	M (R)	SD	M(R)	SD	
Age	35.85 (18-69)	13.23	33.0 (18-69)	11.67	NS
IMD	5.09 (1-10)	2.98	6.23 (1-10)	2.67	$U=10766.5$ , $z=-3.50$ , $p<.001$ , $d=.40$
Age of Autism Diagnosis	29.50 (3-64)	14.98	-	-	-
RAADS-14	30.87 (0-42)	8.38	8.55 (0-40)	9.42	$U=2090$ , $z=-14.69$ , $p<.001$ , $d=2.33$
WASA Total Score	18.46 (2-40)	8.39	18.18 (3-40)	7.30	NS

Note. M=Mean, R=Range, SD=Standard Deviation, NS=Non-Significant. NA=Not Applicable due to violated assumptions.  $\phi$ =Phi and  $d$ =Cohen's  $d$  whereby 0.1=small; 0.3=medium; 0.5=large. For IMD ASD: N=176; NT: N=157.

### Group Comparisons

There were statistically significant differences between the ASD and NT samples on several variables, as outlined in Table 1. The NT sample had a higher proportion of female participants, were more likely to be employed, and have a higher level of education. The



ASD sample comprised of more participants who lived alone, had a lower IMD score, and had at least one additional psychiatric, neurodevelopmental or physical health condition. As expected, average RAADS-14 scores were significantly higher in the ASD sample.

### Scale Reliability

Cronbach's alpha was calculated for the continuous measures used in this study. See Table 2.

**Table 2**

*Cronbach's Alpha Statistics*

Questionnaire/Subscale	ASD Sample (n=199)		NT Sample (n=174)	
	Cronbach's Alpha	Internal Consistency	Cronbach's Alpha	Internal Consistency
RAADS-14	$\alpha=.81$	Good	$\alpha=.88$	Good
DASS-21 Total	$\alpha=.92$	Excellent	$\alpha=.94$	Excellent
DASS-21 Depression	$\alpha=.91$	Excellent	$\alpha=.92$	Excellent
DASS-21 Anxiety	$\alpha=.79$	Acceptable	$\alpha=.84$	Good
DASS-21 Stress	$\alpha=.81$	Good	$\alpha=.86$	Good
Loneliness	$\alpha=.89$	Good	$\alpha=.88$	Good
WASA	$\alpha=.65$	Questionable	$\alpha=.69$	Questionable

### Descriptive Statistics

Means and standard deviations for the independent and dependent variables are summarised for both samples in Table 3. The ASD sample reported to be members of significantly fewer groups and reported fewer groups they deemed to be important and felt positive about belonging to (i.e., scores >7). There were significant differences between samples on all mental wellbeing measures, with the ASD sample scoring significantly higher on the overall DASS-21 score and its subscales, indicating greater levels of these constructs compared with NT participants. Similarly, the ASD sample scored significantly higher on measures of loneliness and lower for self-esteem (indicative of poorer outcomes on these).

**Table 3***Descriptive Statistics*

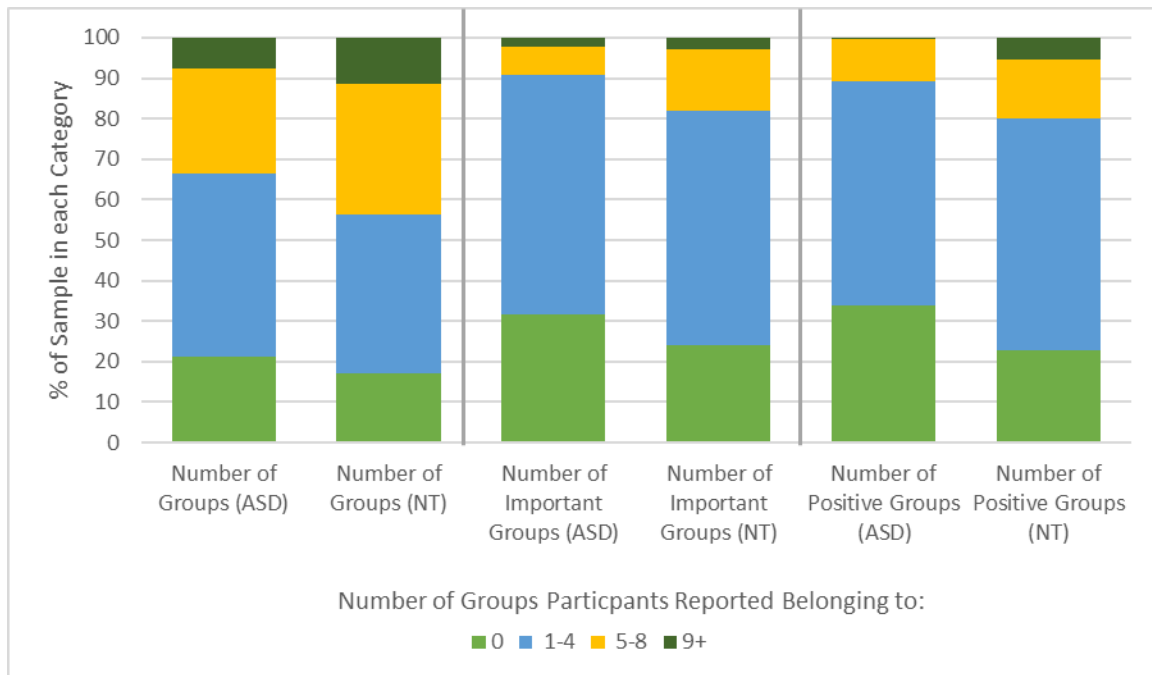
	ASD Sample (N=199)		NT Sample (N=174)		Between-Group Difference
	M (R)	SD	M (R)	SD	
DASS-21 Total	53.66 (0-112)	26.32	31.67 (0-108)	23.83	U=9065, z=- 7.942 p<.001, d=.90
DASS Anxiety	12.76 (0-36)	8.83	6.07 (0-32)	6.07	U=9187.5, z=- 7.87, p<.001, d=.89
DASS Depression	20.06 (0-42)	12.18	12.39 (0-40)	10.58	U=10931.5, z=- 6.15, p<.001, d=.67
DASS Stress	20.83 (0-42)	9.86	13.21 (0-38)	9.09	U=9815, z=- 7.23, p<.001, d=.81
Self-Esteem	2.24 (1-5)	1.12	2.96 (1-5)	1.03	U=10965, z=- 6.32, p<.001, d=.67
Loneliness	6.65 (3-9)	2.03	5.31 (3-9)	1.83	U=10017.5, z=- 6.21, p<.001, d=.68
Number of Groups	3.70 (0-20)	3.38	4.51 (0-20)	3.84	U=15068, z=- 2.18, p=.029, d=.23
Number of Important Groups	1.88 (0-10)	1.99	2.69 (0-16)	2.55	U=12237.5, z=- 3.20, p=.001, d=.34
Number of Positive Groups	1.85 (0-11)	2.00	2.80 (0-16)	2.75	U=12013, z=- 3.44, p=.001, d=.37

*Note:* M, Mean; R, Range; SD, Standard Deviation. For the Loneliness scores ASD: N=188, NT: N=170; for Number of Important and Number of Positive Groups ASD: N=183, NT: N=166.

As seen in Figure 2, a higher proportion of ASD participants reported belonging to no groups, no important groups and no positive groups compared to NT participants. Neurotypical participants reported higher proportions of memberships to 5 or more groups, including important groups and positive groups, compared to the ASD sample.

**Figure 2**

*Comparing ASD and NT Samples on Percentage of Participants Belonging to 0, 1-4, 5-8 and 9+ Groups*



### Correlation Analysis

Spearman Rho correlations are summarised in Table 4. There were positive correlations between number of groups, number of important groups and number of positive groups in both samples, with strong effect sizes (NT:  $r_s=.82-.89$ ; ASD:  $r_s=.77-.85$ ). In both samples, there were significant correlations in the expected direction between the DASS-21 total score, subscales, loneliness and self-esteem measures ranging from weak-strong effect sizes (NT:  $r_s=.25-.91$ ; ASD:  $r_s=.22-.87$ ). In the NT sample, there was also a negative correlation between anxiety and number of groups ( $r_s=-.16$ ) and number of positive groups ( $r_s=-.22$ ). The number of important groups was not significantly correlated with depression, anxiety or stress within either sample. Self-esteem was positively correlated with all social identification measures in the NT sample ( $r_s=.16-.21$ ). In the ASD sample, this was the case for the number of positive groups only ( $r_s=.17$ ). Of note, anxiety was also negatively correlated with age in the ASD sample only ( $r_s=-.23^{**}$ ).

**Table 4***Spearman's Rho Correlation Analysis*

	1	2	3	4	5	6	7	8	9	10	11
1. Age	-	.02	.07	.09	.15	.00	.01	-.02	.01	-.03	.02
2. IMD	-.08	-	.08	.10	.11	-.06	-.06	-.09	-.05	.03	-.09
3. Number of Groups	.01	.07	-	.80***	.82***	-.12	-.05	-.16*	-.12	.21**	-.06
4. Number of Important Groups	-.09	.13	.77***	-	.89***	-.05	-.03	-.14	-.04	.16*	-.05
5. Number of Positive Groups	-.06	.08	.81***	.85***	-	-.15	-.10	-.22**	-.14	.20*	-.11
6. DASS-21 Total	-.13	.02	-.05	-.03	-.10	-	.89***	.78***	.91***	-.43***	.59***
7. DASS-21 Depression	.05	.03	-.06	-.06	-.12	.86***	-	.55***	.69***	-.40***	.61***
8. DASS-21 Anxiety	-.23**	-.03	-.05	-.03	-.07	.79***	.49***	-	.68***	-.25**	.37***
9. DASS-21 Stress	-.11	.04	-.02	-.01	-.06	.87***	.62***	.63***	-	-.37***	.54***
10. Self-Esteem	-.06	.04	.11	.09	.17*	-.53***	-.61***	-.27***	-.40***	-	-.36***
11. Loneliness	-.08	.12	-.06	-.02	-.10	.41***	.48***	.22***	.30***	-.33***	-

Note: NT=Upper half, greyed out. ASD=Lower half. \*p<0.05, \*\*p<0.01, \*\*\*p<0.001.

## Regression Analysis

To investigate whether the main independent variables (number of groups, number of important groups and number of positive groups) explained any variance in DASS-21 depression, anxiety and stress scores above any variance explained by relevant demographic and Covid-19 variables, several hierarchical multiple regressions were conducted. Self-esteem and loneliness were also entered into the regression analyses due to their known association with depression, anxiety and stress symptoms (Wang et al., 2018), as well as their importance more generally in social identity research in ASD and NT populations (Cooper et al., 2017; Thoits, 2013). Separate regression analyses were conducted for the ASD and NT samples, as there were numerous statistically significant differences between these samples in demographic, Covid-19 and wellbeing variables. It was acknowledged that membership in the samples likely defined such differences and therefore full-sample analyses controlling for within- and between- group differences would not have yielded as meaningful results.

Data were examined to assess whether the assumptions for multiple regression analyses were met (Weaver & Wuensch, 2013). Due to the multicollinearity between the three main independent variables, regression analyses were performed using only the number of positive groups. This variable was chosen as the measure of social identity as it showed stronger correlations with the DASS-21 depression, anxiety and stress scores across both ASD and NT samples, and has been shown to be associated with wellbeing variables in previous research (Cruwys et al., 2016). The data in both samples violated the assumption of homogeneity of variance when the DASS-21 depression and anxiety subscales were used as the dependent variables i.e., there was evidence of heteroscedasticity as evaluated by visual inspection of studentised residuals plotted against predicted values, which was confirmed as significant via the Breusch-Pagan Test (Klein et al., 2016). Therefore, weighted least squares regressions were conducted for these sets of data, which controlled for prediction errors. In both samples, a least squares regression was

conducted when the DASS-21 stress subscale was used as the dependent variable, as there was no evidence of heteroscedasticity.

For the NT sample, 166 participants had no missing data for the variables of interest and were included in analyses; three outliers were removed from the depression model, two from the anxiety model and one from the stress model, leaving N=163, N=164 and N=165 respectively. For the ASD sample, 182 participants had no missing data for the variables of interest and were included in all three regression models. Data used for the final regression analyses met all multiple regression assumptions including: linearity, homoscedasticity, independence of residuals, non-multicollinearity, normality of data and no unusual data points.

Initially, forced-entry regression analyses were run for both samples, entering 11 variables including: demographic (age, sex and IMD), Covid-19 variables (current/historic Covid-19 symptoms, clinical vulnerability/risk for Covid-19, living alone, living with children aged <18, WASA, current employment status and whether the participant had lost employment during Covid-19) and recruitment channel (whether the participant was recruited via social media or Prolific). This was to establish which significant predictors should be entered into the main regressions for each sample, and to reduce the numbers of non-significant variables entered in each regression to enhance the accuracy of the final model (Field, 2013). For the ASD sample, significant predictors of depression, anxiety and/or stress included age, WASA, employment status and employment status change. For the NT sample, significant predictors across one or more of the dependent variables included WASA, having current or historic covid-19 symptoms, being in a clinically vulnerable Covid-19 category and being recruited from Prolific. These were therefore entered in the first step of the hierarchical regression, with the second, third and fourth step for each regression including the addition of self-esteem, loneliness and number of positive groups, respectively. See Table 5 and Table 6 for the full regression models. The final model (i.e., block 4) of each regression is explored in greater detail below, given the interest of this research on

understanding whether any additional variance in the outcome variables can be explained by social identity measures (i.e., number of positive groups).

### **ASD Regressions**

For the ASD sample, the full models of age, WASA, employment status, lost employment, self-esteem, loneliness and number of groups one feels positive about belonging to were significant in the Depression ( $R^2 = .56$ ,  $F(7,174)=32.14$ ,  $p<.001$ , adjusted  $R^2 = .55$ ), Anxiety ( $R^2 = .23$ ,  $F(7,174)=7.57$ ,  $p<.001$ , adjusted  $R^2 = .20$ ) and Stress models ( $R^2 = .28$ ,  $F(7,174)=9.41$ ,  $p<.001$ , adjusted  $R^2 = .25$ ). The addition of number of positive groups in the fourth block did not lead to a significant increase in the variance explained in the outcome variable in any of the three models.

**Depression.** The final model included three significant predictors of DASS-21 Depression scores, including higher WASA scores ( $\beta=.14$ ,  $t(174)=2.51$ ,  $p=.01$ ), lower self-esteem ( $\beta=-.55$ ,  $t(174)=-9.38$ ,  $p<.001$ ), and increased loneliness ( $\beta=.28$ ,  $t(174)=4.77$ ,  $p<.001$ ). The  $R^2$  for the overall model was 56% with an adjusted  $R^2$  of 55%, a large effect size (Cohen, 1992).

**Anxiety.** The final model included three significant predictors of DASS-21 Anxiety scores, including younger age ( $\beta=-.25$ ,  $t(174)=-3.67$ ,  $p<.001$ ), higher WASA scores ( $\beta=-.15$ ,  $t(174)=2.09$ ,  $p=.038$ ), and lower self-esteem ( $\beta=-.29$ ,  $t(174)=-3.94$ ,  $p<.001$ ). The  $R^2$  for the overall model was 23% with an adjusted  $R^2$  of 20%, a small effect size.

**Stress.** The final model included two significant predictors of DASS-21 Stress scores, including higher WASA scores ( $\beta=.22$ ,  $t(174)=3.23$ ,  $p=.002$ ), and lower self-esteem ( $\beta=-.39$ ,  $t(174)=-5.42$ ,  $p<.001$ ). The  $R^2$  for the overall model was 28% with an adjusted  $R^2$  of 25%, a small effect size.

### **NT Regressions**

For the NT sample, the full models of WASA, Covid-19 symptoms, Covid-19 risk category, recruitment channel, self-esteem, loneliness and number of groups one feels

positive about belonging to were significant in the Depression ( $R^2 = .56$ ,  $F(7,155)=28.00$ ,  $p<.001$ , adjusted  $R^2 = .55$ ), Anxiety ( $R^2 = .20$ ,  $F(7,156)=10.44$ ,  $p<.001$ , adjusted  $R^2 = .18$ ) and Stress models ( $R^2 = .47$ ,  $F(7,157)=19.65$ ,  $p<.001$ , adjusted  $R^2 = .44$ ). The addition of number of positive groups in the fourth block did not lead to a significant increase in the variance explained in either Depression or Stress, however it did lead to a significant increase in the variance explained in Anxiety ( $F(1,156)=6.17$ ,  $P=.014$ ).

**Depression.** The final model included four significant predictors of DASS-21 Depression scores, including higher WASA scores ( $\beta=.27$ ,  $t(155)=4.51$ ,  $p<.001$ ), having current or historic Covid-19 symptoms ( $\beta=.15$ ,  $t(155)=2.74$ ,  $p=.007$ ), lower self-esteem ( $\beta = -.20$ ,  $t(155)=-3.28$ ,  $p=.001$ ), and increased loneliness ( $\beta=.45$ ,  $t(155)=7.08$ ,  $p<.001$ ). The  $R^2$  for the overall model was 56% with an adjusted  $R^2$  of 54%, a large effect size.

**Anxiety.** The final model included four significant predictors of DASS-21 Anxiety scores, including higher WASA scores ( $\beta=.27$ ,  $t(156)=3.75$ ,  $p<.001$ ), being recruited from prolific ( $\beta=-.17$ ,  $t(156)=-2.45$ ,  $p=.015$ ), having lower self-esteem ( $\beta=-.18$ ,  $t(156)=-2.44$ ,  $p=.016$ ), and belonging to fewer positive groups ( $\beta=-.18$ ,  $t(156)=-2.48$ ,  $p=.014$ ). The  $R^2$  for the overall model was 32% with an adjusted  $R^2$  of 29%, a small-medium effect size.

**Stress.** The final model included four significant predictors of DASS-21 Stress scores, including higher WASA scores ( $\beta=.22$ ,  $t(157)=3.55$ ,  $p=.001$ ), having current or historic Covid-19 Symptoms ( $\beta=.20$ ,  $t(157)=3.26$ ,  $p=.001$ ), having lower self-esteem ( $\beta=-.22$ ,  $t(157)=-3.47$ ,  $p=.001$ ), and having higher loneliness ( $\beta=.40$ ,  $t(157)=5.91$ ,  $p<.001$ ). The  $R^2$  for the overall model was 47% with an adjusted  $R^2$  of 44%, a medium effect size.

## Exploratory Analyses

### Mediation

In the NT anxiety regression model, self-esteem and loneliness were predictive of anxiety in Block 3. With the addition of number of positive groups, loneliness was no longer predictive in the model and self-esteem reduced in its  $B$  value and significance. This



suggests some common variance between self-esteem, loneliness and number of positive groups, indicating an interaction may be present. To test this, two interaction terms were calculated and added to the regression model in subsequent steps (loneliness multiplied by number of positive groups and self-esteem multiplied by number of positive groups). The addition of the loneliness interaction was not significant ( $\beta = -.17$ ,  $t(156) = -.77$ ,  $p = .44$ ). The addition of the self-esteem and number of positive groups interaction was significant in predicting anxiety ( $\beta = .81$ ,  $t(156) = 2.59$ ,  $p = .010$ ) and it significantly increased in the variance explained in Anxiety ( $F(1,156) = 6.73$ ,  $P = .01$ ), resulting in an  $R^2$  for the overall model of 35% with an adjusted  $R^2$  of 31%.

A post-hoc mediation analysis was therefore undertaken using the PROCESS Model for SPSS (Hayes, 2012). WASA and recruitment channel were added as covariates. The path from number of positive groups to self-esteem was significant  $B = .08$ ,  $SE = .03$ ,  $t(160) = 2.66$ ,  $P = .009$ . The direct effect of self-esteem on anxiety was significant  $B = -1.74$ ,  $SE = .46$ ,  $t(159) = 3.82$ ,  $p < .001$ . The effect of number of positive groups on anxiety,  $B = -.69$ ,  $SE = .19$ ,  $t(160) = -3.64$ ,  $p < .001$ , remained significant when self-esteem was controlled for  $B = -.55$ ,  $SE = .19$ ,  $t(159) = -2.92$ ,  $p = .004$ . Using bootstrapping procedures (Preacher & Hayes, 2004), the mediating effect was small yet significant, suggesting self-esteem may partially mediate the relationship between number of positive groups and anxiety in the NT sample  $B = -.052$ ,  $SE = .026$ , 95% CI  $[-.111, -.008]$ .

**Table 5***Hierarchical Multiple Regressions for the ASD sample*

Variable	Depression (N=182)				Anxiety (N=182)				Stress (N=182)			
	B	$\beta$	R <sup>2</sup> (Adj.)	F Change	B	$\beta$	R <sup>2</sup> (Adj.)	F Change	B	$\beta$	R <sup>2</sup> (Adj.)	F Change
<b>Block 1</b>			.11 (.09)	5.22**			.14 (.12)	7.25***			.11 (.09)	5.38***
Age	.04	.05			-.15***	-.25			-.07	-.10		
WASA	.41***	.29			.20**	.20			.31***	.27		
Employment Status	-4.53*	-.18			-2.31	-.13			-2.18	-.11		
Lost Employment	-4.31	-.10			.00	.00			-6.27*	-.17		
<b>Block 2</b>			.51 (.49)	143.22***			.23 (.21)	20.50***			.27 (.25)	38.47***
Age	-.06	-.06			-.16***	-.26			-.10*	-.13		
WASA	.30***	.21			.17*	.17			.29***	.25		
Employment Status	-1.76	-.07			-1.39	-.08			-.66	-.03		
Lost Employment	-.94	-.02			1.21	.04			-4.36	-.12		
Self-Esteem	-6.24***	-.65			-2.18***	-.31			-3.53***	-.41		
<b>Block 3</b>			.56 (.55)	22.58***			.23 (.21)	.43			.27 (.25)	1.25
Age	-.02	-.02			-.16***	-.25			-.09	-.12		
WASA	.20**	.14			.16*	.16			.26**	.23		
Employment Status	-2.02	-.08			-1.37	-.08			-.70	-.04		
Lost Employment	.56	.01			1.49	.05			-3.84	-.11		
Self-Esteem	-5.15***	-.54			-2.04***	-.29			-3.28***	-.38		
Loneliness	1.66***	.28			.21	.05			.39	.08		
<b>Block 4</b>			.56 (.55)	.27			.23 (.20)	.29			.28 (.25)	.26
Age	-.02	-.02			-.15***	-.25			-.09	-.12		
WASA	.19*	.14			.15*	.15			.26**	.22		
Employment Status	-2.16	-.09			-1.47	-.09			-.78	-.04		
Lost Employment	.57	.01			1.52	.05			-3.84	-.11		
Self-Esteem	-5.21***	-.55			-2.09***	-.29			-3.32***	-.39		
Loneliness	1.68***	.28			.22	.05			.40	.09		
Number Positive Groups	.12	.03			.15	.04			.17	.03		

Note. \*p<0.05, \*\*p<0.01, \*\*\*p<0.001. Employment Status (0=Unemployed/Student/Retired/Unable to Work, 1=Employed); Lost Employment (0=No change to employment status or gained employment during lockdown, 1=Lost employment during lockdown).

**Table 6**

Hierarchical Multiple Regressions for the NT sample

Variable	Depression (N=163)				Anxiety (N=164)				Stress (N=165)			
	B	$\beta$	R <sup>2</sup> (Adj.)	F Change	B	$\beta$	R <sup>2</sup> (Adj.)	F Change	B	$\beta$	R <sup>2</sup> (Adj.)	F Change
<b>Block 1</b>			.29 (.27)	16.05***			.20 (.18)	9.74***			.23 (.21)	11.61***
WASA	1.30***	.44			.24***	.29			.39***	.32		
Covid-19 Symptoms	9.86**	.19			2.81	.14			7.26**	.25		
Covid-19 Risk Category	-8.32*	-.15			-1.61	-.09			-4.33*	-.17		
Recruitment Channel	-5.51	-.11			-3.25**	-.21			-.65	-.03		
<b>Block 2</b>			.41 (.40)	33.50***			.27 (.25)	16.86***			.35 (.33)	29.87***
WASA	1.20***	.41			.23***	.28			.39***	.32		
Covid-19 Symptoms	9.65**	3.30			2.40	.12			6.85***	.24		
Covid-19 Risk Category	-8.40*	-.15			-1.74	-.10			-3.75*	-.14		
Recruitment Channel	-5.86	-.12			-2.98**	-.20			-4.4	-.02		
Self-Esteem	-7.32***	-.36			-1.48***	-.28			-3.07***	-.35		
<b>Block 3</b>			.56 (.54)	50.95***			.29 (.27)	3.96*			.47(.45)	35.39***
WASA	.79***	.27			.20**	.24			.27***	.22		
Covid-19 Symptoms	7.92**	.15			2.30	.11			5.64**	.19		
Covid-19 Risk Category	-5.14	-.89			-1.55	-.09			-2.41	-.09		
Recruitment Channel	-3.50	-.07			-2.87**	-.19			.16	.01		
Self-Esteem	-4.08**	-.20			-1.22**	-.23			-1.95***	-.22		
Loneliness	5.64***	.45			.49*	.15			1.96***	.40		
<b>Block 4</b>			.56 (.54)	.06			.32 (.29)	6.17*			.47(.44)	.032
WASA	.80***	.27			.22***	.27			.27**	.22		
Covid-19 Symptoms	7.93**	.15			2.57	.13			5.65**	.20		
Covid-19 Risk Category	-5.04	-.09			-1.80	-.10			-2.39	-.09		
Recruitment Channel	-3.45	-.07			-2.54*	-.17			.18	.01		
Self-Esteem	-4.02**	-.20			-.95*	-.18			-1.93**	-.22		
Loneliness	5.62***	.45			.44	.14			1.95***	.40		
Number Positive Groups	-.09	-.01			-.34*	-.18			-.04	-.01		

Note. \*p<0.05, \*\*p<0.01, \*\*\*p<0.001. Covid-19 Symptoms (0=No Current or Historic Symptoms, 1=Current or Historic Symptoms); Covid-19 Risk Category (0=Low Vulnerability, 1=Medium or High Clinical Vulnerability); Recruitment Channel (0=Prolific, 1=Social Media).

## Discussion

This exploratory study aimed to address two research questions; firstly, whether there was a difference in self-reported number of groups, number of important groups and number of positive groups between the ASD and NT samples, and secondly, whether social identification was associated with- and explained unique variance in- outcome measures of mental wellbeing (as measured through the DASS-21 depression, anxiety and stress scales) in both samples.

Findings support the first hypothesis that there would be significant differences between the ASD and NT samples on all social identification measures, with the NT sample reporting a greater number of groups, important groups and positive groups. Although specific research on multiple-group membership in autism is lacking, these findings are in line with literature relating to social engagement in autism more generally. For example, autistic adults have been reported to be socially isolated more often and report fewer friendships and romantic relationships (Magiati et al., 2014) as well as less social engagement with family (Stacey et al., 2019) compared with neurotypical adults. The reasons for the lower scores on social identification measures in the ASD sample may be influenced by the socio-communication difficulties inherent in ASD, which may challenge their ability to socially engage with groups (Mehling & Tassé, 2015; Orsmond et al., 2004). However, the finding that participants in the ASD sample ascribed themselves as belonging to multiple groups (up to as many as 20, with approximately 68% stating they belonged to at least one important or positive group) adds to literature countering the notion that autistic individuals lack social interest in connecting with others (e.g. Jaswal & Akhtar, 2018).

The second hypothesis that there would be significant differences between the ASD and NT samples on overall DASS-21 score (and the separate subscales of depression, anxiety and stress) was also supported, with the ASD sample reporting higher levels of each. This is in line with previous research reporting autistic adults having a higher incidence

and prevalence of anxiety, depression and stress compared to neurotypical peers (Bishop-Fitzpatrick et al., 2015; Hollocks et al., 2019; Joshi et al., 2013).

The final hypothesis, which related to the NT group only, was partially supported by this study's results. It was hypothesised that there would be significant associations between social identification measures and DASS-21 depression, anxiety, and stress scale scores. In the correlational analysis, significant negative associations were only present between participants' self-reported number of groups and number of positive groups and anxiety, although not depression or stress scores. Contrary to expectation, the number of important groups was not significantly correlated with depression, anxiety or stress. In the hierarchical regression analyses, only the significant association between number of positive groups remained significant and explained unique variance in anxiety scores, after controlling for relevant variables. This suggests that in the NT sample, the higher the number of groups participants felt positive about belonging to, the lower their anxiety scores, lending support to the social cure effect, whereby one's identification with multiple groups is predictive of wellbeing (Haslam et al., 2021; Jetten et al., 2011). Moreover, the finding that this was partially mediated by self-esteem is supported by prior research (Cruwys et al., 2015; Jetten et al., 2015; McIntyre et al., 2018). It has been posited that self-esteem may increase as a result of being proud of, and deriving meaning from, positive group memberships, which buffers against distress, such as anxiety (Jetten et al., 2015). However, mediation analyses cannot establish causal relationships in cross-sectional data (Bullock et al., 2010). It may be that positive self-esteem enables and maintains multiple-group memberships with positively valued groups. Studies of longitudinal design would enable causal relationships between social identification, self-esteem and anxiety to be explicated.

The lack of associations between social identification measures and stress aligns with the study by Cruwys and colleagues (2016), who also used the DASS-21. However, in contrast to the present study, they found significant associations between number of important groups and both anxiety and depression, yet did not find any significant

associations between number of positive groups and social identification measures. It should be noted that correlations between all social identification measures and DASS-21 subscale scores were generally comparable in magnitude between the present study and Cruwys et al. (2016).

The absence of any significant association between social identification measures and the outcome measures in the ASD sample is also notable. This is the first time, to our knowledge, that social identity with multiple-group memberships has been explored in autistic adults. These preliminary findings suggest that, in contrast to the 'social cure' effect, having increasing numbers of groups one positively identifies with may not buffer against mental distress in autistic individuals. It has been theorised that a pre-requisite to deriving benefits from group belongingness is internalising the group as part of one's self-concept through self-categorisation (Hornsey, 2008). That is, one develops a perception of oneself in terms of the shared characteristics of the group as opposed to personally defining attributes. The process of self-categorisation may be disrupted in autism; for example, the Integrated Self-Categorisation Model of Autism proposes that the autistic tendency for localised over global processing extends to self-categorisation processes underlying social identification (Bertschy et al., 2020; Skorich et al., 2016). Although the ASD sample reported feeling positive about belonging to multiple groups, this may not predict wellbeing due to the positivity of group-belongingness not being internalised/self-categorised. The self-reported positivity of group belonging may reflect the increased salience of positive personal attributes, rather than positivity derived from group *belongingness*.

### **Methodological Considerations and Future Directions**

Participatory research in the field of neurodevelopmental disorders is rare (Jivraj et al., 2014); this study was enhanced through the involvement of autistic individuals at the planning and early implementation stages. Feedback following the initial piloting stages and written feedback on the online questionnaire suggested this research was of interest and importance to autistic people. Online participation enabled efficient recruitment and

increased the reach of the survey. However, online convenience sampling methods are subject to selection bias and may result in less generalisability of the findings to the target population, such as those without reliable internet access (Jager et al., 2017). It is notable that there were significant differences in participants recruited by prolific and social media channels e.g., NT participants recruited from prolific reported higher anxiety, however this was controlled for in regression analyses. Although there were more males in the ASD sample compared to the NT sample, the ASD sample had a higher proportion of female participants (over 50%) compared to the usual gender distribution found in autism research, which may limit the generalisation of these findings to the wider autistic population (Halladay et al., 2015).

The high multicollinearity of social identity measures contrasts findings from Cruwys et al. (2016). This may be due to this study using an online format which used uniform scaled responses rather than a face-to-face social identity mapping exercise which included visual representations of identification with groups. Furthermore, high collinearity between social identity measures is not uncommon, and adds to evidence suggesting social identity measures load onto a homogenous construct (Postmes et al., 2013).

All data were self-reported and it was not possible to confirm the autism diagnostic status of participants. Nevertheless, the use of the RAADS-14 screener to compare the mean scores between the ASD and NT samples allowed some confidence in the neurodiversity between groups. Moreover, a strength of this study was the inclusion of self-identified autistic participants; the absence of significant differences between self-reported diagnosed and self-identified autistic participants supports the amalgamation of these into one ASD group. Inclusion of a mental health measure that is validated for use in autistic adults is another strength of this study. However, future studies would benefit from measuring alexithymia, to appropriately control for potentially inaccurate self-reporting resulting from difficulties in identifying and/or describing ones emotional experiences (Poquérusse et al., 2018). Furthermore, the intellectual functioning of participants, and the

existence of additional psychiatric, physical or neurodevelopmental conditions was not formally assessed and therefore was unable to be controlled for in analyses, potentially confounding results.

A major limitation of this study is that data collection occurred during the Covid-19 pandemic, which resulted in major UK-wide social restrictions (Office for National Statistics, 2020). Despite efforts to control for this, findings may not reflect participants' typical social identification with multiple groups and their respective associations with mental health correlates, particularly given the normative increase in mental distress during lockdown (Pierce et al., 2020), as well as reports that this may have impacted ASD individuals more than NT individuals (Baweja et al., 2021). Several Covid-19 variables explained a significant proportion of variance in DASS-21 subscale scores in both samples; the degree of functional impairment participants felt resulted from the changes that occurred due to Covid-19 remained significant predictors of mental health outcomes in all regression analyses after addition of other salient variables including loneliness and self-esteem. Imposed social restrictions may also explain the fewer groups NT participants stated they were members of, relative to previous research (Cruwys et al., 2016). Additionally, government rules on social restrictions changed several times during the data collection period and may have impacted different areas of the UK and British Isles differently. It is therefore recommended that this research is replicated at a time when socialisation in the UK is unrestricted.

Although this study may have reported valid findings that social identities do not hold the same protective mechanisms for autistic adults' wellbeing as compared with neurotypical individuals, there are several limitations which may have compromised detecting a true effect in the ASD sample. Firstly, the a priori power calculations were based on findings from neurotypical samples. It may be that the effect size in autistic populations is relatively smaller due to other, more salient variables predicting the increased incidence and prevalence of mental health difficulties in this population. GPower was used to compute post-hoc analysis; it suggested this study's achieved power for



detecting a small effect size was 0.22, and a sample size of 725 participants would be required to detect small effects. Thus, null effects from this study should not be treated as conclusive, although it is likely that the social cure effect is much smaller in autistic than in neurotypical individuals.

Secondly, this study used measures of social identification which have been shown to be important in predicting wellbeing in neurotypical people. It may be that using other social identity conceptualisations or measurements would yield different results in autistic samples. For example, one's felt prototypicality with other members of the group (i.e., how similar you feel to other members of the same group) has been found to influence relational engagement in group dynamics (Van Kleef et al., 2007). A key difference in the social experiences of autistic adults as compared to neurotypical individuals pertains to autistic individuals' felt need to mask or camouflage autistic traits in order to fit in with society (Cage et al., 2018; Hull et al., 2017). It may be that the extent to which one feels they need to mask in their various social groups to feel they are representative of other members is a more pertinent social identity construct to explore in autistic adults, especially given the link between camouflaging and mental health (Hull et al., 2021).

Research has also shown that others' negative views about one's ingroup may moderate the social cure effect, with perceived discrimination predicting lower wellbeing (DeMarco & Newheiser, 2019; Dinos, 2014). Autistic individuals may be members of more groups that are stigmatised by others, for example autistic people are reported to perceive others as stigmatising autism as a minority group (Botha et al., 2020) which may generalise to groups affiliated with autism such as autistic support groups. Participants' perceptions of how others view their social groups was not explored in the present study and warrants further study given its potential relevance for autistic individuals.

Furthermore, although data were collected on the type of groups people stated belonging to, it was beyond the scope of this study to investigate this in relation to mental health outcomes. This could be an important avenue for future research given autistic and

neurotypical samples may report different types of group memberships that satisfy distinct motivational and psychological needs e.g., affiliative, task-focused, social or achievement-based needs (Crawford & Salaman, 2012), as well as different means of interacting with groups e.g., online or face-to-face (Brownlow et al., 2015).

### **Clinical Implications**

The findings of this study suggest that social identification with groups (as measured by the number of groups one feels positive about belonging to) is associated with lower levels of anxiety in neurotypical individuals. Promoting the number of groups one feels positive about belonging to may therefore be of benefit within neurotypical populations. Indeed, implementation of the 'Groups 4 Health' programme, which specifically aims to improve social connectedness with multiple groups, has demonstrated increased mental wellbeing in the general population (Haslam et al., 2016). The lack of a social cure effect in the ASD sample suggests that interventions aimed at increasing autistic adults' social group memberships may not be justified and should not be assumed to benefit the autistic community e.g., in therapeutic settings. However, the findings of this exploratory study are preliminary and further research exploring social identity and mental health in autistic populations is necessary to be able to consider the implications of this research for clinical practice. Furthermore, in both samples, loneliness and/or self-esteem were more strongly related to wellbeing than number of positive groups and should be considered a higher priority in clinical practice.

### **Conclusions**

This study aimed to establish whether social identification with groups differs in ASD and NT samples and whether multiple-group membership and social identification to such groups is predictive of better mental well-being in both samples. Results suggest the NT sample had increased social identification with groups compared to the ASD sample. Furthermore, social identification, as measured by the number of groups one feels positive about belonging to, was found to explain significant variance in anxiety (although not

depression or stress) scores in the NT sample, which was partially mediated by self-esteem. However, no variance in mental health outcomes was explained by social identification in the ASD sample. These preliminary findings should be interpreted in light of several limitations yet should not preclude future research into social identity in autistic individuals.

## References

- Abdelal, R., Herrera, Y. M., Johnston, A. I., & McDermott, R. (2009). Measuring identity: A guide for social scientists. In *Measuring Identity: A Guide for Social Scientists*. Cambridge University Press. <https://doi.org/10.1017/CBO9780511810909>
- American Psychiatric Association. (2013). *Diagnostic and statistical manual of mental disorders, 5th edition*. American Psychiatric Association. <https://doi.org/10.1176/appi.books.9780890425596>
- Baweja, R., Brown, S. L., Edwards, E. M., & Murray, M. J. (2021). COVID-19 pandemic and impact on patients with autism spectrum disorder. *Journal of Autism and Developmental Disorders, 4*(2), 1–10. <https://doi.org/10.1007/s10803-021-04950-9>
- Bertschy, K., Skorich, D. P., & Haslam, A. S. (2020). Self-categorization and autism: Exploring the relationship between autistic traits and ingroup favouritism in the minimal group paradigm. *Journal of Autism and Developmental Disorders, 50*, 3296–3311. <https://doi.org/10.1007/s10803-019-04149-z>
- Bishop-Fitzpatrick, L., Mazefsky, C. A., Minshew, N. J., & Eack, S. M. (2015). The relationship between stress and social functioning in adults with autism spectrum disorder and without intellectual disability. *Autism Research, 8*(2), 164–173. <https://doi.org/10.1002/aur.1433>
- Botha, M., Dibb, B., & Frost, D. M. (2020). “Autism is me”: An investigation of how autistic individuals make sense of autism and stigma. *Disability and Society*. <https://doi.org/10.1080/09687599.2020.1822782>
- Braun, V., & Clarke, V. (2006). Using thematic analysis in psychology. *Qualitative Research in Psychology, 3*(2), 77–101. <https://doi.org/10.1191/1478088706qp063oa>
- Brownlow, C., Bertilsdotter Rosqvist, H., & O’Dell, L. (2015). Exploring the potential for social networking among people with autism: Challenging dominant ideas of ‘friendship.’ *Scandinavian Journal of Disability Research, 17*(2), 188–193. <https://doi.org/10.1080/15017419.2013.859174>
- Bullock, J. G., Green, D. P., & Ha, S. E. (2010). Yes, but what’s the mechanism? (don’t

- expect an easy answer). *Journal of Personality and Social Psychology*, 98(4), 550–558.  
<https://doi.org/10.1037/a0018933>
- Cage, E., Di Monaco, J., & Newell, V. (2018). Experiences of autism acceptance and mental health in autistic adults. *Journal of Autism and Developmental Disorders*, 48(2), 473–484. <https://doi.org/10.1007/s10803-017-3342-7>
- Chandola, T., Kumari, M., Booker, C. L., & Benzeval, M. J. (2020). The mental health impact of COVID-19 and lockdown related stressors among adults in the UK. *Psychological Medicine*, 1–10. <https://doi.org/10.1017/S0033291720005048>
- Chang, M. X.-L., Jetten, J., Cruwys, T., Haslam, C., & Praherso, N. (2016). The more (social group memberships), the merrier: Is this the case for Asians? *Frontiers in Psychology*, 7, 1001. <https://doi.org/10.3389/fpsyg.2016.01001>
- Chrobak, A. A., & Soltys, Z. (2017). Bergmann Glia, long-term depression, and autism spectrum disorder. *Molecular Neurobiology*, 54, 1156–1166.  
<https://doi.org/10.1007/s12035-016-9719-3>
- Cohen, J. (1992). A power primer. *Psychological Bulletin*, 112, 155–159.  
<https://doi.org/10.1037/0033-2909.112.1.155>
- Cooper, K., Smith, L. G. E., & Russell, A. (2017). Social identity, self-esteem, and mental health in autism. *European Journal of Social Psychology*, 47(7), 844–854.  
<https://doi.org/10.1002/ejsp.2297>
- Cooper, K., Smith, L. G. E., & Russell, A. J. (2018). Gender identity in autism: Sex differences in social affiliation with gender groups. *Journal of Autism and Developmental Disorders*, 48, 3995–4006. <https://doi.org/10.1007/s10803-018-3590-1>
- Crawford, M. T., & Salaman, L. (2012). Entitativity, identity, and the fulfilment of psychological needs. *Journal of Experimental Social Psychology*, 48(3), 726–730.  
<https://doi.org/10.1016/j.jesp.2011.12.015>
- Croen, L. A., Zerbo, O., Qian, Y., Massolo, M. L., Rich, S., Sidney, S., & Kripke, C. (2015). The health status of adults on the autism spectrum. *Autism*, 19, 814–823.  
<https://doi.org/10.1177/1362361315577517>

- Cruwys, T., Dingle, G. A., Haslam, C., Haslam, S. A., Jetten, J., & Morton, T. A. (2013). Social group memberships protect against future depression, alleviate depression symptoms and prevent depression relapse. *Social Science & Medicine*, *98*, 179–186. <https://doi.org/10.1016/j.socscimed.2013.09.013>
- Cruwys, T., Haslam, S. A., Dingle, G. A., Haslam, C., & Jetten, J. (2014). Depression and social identity: An integrative review. *Personality and Social Psychology Review*, *18*, 215–238. <https://doi.org/10.1177/1088868314523839>
- Cruwys, T., South, E. I., Greenaway, K. H., & Haslam, S. A. (2015). Social identity reduces depression by fostering positive attributions. *Social Psychological and Personality Science*, *6*, 65–74. <https://doi.org/10.1177/1948550614543309>
- Cruwys, T., Steffens, N. K., Haslam, S. A., Haslam, C., Jetten, J., & Dingle, G. A. (2016). Social identity mapping: A procedure for visual representation and assessment of subjective multiple group memberships. *British Journal of Social Psychology*, *55*, 613–642. <https://doi.org/10.1111/bjso.12155>
- DeMarco, T. C., & Newheiser, A. K. (2019). When groups do not cure: Group esteem moderates the social cure effect. *European Journal of Social Psychology*, *49*(7), 1421–1438. <https://doi.org/10.1002/ejsp.2594>
- Dinos, S. (2014). Stigma creating stigma: A vicious circle. *Psychiatric Bulletin*, *38*, 145–147. <https://doi.org/10.1192/pb.bp.114.048124>
- Eriksson, J. M., Andersen, L. M., & Bejerot, S. (2013). RAADS-14 screen: Validity of a screening tool for autism spectrum disorder in an adult psychiatric population. *Molecular Autism*, *4*, 49. <https://doi.org/10.1186/2040-2392-4-49>
- Field, A. (2013). *Discovering Statistics using IBM SPSS Statistics* (4th ed.). SAGE Publications Ltd.
- Field, A. (2017). *Discovering Statistics Using IBM SPSS Statistics* (5th ed.). SAGE Publications Ltd. <https://in.sagepub.com/en-in/sas/discovering-statistics-using-ibm-spss-statistics/book257672>

- Forsyth, D. R., & Burnette, J. (2010). Group Processes. In R. F. Baumeister & J. Eli (Eds.), *Advanced Social Psychology: The State of the Science* (pp. 495–534). Oxford University Press. <http://scholarship.richmond.edu/jepson-faculty-publications>
- Goodman, W. K., Price, L. H., Rasmussen, S. A., Mazure, C., Delgado, P., Heninger, G. R., & Charney, D. S. (1989). The Yale-Brown Obsessive Compulsive Scale: II. Validity. *Archives of General Psychiatry*, *46*(11), 1012–1016.  
<https://doi.org/10.1001/archpsyc.1989.01810110054008>
- Hak, T., Veer, K. van der, & Jansen, H. (2008). The three-step test-interview (TSTI): An observation-based method for pretesting self-completion questionnaires. *Survey Research Methods*, *2*, 143–150. <https://doi.org/10.18148/srm/2008.v2i3.1669>
- Halladay, A. K., Bishop, S., Constantino, J. N., Daniels, A. M., Koenig, K., Palmer, K., Messinger, D., Pelphrey, K., Sanders, S. J., Singer, A. T., Taylor, J. L., & Szatmari, P. (2015). Sex and gender differences in autism spectrum disorder: Summarizing evidence gaps and identifying emerging areas of priority. *Molecular Autism*, *6*(1), 36.  
<https://doi.org/10.1186/s13229-015-0019-y>
- Haslam, C., Cruwys, T., Haslam, S. A., Dingle, G., & Chang, M. X.-L. (2016). Groups 4 Health: Evidence that a social-identity intervention that builds and strengthens social group membership improves mental health. *Journal of Affective Disorders*, *194*, 188–195. <https://doi.org/10.1016/j.jad.2016.01.010>
- Haslam, C., Haslam, S. A., Jetten, J., Cruwys, T., & Steffens, N. K. (2021). Life change, social identity, and health. *Annual Review of Psychology*, *72*, 635–661.  
<https://doi.org/10.1146/annurev-psych-060120>
- Haslam, C., Holme, A., Haslam, S. A., Iyer, A., Jetten, J., & Williams, W. H. (2008). Maintaining group memberships: Social identity continuity predicts well-being after stroke. *Neuropsychological Rehabilitation*, *18*, 671–691.  
<https://doi.org/10.1080/09602010701643449>
- Haslam, S. A., Oakes, P. J., Reynolds, K. J., & Turner, J. C. (1999). Social identity salience and the emergence of stereotype consensus. *Personality and Social Psychology*

*Bulletin*, 25, 809–818. <https://doi.org/10.1177/0146167299025007004>

Hayes, A. F. (2012). *PROCESS: A versatile computational tool for observed variable*

*mediation, moderation, and conditional process modeling*. <http://www.afhayes.com/>

Hedley, D., & Young, R. (2006). Social comparison processes and depressive symptoms in children and adolescents with Asperger syndrome. *Autism*, 10(2), 139–153.

<https://doi.org/10.1177/1362361306062020>

Henry, J. D., & Crawford, J. R. (2005). The short-form version of the Depression Anxiety Stress Scales (DASS-21): Construct validity and normative data in a large non-clinical sample. *British Journal of Clinical Psychology*, 44, 227–239.

<https://doi.org/10.1348/014466505X29657>

Herrmann, E., Call, J., Hernández-Lloreda, M. V., Hare, B., & Tomasello, M. (2007). Humans have evolved specialized skills of social cognition: The cultural intelligence hypothesis.

*Science*, 317, 1360–1366. <https://doi.org/10.1126/science.1146282>

Hollocks, M. J., Lerh, J. W., Magiati, I., Meiser-Stedman, R., & Brugha, T. S. (2019). Anxiety and depression in adults with autism spectrum disorder: A systematic review and meta-analysis. *Psychological Medicine*, 49(4), 559–572.

<https://doi.org/10.1017/S0033291718002283>

Hornsey, M. J. (2008). Social identity theory and self-categorization theory: A historical review. *Social and Personality Psychology Compass*, 2(1), 204–222.

<https://doi.org/10.1111/j.1751-9004.2007.00066.x>

Hughes, M. E., Waite, L. J., Hawkey, L. C., & Cacioppo, J. T. (2004). A short scale for measuring loneliness in large surveys: Results from two population-based studies.

*Research on Aging*, 26(6), 655–672. <https://doi.org/10.1177/0164027504268574>

Hull, L., Levy, L., Lai, M. C., Petrides, K. V., Baron-Cohen, S., Allison, C., Smith, P., & Mandy, W. (2021). Is social camouflaging associated with anxiety and depression in autistic adults? *Molecular Autism*, 12(1), 1–13. <https://doi.org/10.1186/s13229-021-00421-1>

Hull, L., Petrides, K. V., Allison, C., Smith, P., Baron-Cohen, S., Lai, M.-C., & Mandy, W.



- (2017). "Putting on my best normal": Social camouflaging in adults with autism spectrum conditions. *Journal of Autism and Developmental Disorders*, 47(8), 2519–2534. <https://doi.org/10.1007/s10803-017-3166-5>
- Iyer, A., Jetten, J., Tsivrikos, D., Postmes, T., & Haslam, S. A. (2009). The more (and the more compatible) the merrier: Multiple group memberships and identity compatibility as predictors of adjustment after life transitions. *British Journal of Social Psychology*, 48, 707–733. <https://doi.org/10.1348/014466608X397628>
- Jackson, J. W. (2002). The relationship between group identity and intergroup prejudice is moderated by sociostructural variation. *Journal of Applied Social Psychology*, 32, 908–933. <https://doi.org/10.1111/j.1559-1816.2002.tb00248.x>
- Jager, J., Putnick, D. L., & Bornstein, M. H. (2017). More than just convenient: The scientific merits of homogeneous convenience samples. *Monographs of the Society for Research in Child Development*, 82(2), 13–30. <https://doi.org/10.1111/mono.12296>
- Jaswal, V. K., & Akhtar, N. (2018). Being vs. appearing socially uninterested: Challenging assumptions about social motivation in autism. *Behavioral and Brain Sciences*, 42, 1–84. <https://doi.org/10.1017/S0140525X18001826>
- Jetten, J., Branscombe, N. R., Haslam, S. A., Haslam, C., Cruwys, T., Jones, J. M., Cui, L., Dingle, G., Liu, J., Murphy, S., Thai, A., Walter, Z., & Zhang, A. (2015). Having a lot of a good thing: Multiple important group memberships as a source of self-esteem. *PLoS ONE*, 10(6). <https://doi.org/10.1371/journal.pone.0124609>
- Jetten, J., Haslam, C., & Haslam, S. A. (2011). *The Social Cure* (1st ed.). Routledge. <https://doi.org/10.4324/9780203813195>
- Jetten, J., Haslam, C., Haslam, S. A., Dingle, G., & Jones, J. M. (2014). How groups affect our health and well-being: The path from theory to policy. *Social Issues and Policy Review*, 8, 103–130. <https://doi.org/10.1111/sipr.12003>
- Jia, R., Ayling, K., Chalder, T., Massey, A., Broadbent, E., Coupland, C., & Vedhara, K. (2020). Mental health in the UK during the COVID-19 pandemic: Cross-sectional analyses from a community cohort study. *BMJ Open*, 10(9).

<https://doi.org/10.1136/bmjopen-2020-040620>

- Jivraj, J., Sacrey, L. A., Newton, A., Nicholas, D., & Zwaigenbaum, L. (2014). Assessing the influence of researcher-partner involvement on the process and outcomes of participatory research in autism spectrum disorder and neurodevelopmental disorders: A scoping review. *Autism, 18*(7), 782–793. <https://doi.org/10.1177/1362361314539858>
- Kenny, L., Hattersley, C., Molins, B., Buckley, C., Povey, C., & Pellicano, E. (2016). Which terms should be used to describe autism? Perspectives from the UK autism community. *Autism, 20*, 442–462. <https://doi.org/10.1177/1362361315588200>
- Klein, A. G., Gerhard, C., Büchner, R. D., Diestel, S., & Schermelleh-Engel, K. (2016). The detection of heteroscedasticity in regression models for psychological data model fit of nonlinear structural equation models view project. *Psychological Test and Assessment Modeling, 58*(4), 542–568. <https://www.researchgate.net/publication/311518028>
- Li, L. Z., & Wang, S. (2020). Prevalence and predictors of general psychiatric disorders and loneliness during COVID-19 in the United Kingdom. *Psychiatry Research, 291*. <https://doi.org/10.1016/j.psychres.2020.113267>
- Lovibond, P. F., & Lovibond, S. H. (1995). The structure of negative emotional states: Comparison of the Depression Anxiety Stress Scales (DASS) with the Beck Depression and Anxiety Inventories. *Behaviour Research and Therapy, 33*, 335–343. [https://doi.org/10.1016/0005-7967\(94\)00075-U](https://doi.org/10.1016/0005-7967(94)00075-U)
- Magiati, I., Tay, X. W., & Howlin, P. (2014). Cognitive, language, social and behavioural outcomes in adults with autism spectrum disorders: A systematic review of longitudinal follow-up studies in adulthood. *Clinical Psychology Review, 34*(1), 78–86. <https://doi.org/10.1016/j.cpr.2013.11.002>
- Mazurek, M. O. (2014). Loneliness, friendship, and well-being in adults with autism spectrum disorders. *Autism, 18*(3), 223–232. <https://doi.org/10.1177/1362361312474121>
- McIntyre, J. C., Wickham, S., Barr, B., & Bentall, R. P. (2018). Social identity and psychosis: Associations and psychological mechanisms. *Schizophrenia Bulletin, 44*(3), 681–690. <https://doi.org/10.1093/schbul/sbx110>

- McIntyre, J. C., Worsley, J., Corcoran, R., Harrison Woods, P., & Bentall, R. P. (2018). Academic and non-academic predictors of student psychological distress: The role of social identity and loneliness. *Journal of Mental Health, 27*(3), 230–239.  
<https://doi.org/10.1080/09638237.2018.1437608>
- Mehling, M. H., & Tassé, M. J. (2015). Impact of choice on social outcomes of adults with ASD. *Journal of Autism and Developmental Disorders, 45*(6), 1588–1602.  
<https://doi.org/10.1007/s10803-014-2312-6>
- Meissner, H. I., Creswell, J. W., Klassen, A. C., Clark, V. L. P., & Smith, K. C. (2011). *Best practices for mixed methods research in the health sciences*.  
[http://www2.jabsom.hawaii.edu/native/docs/tsudocs/Best\\_Practices\\_for\\_Mixed\\_Methods\\_Research\\_Aug2011.pdf](http://www2.jabsom.hawaii.edu/native/docs/tsudocs/Best_Practices_for_Mixed_Methods_Research_Aug2011.pdf)
- Meuret, A. E., Chmielewski, M., Steele, A. M., Rosenfield, D., Petersen, S., Smits, J. A. J., Simon, N. M., Otto, M. W., Marques, L., Pollack, M. H., & Hofmann, S. G. (2016). The desire to belong: Social identification as a predictor of treatment outcome in social anxiety disorder. *Behaviour Research and Therapy, 81*, 21–34.  
<https://doi.org/10.1016/j.brat.2016.03.008>
- Milton, D., & Sims, T. (2016). How is a sense of well-being and belonging constructed in the accounts of autistic adults? *Disability & Society, 31*, 520–534.  
<https://doi.org/10.1080/09687599.2016.1186529>
- Mundt, J. C., Marks, I. M., Shear, M. K., & Greist, J. H. (2002). The Work and Social Adjustment Scale: A simple measure of impairment in functioning. *British Journal of Psychiatry, 180*, 461–464. <https://doi.org/10.1192/bjp.180.5.461>
- Nieuwenhuijsen, K., de Boer, A. G. E. M., Verbeek, J. H. A. M., Blonk, R. W. B., & van Dijk, F. J. H. (2003). The Depression Anxiety Stress Scales (DASS): Detecting anxiety disorder and depression in employees absent from work because of mental health problems. *Occupational and Environmental Medicine, 60*, 77–82.  
[https://doi.org/10.1136/oem.60.suppl\\_1.i77](https://doi.org/10.1136/oem.60.suppl_1.i77)
- Office for National Statistics. (2019). *English indices of deprivation*. <https://imd-by->

postcode.opendatacommunities.org/imd/2019

Office for National Statistics. (2020, October 2). *Coronavirus and the social impacts on Great Britain*. Open Government Licence.

<https://www.ons.gov.uk/peoplepopulationandcommunity/healthandsocialcare/healthandwellbeing/bulletins/coronavirusandthesocialimpactsongreatbritain/2october2020>

Orsmond, G. I., Krauss, M. W., & Seltzer, M. M. (2004). Peer relationships and social and recreational activities among adolescents and adults with autism. *Journal of Autism and Developmental Disorders*, *34*(3), 245–256.

<https://doi.org/10.1023/B:JADD.0000029547.96610.df>

Park, S. H., Song, Y. J. C., Demetriou, E. A., Pepper, K. L., Thomas, E. E., Hickie, I. B., & Guastella, A. J. (2020). Validation of the 21-item Depression, Anxiety, and Stress Scales (DASS-21) in individuals with autism spectrum disorder. *Psychiatry Research*, *291*, 1–8. <https://doi.org/10.1016/j.psychres.2020.113300>

Pellicano, E., Dinsmore, A., & Charman, T. (2014). What should autism research focus upon? Community views and priorities from the United Kingdom. *Autism : The International Journal of Research and Practice*, *18*, 756–770.

<https://doi.org/10.1177/1362361314529627>

Pierce, M., Hope, H., Ford, T., Hatch, S., Hotopf, M., John, A., Kontopantelis, E., Webb, R., Wessely, S., McManus, S., & Abel, K. M. (2020). Mental health before and during the COVID-19 pandemic: A longitudinal probability sample survey of the UK population. *The Lancet Psychiatry*, *7*(10), 883–892. [https://doi.org/10.1016/S2215-0366\(20\)30308-](https://doi.org/10.1016/S2215-0366(20)30308-4)

4

Poquérusse, J., Pastore, L., Dellantonio, S., & Esposito, G. (2018). Alexithymia and autism spectrum disorder: A complex relationship. *Frontiers in Psychology*, *9*.

<https://doi.org/10.3389/fpsyg.2018.01196>

Postmes, T., Haslam, S. A., & Jans, L. (2013). A single-item measure of social identification: Reliability, validity, and utility. *British Journal of Social Psychology*, *52*(4), 597–617.

<https://doi.org/10.1111/bjso.12006>

- Preacher, K. J., & Hayes, A. F. (2004). SPSS and SAS procedures for estimating indirect effects in simple mediation models. *Behavior Research Methods, Instruments, and Computers*, *36*(4), 717–731. <https://doi.org/10.3758/BF03206553>
- Ritvo, R. A., Ritvo, E. R., Guthrie, D., Ritvo, M. J., Hufnagel, D. H., McMahon, W., Tonge, B., Mataix-Cols, D., Jassi, A., Attwood, T., & Eloff, J. (2011). The Ritvo autism Asperger diagnostic scale-revised (RAADS-R): A scale to assist the diagnosis of autism spectrum disorder in adults: An international validation study. *Journal of Autism and Developmental Disorders*, *41*, 1076–1089. <https://doi.org/10.1007/s10803-010-1133-5>
- Robins, R. W., Hendin, H. M., & Trzesniewski, K. H. (2001). Measuring global self-esteem: Construct validation of a single-item measure and the Rosenberg self-esteem scale. *Personality and Social Psychology Bulletin*, *27*, 151–161. <https://doi.org/10.1177/0146167201272002>
- Roccas, S., & Brewer, M. B. (2002). Social identity complexity. *Personality and Social Psychology Review*, *6*, 88–106. [https://doi.org/10.1207/S15327957PSPR0602\\_01](https://doi.org/10.1207/S15327957PSPR0602_01)
- Rosenberg, M. (1965). *Society and the adolescent self-image*. Princeton University Press.
- Sani, F., Herrera, M., Wakefield, J. R. H., Boroch, O., & Gulyas, C. (2012). Comparing social contact and group identification as predictors of mental health. *British Journal of Social Psychology*, *51*, 781–790. <https://doi.org/10.1111/j.2044-8309.2012.02101.x>
- Schmitt, M. T., Spears, R., & Branscombe, N. R. (2003). Constructing a minority group identity out of shared rejection: The case of international students. *European Journal of Social Psychology*, *33*, 1–12. <https://doi.org/10.1002/ejsp.131>
- Skorich, D. P., May, A. R., Talipski, L. A., Hall, M. H., Dolstra, A. J., Gash, T. B., & Gunningham, B. H. (2016). Is social categorization the missing link between weak central coherence and mental state inference abilities in autism? Preliminary evidence from a general population sample. *Journal of Autism and Developmental Disorders*, *46*(3), 862–881. <https://doi.org/10.1007/s10803-015-2623-2>
- Sønderlund, A. L., Morton, T. A., & Ryan, M. K. (2017). Multiple group membership and well-being: Is there always strength in numbers? *Frontiers in Psychology*, *8*, 1038.

<https://doi.org/10.3389/fpsyg.2017.01038>

- Spain, D., Sin, J., Linder, K. B., McMahon, J., & Happé, F. (2018). Social anxiety in autism spectrum disorder: A systematic review. *Research in Autism Spectrum Disorders*, *52*, 51–68. <https://doi.org/10.1016/J.RASD.2018.04.007>
- Stacey, T. L., Froude, E. H., Trollor, J., & Foley, K. R. (2019). Leisure participation and satisfaction in autistic adults and neurotypical adults. *Autism*, *23*(4), 993–1004. <https://doi.org/10.1177/1362361318791275>
- Stets, J. E., & Burke, P. J. (2000). Identity theory and social identity theory. *Social Psychology Quarterly*, *63*, 224. <https://doi.org/10.2307/2695870>
- Tajfel, H. (1974). Social identity and intergroup behaviour. *Social Science Information*, *13*, 65–93. <https://doi.org/10.1177/053901847401300204>
- Tajfel, H., & Turner, J. C. (1979). An integrative theory of intergroup conflict. In W. G. Austin & S. Worehel (Eds.), *The social psychology of intergroup relations* (pp. 33–47). Brooks/Cole.
- Thoits, P. A. (2013). Self, Identity, Stress, and Mental Health. In Aneshensel C.S., Phelan, J.C., & B. A. (Eds.), *Handbook of the Sociology of Mental Health* (pp. 357–377). Springer, Dordrecht. [https://doi.org/10.1007/978-94-007-4276-5\\_18](https://doi.org/10.1007/978-94-007-4276-5_18)
- Turner, J. C., & Oakes, P. J. (1986). The significance of the social identity concept for social psychology with reference to individualism, interactionism and social influence. *British Journal of Social Psychology*, *25*, 237–252. <https://doi.org/10.1111/j.2044-8309.1986.tb00732.x>
- Van Kleef, G. A., Steinel, W., Van Knippenberg, D., Hogg, M. A., & Svensson, A. (2007). Group member prototypicality and intergroup negotiation: How one's standing in the group affects negotiation behaviour. *British Journal of Social Psychology*, *46*(1), 129–152. <https://doi.org/10.1348/014466605X89353>
- Wang, J., Mann, F., Lloyd-Evans, B., Ma, R., & Johnson, S. (2018). Associations between loneliness and perceived social support and outcomes of mental health problems: A systematic review. *BMC Psychiatry*, *18*(1), 156. <https://doi.org/10.1186/s12888-018->

1736-5

Weaver, B., & Wuensch, K. L. (2013). SPSS and SAS programs for comparing Pearson correlations and OLS regression coefficients. *Behavior Research Methods*, *45*(3), 880–895. <https://doi.org/10.3758/s13428-012-0289-7>

## Appendices

### Appendix A

*Amendments to the data collection procedures and survey questions which were deemed minor amendments and granted via chair's action between February 2020-October 2020:*

- The Three-Step Test-Interview (TSTI; Hak, Veer, & Jansen, 2008), an observation-based method for pretesting self-completion questionnaires, was going to be used in the pilot stage to gain feedback on the feasibility of questions and timing of survey completion. However, due to the restrictions imposed by the ongoing Covid-19 pandemic, this face-to-face method of data collection could not happen. It was therefore decided that initial feedback on the survey would instead be conducted via telephone, video call or email correspondence with volunteers.
- Additional measures were added to the questionnaire in an attempt to control for variables related to Covid-19 that had emerged as significant in predicting wellbeing in recent psychosocial research – this was kept to a minimum to reduce burden on participants given the already long questionnaire. These included: whether someone had or has Covid-19 symptoms, whether someone was in a clinically vulnerable group, whether someone lived alone, presence of children under 18 years in the home and current employment status (including whether employment status changed directly or indirectly due to Covid-19).
- Information sheets and debrief sheets were amended to signpost individuals to specific support sites for coping with covid-19 related distress, given questions pertained to the impact of Covid-19 and people's medical vulnerability to it.
- The recruitment period was delayed and the recruitment period reduced to three months (December 2020-March 2021). Therefore, additional recruitment channels were employed to enable sufficient participants to be recruited.



## **Appendix B**

### *Prompt Questions for Pilot Stage 1 (Questions on Social Identity and Multiple Group Membership):*

1. What thoughts/queries did you have as you completed the questionnaire?
2. Overall, how did you find the task?
3. Did the examples of groups given at the beginning make sense to you?
4. What do you understand by the term 'social identity'?
5. Did you find any part of the task confusing? If so, which part(s)?
6. Were there any words or phrases you would change to help make them more understandable?
7. Do you think any other questions should be added to the questionnaire?
8. How did you find having to write down what you were thinking?
9. Is there any other feedback you would like to give about the task today?
10. Do you think that your answers would have been any different without the current social distancing measures in place?

### *Prompt Questions for Pilot Stage 2 (Full Survey):*

1. How long did it take you (approximately) to fill out the questionnaire?
2. How did this length feel for you (e.g., was it too long)?
3. How did you find filling out this questionnaire (e.g., was it interesting, boring, anxiety-provoking...)?
4. Did you find any questions confusing or hard to understand? If yes, can you remember which one(s)?
5. Do you have any recommendations or suggested changes to the wording used in the questions to make them easier to understand?
6. Is there any other feedback you would like to give on your experience of completing this questionnaire?

## **Appendix C**

### *Changes made to the survey following the pilot stage:*

- The addition of free-text boxes after questions on loneliness and group memberships as participants felt they wanted to explain the nuances of their answers.
- All participants commented on the limiting nature of the standardised RAADS-14 questionnaire and the lack of the option to report nuances in socio-communication skills based on contextual factors. A free-text box response was therefore added following this questionnaire.
- Bullet-pointing sentences to enhance understanding and processing of information.
- Repeating group membership examples at the beginning of subsequent questions to help prompt participants with examples they could relate to their own lives.
- Clarifying that groups can consist of at least 2 members, and people do not need to physically meet up for this to be a group.
- Clarifying that support from the group could be social, emotional or practical (after one participant associated this with only practical/personal support).

## Appendix D

### *Invitation Email to ShARL Database of Research Volunteers*

Dear.....,

My name is Becky and you are receiving this email because you have previously signed up to Sheffield Autism Research Lab's research database. This database is overseen by Professor Elizabeth (Liz) Milne at the University of Sheffield. I work with Liz, and we are inviting you to participate in a study looking at how group membership and social identification with groups is understood by autistic adults and whether there are links between social identity and mental health in autistic adults.

Social identity can be defined as your association with various social groups (such as your family, friendship groups, sports teams, volunteering groups etc.) and what these groups mean to you. Some people might define themselves as belonging to lots of social groups, whereas other people may be a member of none or very few.

The study would involve you completing an online questionnaire, lasting approximately 20-30 minutes. If you choose, you can also be entered into a prize draw to win one of two £25 Amazon vouchers. If you would like to find out more about this study, I have also enclosed an information sheet within this email which provides further details on the study and what is involved. If you have any questions about the study please contact me on my email address ([rhymas1@sheffield.ac.uk](mailto:rhymas1@sheffield.ac.uk)).

If you would like to take part in the study, please click on the following link after reading the information sheet:

[https://sheffieldpsychology.eu.qualtrics.com/jfe/form/SV\\_b7s0UqJfV9duJnL](https://sheffieldpsychology.eu.qualtrics.com/jfe/form/SV_b7s0UqJfV9duJnL)

Please note, if you no longer want to be on the research database or to be contacted about future research, please respond to this email with "unsubscribe" either in the subject heading or in the main body of the email and we will remove your details from the database. If you do not want to be part of this study but would like to continue to be on the research database, you do not need to respond to this email.

Thank you very much for taking the time to read this email, and for your interest in the research being carried out by the Sheffield Autism Research Lab.

Yours faithfully,

**Becky Hymas**

Trainee Clinical Psychologist

Under the supervision of Professor Elizabeth Milne

### **Contact Details**

**Email:** [rhymas1@sheffield.ac.uk](mailto:rhymas1@sheffield.ac.uk)

## Appendix E

### Study Advert (Poster)



The  
University  
Of  
Sheffield.

# Wanted

Autistic and non-Autistic participants, to take part in an online questionnaire.

Optional entry into a prize draw to win a £25 Amazon Voucher.

### What?

Research among non-Autistic people suggest an association between someone's social identity and their wellbeing. We would like to explore whether this association also exists in Autistic people, and how it may be different or similar to non-Autistic people.

### Who?

We want to recruit Autistic and non-Autistic people aged 18 or over, living in the UK.

### How?

Participation involves completing a questionnaire taking around 20-30 minutes to complete. For more information and to take part please follow the link below:

- If you **are Autistic** please follow this Link:  
[https://sheffieldpsychology.eu.qualtrics.com/jfe/form/SV\\_b7s0UqJfV9duJnL](https://sheffieldpsychology.eu.qualtrics.com/jfe/form/SV_b7s0UqJfV9duJnL)
- If you **are not Autistic** please follow this Link:  
[https://sheffieldpsychology.eu.qualtrics.com/jfe/form/SV\\_2rSUNpnn0IZa69L](https://sheffieldpsychology.eu.qualtrics.com/jfe/form/SV_2rSUNpnn0IZa69L)

If you have any questions about the study please contact me using the contact details below.

#### **Principal Investigator**

Becky Hymas  
Trainee Clinical Psychologist

#### **Research Supervisor**

Professor Elizabeth Milne

**Email:** [rhymas1@sheffield.ac.uk](mailto:rhymas1@sheffield.ac.uk)

## Appendix F

### Information Sheet: Pilot Stage 1



## Participant Information Sheet

### Multiple group membership, social identity and mental health in Autistic Adults

You are being invited to take part in a research project looking at social identity in Autistic adults. Before you decide whether or not to participate, it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully and discuss it with others if you wish. Ask us if there is anything that is not clear or if you would like more information; our contact details are at the end of this information leaflet.

#### What is the purpose of the study?

Social identity can be defined as your association with various social groups (such as your family, friendship groups, sports teams, volunteering groups etc.) and what these groups mean to you. Some people might define themselves as belonging to lots of social groups, whereas other people may be a member of none, or only a few.

Research within the neurotypical population (i.e., those without a diagnosis of an Autism Spectrum Condition; ASC) suggest a link between someone's social identity (the number of multiple-social groups they belong to, and their perception of these groups) and their wellbeing, for example their levels of anxiety, depression and stress. We would like to explore whether this association also exists in those with Autism, and how it may be different or similar to people without Autism.

#### What will happen if I take part? What will I have to do?

The study would involve you being sent an online link to fill out some questionnaires and answer questions in a one-to-one phone call or video call with me (the primary researcher in this study).

We are also collecting additional information from you including the postcode of your home, your age, gender, ethnicity, marital status, education level, employment status and some information about your Autism diagnosis. We will also ask whether you have any other neurodevelopmental or psychiatric diagnoses.

#### Why am I being asked to take part?

The aim of this interview is to get your opinion and feedback on the types of questions we expect to be using in a future study. It is expected that this interview will last approximately one hour.

#### Do I have to take part?

Taking part in this research is entirely voluntary. If you do not wish to take part, there will be no negative consequences. You may also stop your participation at any time, without needing to explain why.

It is up to you to decide whether or not to take part. If you decide to take part you will be given this information sheet to keep and be asked to sign a consent form, before you complete the questionnaire.

### **Will I be recorded in the interview?**

The audio or video interview will not be recorded, however the researcher will write down notes of your answers to questions. These notes will be kept in a secure location online (in a password-protected document). Information about you collected during this research will be anonymised and used only for analysis purposes. No other use will be made of them without your written permission.

### **What are the possible disadvantages and risks of taking part?**

The questionnaire asks you about personal topics (such as your social relationships) which may be distressing for you.

We are aware that we are asking you to answer questions on your social relationships at a time when you are perhaps practicing social distancing, and your physical contact with others may have reduced. This may increase the distress you feel at this current time. If any of the questions cause you distress, you can discuss this with the interviewer.

If taking part in the study raises any concerns about your mental health or social experiences, the interviewer can signpost you to services that can offer advice and support. We will also signpost you to services at the end of the questionnaire as part of the debrief procedure.

You can also access a link to a webpage aimed at those with ASD who may be experiencing understandable anxiety around the current COVID-19 situation here: <https://www.autistica.org.uk/what-is-autism/coping-with-uncertainty>

### **What are the possible benefits of taking part?**

A lot of people who take part in research find it a rewarding experience. It is hoped that this initial study will help us to understand the experiences of autistic adults' social groups and social identification. Feedback from the interviews will be used to inform the next part of our study which will be piloting the full online questionnaire.

### **Will my taking part in this project be kept confidential?**

All the information that you provide will be kept strictly confidential and will only be accessible to members of the research team. The only exception for this would be if information arose which caused the research team to have any concerns for your welfare or the welfare of others. In these circumstances we would have a duty of care to pass the information on.

You will not be able to be identified in any reports or publications as your data will be anonymised. If you agree to us sharing the information you provide with other researchers (e.g. by making it available in a data archive) then your personal details will not be included.

### **What is the legal basis for processing my personal data?**

According to data protection legislation, we are required to inform you that the legal basis we are applying in order to process your personal data is that 'processing is necessary for the performance of a task carried out in the public interest' (Article 6(1)(e)).

As we will be collecting some data that is defined in the legislation as more sensitive (i.e. information about your ethnic origin), we also need to let you know that we are applying the following condition in law: that the use of your data is 'necessary for scientific or historical research purposes'.

### **What will happen to the data collected, and the results of the research project?**

You will be assigned a unique code, and so your research data will be anonymised. Your data will be stored securely at the University of Sheffield, accessible only to members of the research team. Anonymised data will be kept indefinitely and, if you consent (see below) may be shared with other researchers, in-line with good scientific practise and transparency in research. However, because the data will be anonymised, it will not be possible to link the data back to any particular individual. Any personal data we hold about you (e.g your name) will be stored separately from your research data. We will retain this personal data until November 2020, at which point we will delete it.

You may withdraw your consent to use your data without giving a reason why up until November 2020, which is when we will start analysing the data. To do so you can contact the lead researcher (details below) and we can withdraw your data if you wish. However, after data analysis commences you will no longer be able to withdraw your data from the study.

The results of this study will form part of a Clinical Psychology Doctoral thesis. We also aim to publish the results in an academic journal. As stated above, you won't be personally identified in any reports or publications.

Due to the nature of this research it is very likely that other researchers may find the data collected to be useful in answering future research questions. We will ask for your explicit consent for your data to be shared in this way.

### **Who is organising and funding the research?**

This study is being conducted by Becky Hymas (Trainee Clinical Psychologist), as part of the qualification towards becoming a Doctor of Clinical Psychology at the University of Sheffield. Becky is supervised by Professor Elizabeth Milne, who is also based at the University of Sheffield.

The University of Sheffield will act as the Data Controller for this study. This means that the University is responsible for looking after your information and using it properly.

### **Who has ethically reviewed the project?**

This project has been approved by the University of Sheffield ethical review board. This means that it has been agreed that the project is safe to be conducted in the community.

### **What if something goes wrong and I want to complain about the research?**

If you would like to make a complaint about this project, in the first instance you should contact the lead researcher (Becky Hymas) or their supervisor (Professor Elizabeth Milne). If you do not feel satisfied that your complaint has been dealt with appropriately you can contact the Head of the Psychology Department, Professor Glenn Waller. He can be contacted at the following address: Department of Psychology, University of Sheffield, Cathedral Court, 1 Vicar Lane, Sheffield, S1 2LT.

If your complaint relates to how your personal data has been handled, additional information about how to raise a complaint can be found in the University's Privacy Notice:

<https://www.sheffield.ac.uk/govern/data-protection/privacy/general>.

### **Contact Details**

#### *Lead researcher*

Name: Becky Hymas

Address: Department of Psychology, University of Sheffield, Cathedral Court, 1 Vicar Lane, Sheffield, S1 2LT

Email: rhymas1@sheffield.ac.uk

Telephone: Please email Becky on the above email with your phone number and she will return your call.

#### *Supervisor*

Name: Professor Elizabeth Milne:

Address: Department of Psychology, University of Sheffield, Cathedral Court, 1 Vicar Lane, Sheffield, S1 2LT

Email: e.milne@sheffield.ac.uk

**Thank you very much for taking time to read about this project.**





## **Participant Information Sheet**

### **Multiple group membership, social identity and mental health in Autistic Adults**

You are being invited to take part in a research project looking at social identity in Autistic adults. Before you decide whether or not to participate, it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully and discuss it with others if you wish. Ask us if there is anything that is not clear or if you would like more information; our contact details are at the end of this information leaflet.

#### **What is the purpose of the study/ Why am I being asked to take part?**

Social identity can be defined as your association with various social groups (such as your family, friendship groups, sports teams, volunteering groups etc.) and what these groups mean to you. Some people might define themselves as belonging to lots of social groups, whereas other people may be a member of none, or only a few.

Research within the neurotypical population (i.e., those without a diagnosis of an Autism Spectrum Disorder; ASD) suggest a link between someone's social identity (the number of multiple-social groups they belong to, and their perception of these groups) and their wellbeing, for example their levels of anxiety, depression and stress. We would like to explore whether this association also exists in those with Autism, and how it may be different or similar to people without Autism.

#### **Do I have to take part?**

Taking part in this research is entirely voluntary. If you do not wish to take part, there will be no negative consequences. You may also stop your participation at any time, without needing to explain why.

It is up to you to decide whether or not to take part. If you decide to take part you will be given this information sheet to keep and be asked to complete a consent form, before you complete the questionnaires online.

#### **What will happen if I take part? What will I have to do?**

The study would involve you being sent an online link to fill out some questionnaires. You will be asked to list the social groups you belong to, and to rate statements about aspects of your social life, autism diagnosis and aspects of your mental wellbeing. You will also be asked questions about the impact that the coronavirus (COVID-19) has had on you and your life.

We are also collecting additional information from you including the postcode of your home, your age, gender, ethnicity, marital status, education level, employment status and some information about your Autism diagnosis. We will also ask whether you have any other neurodevelopmental or psychiatric diagnoses.

You will be asked to give some feedback on the experience of completing the online questionnaire. You will be able to offer your feedback via email or telephone, whichever you prefer.

### **What are the possible disadvantages and risks of taking part?**

The questionnaires ask about topics that may be distressing for you. If any of the questions cause you distress, you can contact a member of the research team using the details below.

We are aware that we are asking you to answer questions on your social relationships at a time when you are perhaps practicing social distancing, and your physical contact with others may have reduced. This may increase the distress you feel at this current time. If any of the questions cause you distress, you can discuss this with the main researcher, Becky Hymas.

If taking part in the study raises any concerns about your mental health or social experiences, Becky Hymas can signpost you to services that can offer advice and support. We will also signpost you to services at the end of the questionnaire as part of the debrief procedure.

You can also access a link to a webpage aimed at those with Autism who may be experiencing understandable anxiety around the current COVID-19 situation here: <https://www.autistica.org.uk/what-is-autism/coping-with-uncertainty>

### **What are the possible benefits of taking part?**

A lot of people who take part in research find it a rewarding experience. It is hoped that this work will help us to better understand the experiences of autistic adults' social worlds, and whether this is associated with mental wellbeing.

### **Will my taking part in this project be kept confidential?**

Any written feedback provided by you, or noted down by the researcher will be kept in a secure location online (in a password-protected document). Information about you collected during this research will be anonymised and used only for analysis purposes. All the information that you provide will be kept strictly confidential and will only be accessible to members of the research team. The only exception for this would be if information arose which caused the research team to have any concerns for your welfare or the welfare of others. In these circumstances we would have a duty of care to pass the information on.

You will not be able to be identified in any reports or publications as your data will be anonymised. If you agree to us sharing the information you provide with other researchers (e.g. by making it available in a data archive) then your personal details will not be included.

### **What is the legal basis for processing my personal data?**

According to data protection legislation, we are required to inform you that the legal basis we are applying in order to process your personal data is that 'processing is necessary for the performance of a task carried out in the public interest' (Article 6(1)(e)).

As we will be collecting some data that is defined in the legislation as more sensitive (i.e. information about your ethnic origin), we also need to let you know that we are applying the following condition in law: that the use of your data is 'necessary for scientific or historical research purposes'.

### **What will happen to the data collected, and the results of the research project?**

You will be assigned a unique code, and so your research data will be anonymised. Your data will be stored securely at the University of Sheffield, accessible only to members of the research team. Anonymised data will be kept indefinitely and, if you consent (see below) may be shared with other researchers, in-line with good scientific practise and transparency in research. However, because the data will be anonymised, it will not be possible to link the data back to any particular individual. Any personal data we hold about you (e.g your name) will be stored separately from your research data. We will retain this personal data until December 2020, at which point we will delete it.

You may withdraw your consent to use your data without giving a reason why up until December 2020, which is when we will start analysing the data. To do so you can contact Becky Hymas (details below) and we can withdraw your data if you wish. However, after data analysis commences you will no longer be able to withdraw your data from the study.

The results of this study will form part of a Clinical Psychology Doctoral thesis. We also aim to publish the results in an academic journal. As stated above, you wont be personally identified in any reports or publications.

Due to the nature of this research it is very likely that other researchers may find the data collected to be useful in answering future research questions. We will ask for your explicit consent for your data to be shared in this way.

### **Who is organising and funding the research?**

This study is being conducted by Becky Hymas (Trainee Clinical Psychologist), as part of the qualification towards becoming a Doctor of Clinical Psychology at the University of Sheffield. Becky is supervised by Professor Elizabeth Milne, who is also based at the University of Sheffield.

The University of Sheffield will act as the Data Controller for this study. This means that the University is responsible for looking after your information and using it properly.

### **Who has ethically reviewed the project?**

This project has been approved by the University ethical review board. This means that it has been agreed that the project is safe to be conducted in the community.

### **What if something goes wrong and I want to complain about the research?**

If you would like to make a complaint about this project, in the first instance you should contact the lead researcher (Becky Hymas). If you do not feel satisfied that your complaint

has been dealt with appropriately you can contact the Head of the Psychology Department, Professor Elizabeth Milne. She can be contacted via the details below.

If your complaint relates to how your personal data has been handled, additional information about how to raise a complaint can be found in the University's Privacy Notice: <https://www.sheffield.ac.uk/govern/data-protection/privacy/general>.

### **Contact Details**

#### *Lead researcher*

Name: Becky Hymas

Address: Department of Psychology, University of Sheffield, Cathedral Court, 1 Vicar Lane, Sheffield, S1 2LT

Email: rhymas1@sheffield.ac.uk

Telephone: Please email Becky on the above email with your phone number and she will return your call.

#### *Supervisor*

Name: Professor Elizabeth Milne:

Address: Department of Psychology, University of Sheffield, Cathedral Court, 1 Vicar Lane, Sheffield, S1 2LT

Email: e.milne@sheffield.ac.uk

**Thank you very much for taking time to read about this project.**



## Participant Information Sheet

### **Multiple group membership, social identity and mental health in Autistic and Neurotypical Adults**

You are being invited to take part in a research project looking at social identity in Autistic adults and adults without a diagnosis of Autism Spectrum Disorder (i.e., 'neurotypical adults'). Before you decide whether or not to participate, it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully and discuss it with others if you wish. Ask us if there is anything that is not clear or if you would like more information; our contact details are at the end of this information leaflet.

#### **What is the purpose of the study/ Why am I being asked to take part?**

Social identity can be defined as your association with various social groups (such as your family, friendship groups, sports teams, volunteering groups etc.) and what these groups mean to you. Some people might define themselves as belonging to lots of social groups, whereas other people may be a member of none, or only a few.

Research within the neurotypical population suggest a link between someone's social identity (the number of multiple-social groups they belong to, and their perception of these groups) and their wellbeing, for example their levels of anxiety, depression and stress. We would like to explore whether this association also exists in those with Autism, and how it may be different or similar to people without Autism.

#### **Do I have to take part?**

Taking part in this research is entirely voluntary. If you do not wish to take part, there will be no negative consequences. You may also stop your participation at any time, without needing to explain why.

It is up to you to decide whether or not to take part. If you decide to take part you will have the opportunity to download this information sheet to keep and be asked to complete an online consent form, before you complete the questionnaires online.

#### **What will happen if I take part? What will I have to do?**

The study would involve you completing some questionnaires. You will be asked to list the social groups you belong to, and to rate statements about aspects of your social life, autism diagnosis (if you have one) and aspects of your mental wellbeing. You will also be asked questions about the impact that the coronavirus (COVID-19) has had on you and your life.

We are also collecting additional information from you including the postcode of your home, your age, gender, ethnicity, marital status, education level, employment status and some information about your Autism diagnosis (if you have one). We will also ask whether you have any other neurodevelopmental or psychiatric diagnoses.

### **What are the possible disadvantages and risks of taking part?**

The questionnaires ask about topics that may be distressing for you. If any of the questions cause you distress, you can contact Becky Hymas using the details below.

We are aware that we are asking you to answer questions on your social relationships at a time when you are perhaps practicing social distancing, and your physical contact with others may have reduced. This may increase the distress you feel at this current time. If any of the questions cause you distress, you can discuss this with the main researcher, Becky Hymas.

If taking part in the study raises any concerns about your mental health or social experiences, Becky Hymas can signpost you to services that can offer advice and support. We will also signpost you to services at the end of the questionnaire as part of the debrief procedure.

If you feel distressed about the current COVID-19 situation, you can access a link to a webpage which offers advice and can signpost you to support here: <https://www.helpguide.org/articles/anxiety/coronavirus-anxiety.htm>. You can also access a link to a webpage aimed at those with Autism who may be experiencing understandable anxiety around the current COVID-19 situation here: <https://www.autistica.org.uk/what-is-autism/coping-with-uncertainty>

### **What are the possible benefits of taking part?**

A lot of people who take part in research find it a rewarding experience. It is hoped that this work will help us to better understand the experiences of autistic and neurotypical adults' social worlds, and whether this is associated with mental wellbeing.

### **Will my taking part in this project be kept confidential?**

Information about you collected during this research will be anonymised and used only for analysis purposes. All the information that you provide will be kept strictly confidential and will only be accessible to members of the research team.

You will not be able to be identified in any reports or publications as your data will be anonymised. If you agree to us sharing the information you provide with other researchers (e.g. by making it available in a data archive) then your personal details will not be included.

### **What is the legal basis for processing my personal data?**

According to data protection legislation, we are required to inform you that the legal basis we are applying in order to process your personal data is that 'processing is necessary for the performance of a task carried out in the public interest' (Article 6(1)(e)).

As we will be collecting some data that is defined in the legislation as more sensitive (i.e. information about your ethnic origin), we also need to let you know that we are applying the

following condition in law: that the use of your data is 'necessary for scientific or historical research purposes'.

### **What will happen to the data collected, and the results of the research project?**

You will be assigned a unique code, and so your research data will be anonymised. Your data will be stored securely at the University of Sheffield, accessible only to members of the research team. Anonymised data will be kept indefinitely and, if you consent (see below) may be shared with other researchers, in-line with good scientific practise and transparency in research. However, because the data will be anonymised, it will not be possible to link the data back to any particular individual. Any personal data we hold about you (e.g., your email address, if you decide to provide this) will be stored separately from your research data. We will retain this personal data until June 2021, at which point we will delete it.

You may withdraw your consent to use your data without giving a reason why up until March 2021, which is when we will start analysing the data. To do so you can contact Becky Hymas (details below) and we can withdraw your data if you wish. However, after data analysis commences you will no longer be able to withdraw your data from the study.

The results of this study will form part of a Clinical Psychology Doctoral thesis. We also aim to publish the results in an academic journal. As stated above, you won't be personally identified in any reports or publications.

Due to the nature of this research it is very likely that other researchers may find the data collected to be useful in answering future research questions. We will ask for your explicit consent for your data to be shared in this way.

### **Who is organising and funding the research?**

This study is being conducted by Becky Hymas (Trainee Clinical Psychologist), as part of the qualification towards becoming a Doctor of Clinical Psychology at the University of Sheffield. Becky is supervised by Professor Elizabeth Milne, who is also based at the University of Sheffield.

The University of Sheffield will act as the Data Controller for this study. This means that the University is responsible for looking after your information and using it properly.

### **Who has ethically reviewed the project?**

This project has been approved by the University ethical review board. This means that it has been agreed that the project is safe to be conducted in the community.

### **What if something goes wrong and I want to complain about the research?**

If you would like to make a complaint about this project, in the first instance you should contact the lead researcher (Becky Hymas). If you do not feel satisfied that your complaint has been dealt with appropriately you can contact the Head of the Psychology Department, Professor Elizabeth Milne. She can be contacted via the details below.

If your complaint relates to how your personal data has been handled, additional information about how to raise a complaint can be found in the University's Privacy Notice:

<https://www.sheffield.ac.uk/govern/data-protection/privacy/general>.

**Contact Details***Lead researcher*

Name: Becky Hymas

Address: Department of Psychology, University of Sheffield, Cathedral Court, 1 Vicar Lane, Sheffield, S1 2LT

Email: rhymas1@sheffield.ac.uk

Telephone: Please email Becky on the above email with your phone number and she will return your call.

*Supervisor*

Name: Professor Elizabeth Milne:

Address: Department of Psychology, University of Sheffield, Cathedral Court, 1 Vicar Lane, Sheffield, S1 2LT

Email: e.milne@sheffield.ac.uk

**Thank you very much for taking time to read about this project.**



## Appendix G

### Consent Form: Pilot Stage 1

<b>Please tick the appropriate boxes (responses will be able to be clicked through the online questionnaire platform, Qualtrics)</b>	<b>Yes</b>	<b>No</b>
<b>Taking Part in the Project</b>		
I have read and understood the project information sheet or the project has been fully explained to me. (If you will answer No to this question please do not proceed with this consent form until you are fully aware of what your participation in the project will mean.)		
I have been given the opportunity to ask questions about the project.		
I agree to take part in the project. I understand that taking part in the project will involve me completing questionnaires online and being interviewed via audio or video-call.		
I understand that my participation is voluntary and that I can withdraw from the study at any time before November 2020. I do not have to give any reasons for why I no longer want to take part and there will be no adverse consequences if I choose to withdraw from the project.		
<b>How my information will be used during and after the project</b>		
I understand my personal details such as name, address and contact details etc. will not be revealed to people outside the project.		
I understand and agree that my words may be quoted in publications, reports, web pages, and other research outputs. I understand that I will not be named in these outputs.		
I understand and agree that other authorised researchers will have access to this data only if they agree to preserve the confidentiality of the information as requested in this form.		
I understand and agree that other authorised researchers may use my data in publications, reports, web pages, and other research outputs, only if they agree to preserve the confidentiality of the information as requested in this form.		
I give permission for the questionnaire data that I provide to be stored in White Rose depository, so it can be used for future research and learning.		
<b>So that the information you provide can be used legally by the researchers</b>		
I agree to assign the copyright I hold in any materials generated as part of this project to The University of Sheffield.		

## Consent Form: Pilot Stage 2

<b>Please tick the appropriate boxes (responses will be able to be clicked through the online questionnaire platform, Qualtrics)</b>	<b>Yes</b>	<b>No</b>
<b>Taking Part in the Project</b>		
I have read and understood the project information sheet or the project has been fully explained to me. (If you will answer No to this question please do not proceed with this consent form until you are fully aware of what your participation in the project will mean.)		
I have been given the opportunity to ask questions about the project.		
I agree to take part in the project. I understand that taking part in the project will involve me completing questionnaires online and providing feedback on this through email or telephone.		
I understand that my participation is voluntary and that I can withdraw from the study at any time before November 2020. I do not have to give any reasons for why I no longer want to take part and there will be no adverse consequences if I choose to withdraw from the project.		
<b>How my information will be used during and after the project</b>		
I understand my personal details such as name, address and contact details etc. will not be revealed to people outside the project.		
I understand and agree that my words may be quoted in publications, reports, web pages, and other research outputs. I understand that I will not be named in these outputs.		
I understand and agree that other authorised researchers will have access to this data only if they agree to preserve the confidentiality of the information as requested in this form.		
I understand and agree that other authorised researchers may use my data in publications, reports, web pages, and other research outputs, only if they agree to preserve the confidentiality of the information as requested in this form.		
I give permission for the questionnaire data that I provide to be stored in White Rose depository, so it can be used for future research and learning.		
<b>So that the information you provide can be used legally by the researchers</b>		
I agree to assign the copyright I hold in any materials generated as part of this project to The University of Sheffield.		

*Consent Form: Final Survey*

<b>Please tick the appropriate boxes (responses will be able to be clicked through the online questionnaire platform, Qualtrics)</b>	<b>Yes</b>	<b>No</b>
<b>Taking Part in the Project</b>		
I have read and understood the project information sheet or the project has been fully explained to me. (If you will answer No to this question please do not proceed with this consent form until you are fully aware of what your participation in the project will mean.)		
I have been given the opportunity to ask questions about the project.		
I agree to take part in the project. I understand that taking part in the project will involve me completing questionnaires online.		
I understand that my participation is voluntary and that I can withdraw from the study at any time before March 2021. I do not have to give any reasons for why I no longer want to take part and there will be no adverse consequences if I choose to withdraw from the project.		
<b>How my information will be used during and after the project</b>		
I understand my personal details such as name, address and contact details etc. will not be revealed to people outside the project.		
I understand and agree that my words may be quoted in publications, reports, web pages, and other research outputs. I understand that I will not be named in these outputs.		
I understand and agree that other authorised researchers will have access to this data only if they agree to preserve the confidentiality of the information as requested in this form.		
I understand and agree that other authorised researchers may use my data in publications, reports, web pages, and other research outputs, only if they agree to preserve the confidentiality of the information as requested in this form.		
I give permission for the questionnaire data that I provide to be stored in White Rose depository, so it can be used for future research and learning.		
<b>So that the information you provide can be used legally by the researchers</b>		
I agree to assign the copyright I hold in any materials generated as part of this project to The University of Sheffield.		

## Appendix H

### Debrief Form: Pilot Stage 1



Thank you for taking part in this study.

The aim of the study was to get your feedback on how it felt to answer questions on group membership and social identity in this format. Please [email me](#) now you have finished the study so we can arrange a telephone or video call to discuss your thoughts and experiences of this questionnaire.

The study asked some personal questions which may have been distressing. If you feel you need further support regarding your mental health, you can contact the support services below which are open 24/7.

**Samaritans:** 116 123

**Sheffield Rethink Helpline:** 0808 801 0440

**NHS** 111

You can also make an appointment with your GP.

We are aware that the current situation with Covid19 may mean that this is a particularly anxious time for you, clicking this [link](#) takes you to a webpage which details guidance around coping with the uncertainty of the Coronavirus and its impact, including strategies to alleviate anxiety and further signposting to resources if required. The information on this webpage is specific for Autistic people. Alternatively, clicking on this [link](#) will take you to a more general website aimed at people who may feel distressed as a result of the Coronavirus and its impact. This also includes advice and signposting to additional services.

If you would like to raise any concerns regarding this study please contact me to discuss this with me.

Thank you for taking the time to be involved in this research.

Becky Hymas

Trainee Clinical Psychologist

Under the supervision of Professor Elizabeth Milne

Contact Details

Email:

[rhymas1@sheffield.ac.uk](mailto:rhymas1@sheffield.ac.uk)

*Debrief Form: Pilot Stage 2*

Thank you for taking part in this study.

The aim of the study was to get your feedback on how it felt to answer questions on group membership, social identity, COVID-19 and mental health in this format. Please [email me](#) now you have finished the study so we can arrange a telephone call to discuss your thoughts and experiences of this questionnaire. Alternatively, you can email me your feedback if you have opted to do this instead.

The study asked some personal questions which may have been distressing. If you feel you need further support regarding your mental health, you can contact the support services below which are open 24/7.

**Samaritans:** 116 123

**Sheffield Rethink Helpline:** 0808 801 0440

**NHS** 111

You can also make an appointment with your GP.

We are aware that the current situation with Covid19 may mean that this is a particularly anxious time for you, clicking this [link](#) takes you to a webpage which details guidance around coping with the uncertainty of the Coronavirus and its impact, including strategies to alleviate anxiety and further signposting to resources if required. The information on this webpage is specific for Autistic people. Alternatively, clicking on this [link](#) will take you to a more general website aimed at people who may feel distressed as a result of the Coronavirus and its impact. This also includes advice and signposting to additional services.

If you would like to raise any concerns regarding this study please contact me to discuss this with me.

Thank you for taking the time to be involved in this research.

Becky Hymas

Trainee Clinical Psychologist

Under the supervision of Professor Elizabeth Milne

Contact Details

Email:

rhymas1@sheffield.ac.uk

*Debrief Form: Final Survey*



Thank you for taking part in this study.

The aim of this study was to explore the relationship between group membership, social identity and mental health, whilst also considering the impact of Covid-19.

The study asked some personal questions which may have been distressing. If you feel you need further support regarding your mental health, you can contact the support services below which are open 24/7.

**Samaritans:** 116 123

**Sheffield Rethink Helpline:** 0808 801 0440

**NHS** 111

You can also make an appointment with your GP.

We are aware that the current situation with Covid-19 may mean that this is a particularly anxious time for you, clicking this [link](#) takes you to a webpage which details guidance around coping with the uncertainty of the Coronavirus and its impact, including strategies to alleviate anxiety and further signposting to resources if required. The information on this webpage is specific for Autistic people. Alternatively, clicking on this [link](#) will take you to a more general website aimed at people who may feel distressed as a result of the Coronavirus and its impact. This also includes advice and signposting to additional services.

If you would like to raise any concerns regarding this study please contact me to discuss this with me.

Thank you for taking the time to be involved in this research.

Becky Hymas

Trainee Clinical Psychologist

Under the supervision of Professor Elizabeth Milne

Contact Details

Email:

[rhymas1@sheffield.ac.uk](mailto:rhymas1@sheffield.ac.uk)

## Appendix I

### *Ethical Approval Letter*



Downloaded: 10/01/2020

Approved: 20/12/2019

Rebecca Hymas  
 Registration number: 180156900  
 Psychology  
 Programme: Doctorate in Clinical Psychology

Dear Rebecca

**PROJECT TITLE:** Social Identity in Autistic Adults: An Exploratory Study

**APPLICATION:** Reference Number 032107

On behalf of the University ethics reviewers who reviewed your project, I am pleased to inform you that on 20/12/2019 the above-named project was **approved** on ethics grounds, on the basis that you will adhere to the following documentation that you submitted for ethics review:

- University research ethics application form 032107 (form submission date: 09/12/2019); (expected project end date: 28/05/2021).
- Participant information sheet 1073576 version 1 (09/12/2019).
- Participant information sheet 1073570 version 1 (09/12/2019).
- Participant information sheet 1073569 version 1 (09/12/2019).
- Participant consent form 1073574 version 1 (09/12/2019).
- Participant consent form 1073573 version 1 (09/12/2019).
- Participant consent form 1073572 version 1 (09/12/2019).

If during the course of the project you need to [deviate significantly from the above-approved documentation](#) please inform me since written approval will be required.

Your responsibilities in delivering this research project are set out at the end of this letter.

Yours sincerely

Thomas Webb  
 Ethics Administrator  
 Psychology

Please note the following responsibilities of the researcher in delivering the research project:

- The project must abide by the University's Research Ethics Policy: <https://www.sheffield.ac.uk/rs/ethicsandintegrity/ethicspolicy/approval-procedure>
  - The project must abide by the University's Good Research & Innovation Practices Policy: [https://www.sheffield.ac.uk/po/po/poly\\_fs/1\\_6710661/file/GRIPPolicy.pdf](https://www.sheffield.ac.uk/po/po/poly_fs/1_6710661/file/GRIPPolicy.pdf)
  - The researcher must inform their supervisor (in the case of a student) or Ethics Administrator (in the case of a member of staff) of any significant changes to the project or the approved documentation.
  - The researcher must comply with the requirements of the law and relevant guidelines relating to security and confidentiality of personal data.
  - The researcher is responsible for effectively managing the data collected both during and after the end of the project in line with best practice, and any relevant legislative, regulatory or contractual requirements.
-

**Appendix J***Demographics and Covid-19 Questionnaire*

What is your home postcode? \_\_\_\_\_

---

What is your date of birth? (dd/mm/yyyy e.g., 01/03/1980) \_\_\_\_\_

---

What was your Sex at birth?

- Male
  - Female
  - Intersex
  - Prefer not to answer
- 

To which gender identity do you most identify with?

- Male
  - Female
  - Transgender Male
  - Transgender Female
  - Gender Variant/Non-conforming
  - Other (please specify) \_\_\_\_\_
  - Prefer not to say
- 

What is your ethnicity?

- White (English/ Welsh/ Scottish/ Northern Irish)
- White (Irish)
- White (Gypsy/Traveller)



- Black (African)*
  - Black (Caribbean)*
  - Black (British)*
  - Mixed/Multiple ethnic groups (White and Black Caribbean)*
  - Mixed/Multiple ethnic groups (White and Black African)*
  - Mixed/Multiple ethnic groups (White and Asian)*
  - Asian (Indian)*
  - Asian (Pakistani)*
  - Asian (Bangladeshi)*
  - Asian (Chinese)*
  - Arab*
  - Other ethnic group (please specify)\_\_\_\_\_*
- 

*What is your highest degree or level of school you have completed?*

- Less than Secondary School*
  - Secondary School*
  - Sixth form/College*
  - University (Undergraduate Bachelor's degree)*
  - University (Postgraduate Master's degree)*
  - University (PhD or Doctorate Postgraduate degree)*
- 

*What is your current employment status?*

- Full-time paid work (37+ hours)*
- Part-time paid work (less than 37 hours)*

- Self-employed
  - Unemployed (looking for work)
  - Unemployed (not looking for work)
  - Student
  - Retired
  - Unable to work
- 

*Please select how your employment has changed since March 2020 (as a direct or indirect consequence of the government-enforced lockdown). Please read all the options before selecting your choice.*

- I continue to be unemployed, a student, retired or unable to work
  - I am still employed in the same job I was in before lockdown
  - I am still employed, however I am employed in a different job compared to before lockdown
  - Before lockdown I was employed, however I am now unemployed and I am receiving some financial support from the government
  - Before lockdown I was employed, however I am now unemployed and I am not receiving any financial support from the government
- 

*Are you currently living alone?*

- Yes
  - No (If so, please state how many people live in your household, including yourself)\_\_\_\_\_
- 

*Q2.16 Do you have any children (under the age of 18) living in your household?*

- Yes (If so, please state how many)\_\_\_\_\_
  - No
-

Coronavirus (COVID-19) can make anyone seriously ill. But for some people, the risk is higher.

There are 2 levels of higher risk:

1. *High risk (clinically extremely vulnerable).* If you are at high risk, you should have received a letter from the National Health Service or Chief Medical Officer indicating that you have been identified as someone at risk of severe illness should you contract COVID-19, because you have an underlying disease or health condition. You would have been advised to take extra steps to protect yourself until 1st August 2020. This was called 'shielding'.

2. *Moderate risk (clinically vulnerable).* You are at moderate risk if you are aged 70 or over, are pregnant, very obese, are taking medication that affects your immune system, or have a health condition outlined by the government as making you at moderate risk.

Please choose which category you belong to:

- I am considered at high risk (clinically extremely vulnerable)
- I am considered at moderate risk (clinically vulnerable)
- I am not considered at moderate or high risk and I have not had to 'shield'
- I am not considered at moderate or high risk although I have had to shield due to a member of my household being at moderate or high risk.

Have you had, or do you currently consider yourself to have COVID-19 symptoms (e.g., a high temperature, a new, continuous cough and/or a loss or change to your sense of smell or taste) which has required you to self-isolate in line with government guidelines?

- Yes, I have officially tested positive for COVID-19 currently or previously.
- Yes, I consider myself to have (or have previously had) COVID-19 symptoms, although I have not been officially tested.
- No, I do not consider myself to have had COVID-19 symptoms, or I have officially tested negative for COVID-19.
- I am unsure whether I currently have (or have previously had) COVID-19 symptoms.

#### Work and Social Adjustment Scale (WASA)

The following questions ask about whether you feel your life has been impaired due to the changes that have occurred because of COVID-19. Rate each of the following questions on a 0-8 scale: 0 indicates no impairment at all and 8 indicates very severe impairment.

0 = No impairment at all

8 = Very severe impairment

1. Because of the impact of COVID-19, my ability to work is impaired.



2. Because of the impact of COVID-19 my home management (cleaning, tidying, shopping, cooking, looking after home or children, paying bills) is impaired.



3. Because of the impact of COVID-19 my social leisure activities (with other people, such as parties, bars, clubs, outings, visits, dating, home entertainment) are impaired.



4. Because of the impact of COVID-19 my private leisure activities (done alone, such as reading, gardening, collecting, sewing, walking alone) are impaired.



5. Because of the impact of COVID-19 my ability to form and maintain close relationships with others, including those I live with, is impaired.



Have you been diagnosed with an autism spectrum condition? E.g., Autism, Asperger's, Autism Spectrum Disorder (ASD), Autism Spectrum Condition (ASC), Pervasive Developmental Disorder- Not Otherwise Specified (PDD)? If so, please specify which diagnosis you have, or how you refer to your condition.

- Yes, I have an official diagnosis (please specify) \_\_\_\_\_
- No, I don't have an official diagnosis, but I self-identify as having Autism (please specify) \_\_\_\_\_
- No I do not have a diagnosis, nor do I identify as having Autism

How old were you (in years) when you were diagnosed, or self-identified as having an Autism Spectrum Condition? \_\_\_\_\_

Do you have a diagnosis of any psychiatric (mental health), physical, or neurodevelopmental conditions (other than an Autism Spectrum Condition)?

- Yes (please specify) \_\_\_\_\_
- No

**Appendix K**  
RAADS-14

Name:	Patient ID:
Date:	Clinician:

Please choose one of the following alternatives:

This is true or describes me now and when I was young.

This was true or describes me only now (refers to skills acquired).

This was true only when I was young (16 years or younger).

This was never true and never described me.

Please answer the questions according to what is true for you. Check only one column per statement!

Some life experiences and personality characteristics that may apply to you	True now and when I was young	True only now	True only when I was younger than 16	Never true
1. It is difficult for me to understand how other people are feeling when we are talking.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
2. Some ordinary textures that do not bother others feel very offensive when they touch my skin.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
3. It is very difficult for me to work and function in groups.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
4. It is difficult to figure out what other people expect of me.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
5. I often don't know how to act in social situations.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
6.* I can chat and make small talk with people.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
7. When I feel overwhelmed by my senses, I have to isolate myself to shut them down.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
8. How to make friends and socialize is a mystery to me.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
9. When talking to someone, I have a hard time telling when it is my turn to talk or to listen.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
10. Sometimes I have to cover my ears to block out painful noises (like vacuum cleaners or people talking too much or too loudly).	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
11. It can be very hard to read someone's face, hand, and body movements when we are talking.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
12. I focus on details rather than the overall idea.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
13. I take things too literally, so I often miss what people are trying to say.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
14. I get extremely upset when the way I like to do things is suddenly changed	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

## Appendix L

### *Social Identification with Groups Questionnaire*

*Please think about all the groups you belong to. A group can be two or more people (including you). You do not need to physically 'meet up' with members for it to count as a group.*

*These groups can take any form, for example they could be:*

- *Demographic groups (e.g., your nationality, gender, ethnic groups)*
- *Family or friendship groups*
- *Broad opinion-based groups (e.g., political or activist groups)*
- *Leisure, social or sports groups (e.g., book clubs, gardening groups, tennis club)*
- *Community groups (e.g., church groups)*
- *Work or professional groups (e.g., university, sales team)*
- *Online groups (e.g., gaming or social media groups)*
- *Any other groups you can think of.*

*Your memberships to social groups may have changed since COVID-19 lockdown restrictions came into place in March 2020. For example:*

- *You may have changed the way you communicate with other members of a group (e.g., communicating online instead of face-to-face).*
- *You may have stopped communication with members of a group, but still consider yourself to be a member of it.*
- *You may have joined additional groups.*
- *You may have stopped being a member of a group.*

*On the next page you will be asked to list the groups you belong to, and you will be asked further questions for each group you state you belong to.*

*I do not belong to any groups*

*I belong to groups that I would like to list*

---

*Please enter all the groups you feel you belong to currently (only enter one group per box), up to a maximum of 20 groups.*

*Group 1* \_\_\_\_\_

*Group 2)* \_\_\_\_\_

*Group 3* \_\_\_\_\_

*Group 4* \_\_\_\_\_

*Group 5* \_\_\_\_\_

- Group 6* \_\_\_\_\_
  - Group 7* \_\_\_\_\_
  - Group 8* \_\_\_\_\_
  - Group 9* \_\_\_\_\_
  - Group 10* \_\_\_\_\_
  - Group 11* \_\_\_\_\_
  - Group 12* \_\_\_\_\_
  - Group 13* \_\_\_\_\_
  - Group 14* \_\_\_\_\_
  - Group 15* \_\_\_\_\_
  - Group 16* \_\_\_\_\_
  - Group 17* \_\_\_\_\_
  - Group 18* \_\_\_\_\_
  - Group 19* \_\_\_\_\_
  - Group 20* \_\_\_\_\_
-

With regards to your [.....] group you wrote down:

1 2 3 4 5 6 7 8 9 10

*How important is this group to you? Where 1 is not at all important and 10 is very important*



*How positive do you feel about belonging to this group? Where 1 is not at all positive and 10 is very positive*



*How similar are you to other members of this group (i.e., How representative or typical are you of this group as a whole)? Where 1 is not at all similar and 10 is very similar*



*How much support (social, emotional or practical) do you receive from this group? Where 1 is no support at all and 10 is a lot of support*



*How many days per month, on average, do you spend on activities relating to this group? (0-30)*




---

*Please use the space below if you want to comment on your answers to any of the questions relating to your group membership.*

---



---



---



---



## Appendix M

## DASS-21

<b>DASS<sub>21</sub></b>		Name:	Date:
<p>Please read each statement and circle a number 0, 1, 2 or 3 which indicates how much the statement applied to you over <i>the past week</i>. There are no right or wrong answers. Do not spend too much time on any statement.</p> <p><i>The rating scale is as follows:</i></p> <p>0 Did not apply to me at all            1 Applied to me to some degree, or some of the time            2 Applied to me to a considerable degree, or a good part of time            3 Applied to me very much, or most of the time</p>			
1	I found it hard to wind down	0	1 2 3
2	I was aware of dryness of my mouth	0	1 2 3
3	I couldn't seem to experience any positive feeling at all	0	1 2 3
4	I experienced breathing difficulty (eg, excessively rapid breathing, breathlessness in the absence of physical exertion)	0	1 2 3
5	I found it difficult to work up the initiative to do things	0	1 2 3
6	I tended to over-react to situations	0	1 2 3
7	I experienced trembling (eg, in the hands)	0	1 2 3
8	I felt that I was using a lot of nervous energy	0	1 2 3
9	I was worried about situations in which I might panic and make a fool of myself	0	1 2 3
10	I felt that I had nothing to look forward to	0	1 2 3
11	I found myself getting agitated	0	1 2 3
12	I found it difficult to relax	0	1 2 3
13	I felt down-hearted and blue	0	1 2 3
14	I was intolerant of anything that kept me from getting on with what I was doing	0	1 2 3
15	I felt I was close to panic	0	1 2 3
16	I was unable to become enthusiastic about anything	0	1 2 3
17	I felt I wasn't worth much as a person	0	1 2 3
18	I felt that I was rather touchy	0	1 2 3
19	I was aware of the action of my heart in the absence of physical exertion (eg, sense of heart rate increase, heart missing a beat)	0	1 2 3
20	I felt scared without any good reason	0	1 2 3
21	I felt that life was meaningless	0	1 2 3

**Appendix N***Loneliness Measure*

How often do you feel the following?

	Hardly ever or never	Some of the time	Often
How often do you feel you lack companionship?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
How often do you feel left out?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
How often do you feel isolated from others?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

## Appendix O

### Normality Checks for Samples

#### Neurotypical Sample

	Kolmogorov-Smirnov <sup>b</sup>			Shapiro-Wilk		
	Statistic	df	Sig.	Statistic	df	Sig.
Index of Multiple Deprivation	.141	157	.000	.929	157	.000
Age of Participants	.201	174	.000	.863	174	.000
Work and Social Adjustment Scale Total Score	.070	174	.036	.983	174	.032
RAADS-14 Total Score	.193	174	.000	.841	174	.000
DASS Stress Score x2	.122	174	.000	.948	174	.000
DASS Depression Score x2	.141	174	.000	.908	174	.000
DASS Anxiety Score x2	.223	174	.000	.802	174	.000
DASS Total Score x2	.117	174	.000	.920	174	.000
Self-Esteem	.205	174	.000	.911	174	.000
Number of Groups Participant Belongs To	.171	174	.000	.862	174	.000
Participant's Number of Important Groups	.149	166	.000	.862	166	.000
Participant's Number of Groups they Feel Positive about Belonging to	.154	166	.000	.849	166	.000
Total UCLA Loneliness Score	.160	170	.000	.899	170	.000

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

a. Identified Group = Neurotypical

b. Lilliefors Significance Correction

#### Autistic Sample

	Kolmogorov-Smirnov <sup>b</sup>			Shapiro-Wilk		
	Statistic	df	Sig.	Statistic	df	Sig.
Index of Multiple Deprivation	.123	176	.000	.921	176	.000
Age of Participants	.136	199	.000	.925	199	.000
Work and Social Adjustment Scale Total Score	.082	199	.002	.983	199	.019
RAADS-14 Total Score	.103	199	.000	.930	199	.000
DASS Stress Score x2	.072	199	.014	.983	199	.018

DASS Depression Score x2	.088	199	.001	.960	199	.000
DASS Anxiety Score x2	.101	199	.000	.956	199	.000
DASS Total Score x2	.060	199	.079	.985	199	.028
Self-Esteem	.199	199	.000	.869	199	.000
Number of Groups Participant Belongs To	.137	199	.000	.880	199	.000
Participant's Number of Important Groups	.173	183	.000	.831	183	.000
Participant's Number of Groups they Feel Positive about Belonging to	.186	183	.000	.841	183	.000
Total UCLA Loneliness Score	.163	188	.000	.884	188	.000

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

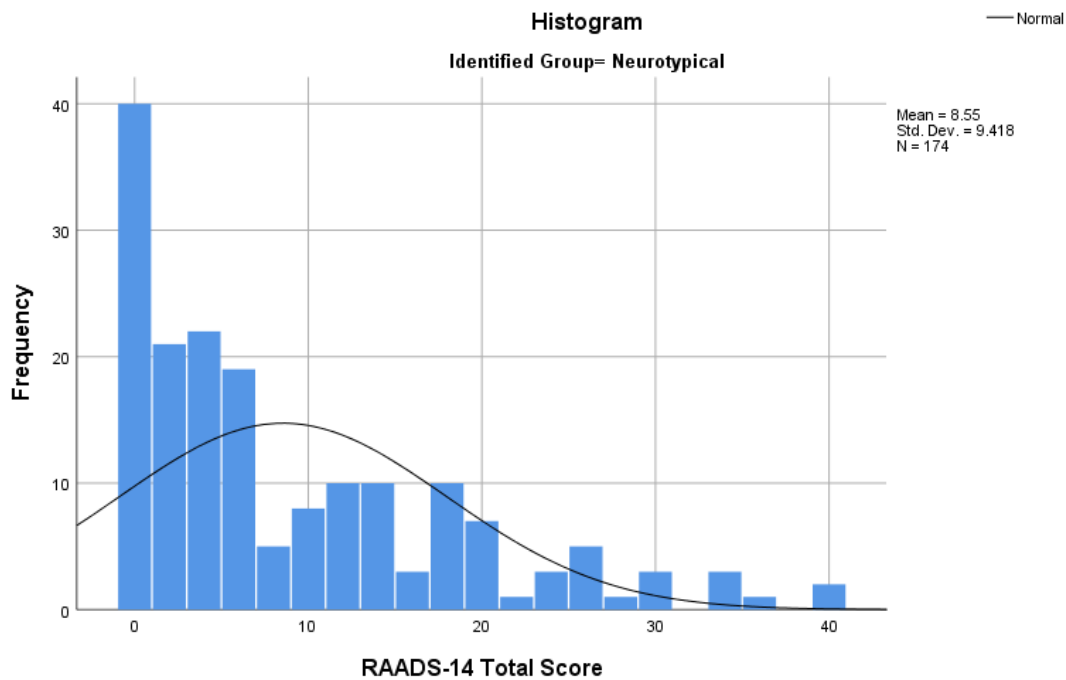
a. Identified Group = Autistic

b. Lilliefors Significance Correction

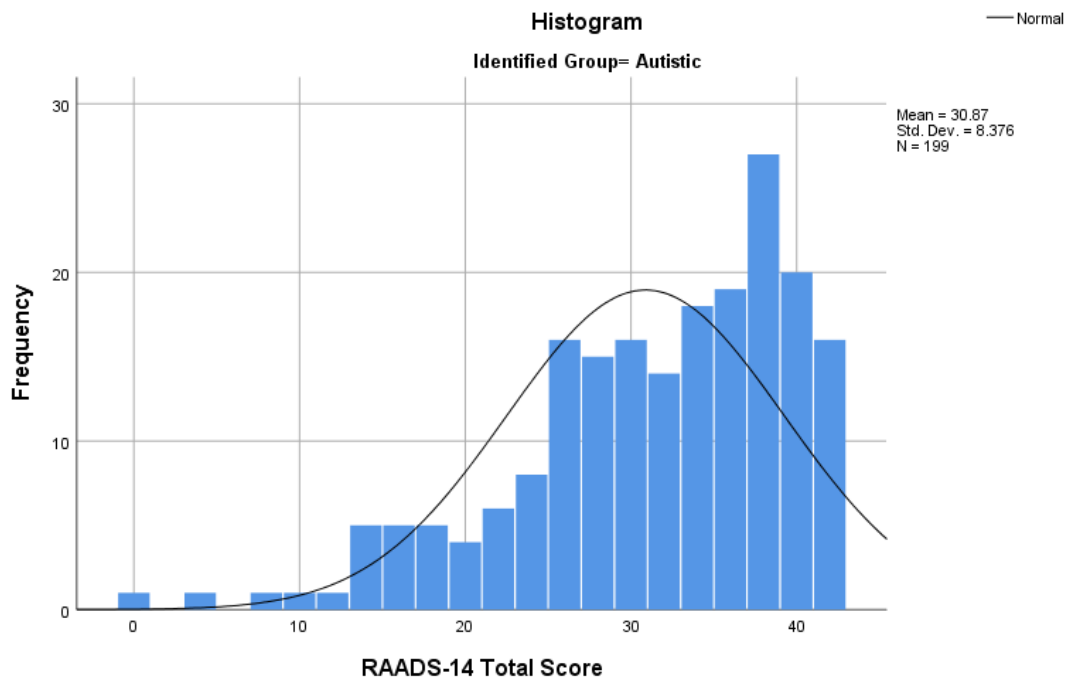
### RAADS-14

#### Histograms

#### Neurotypical Sample

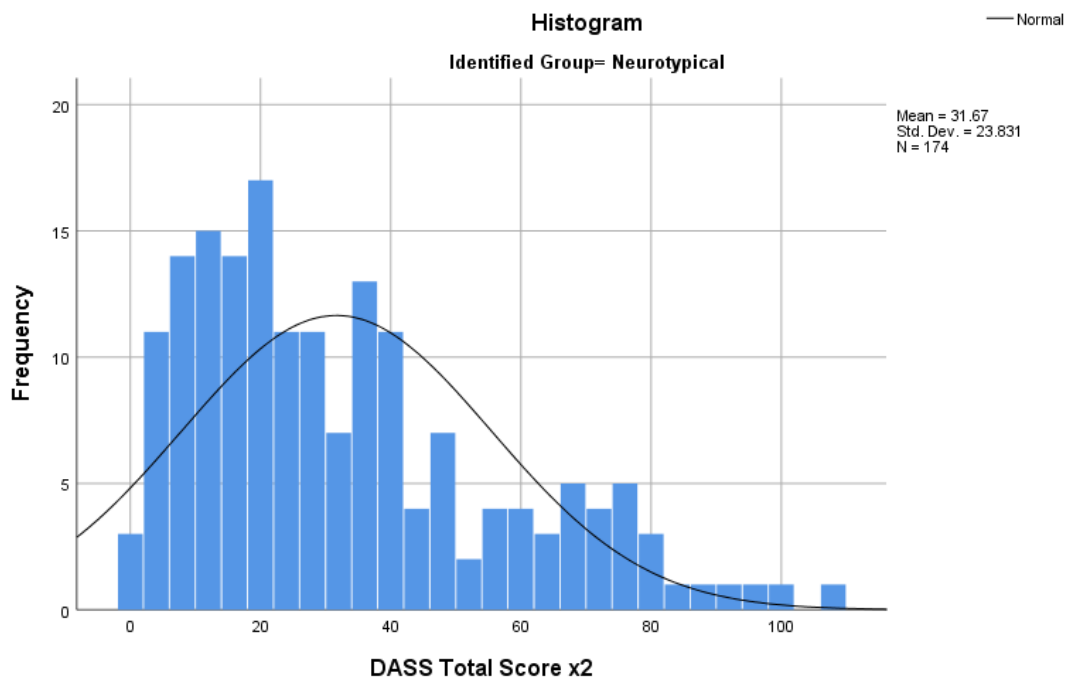


ASD Sample

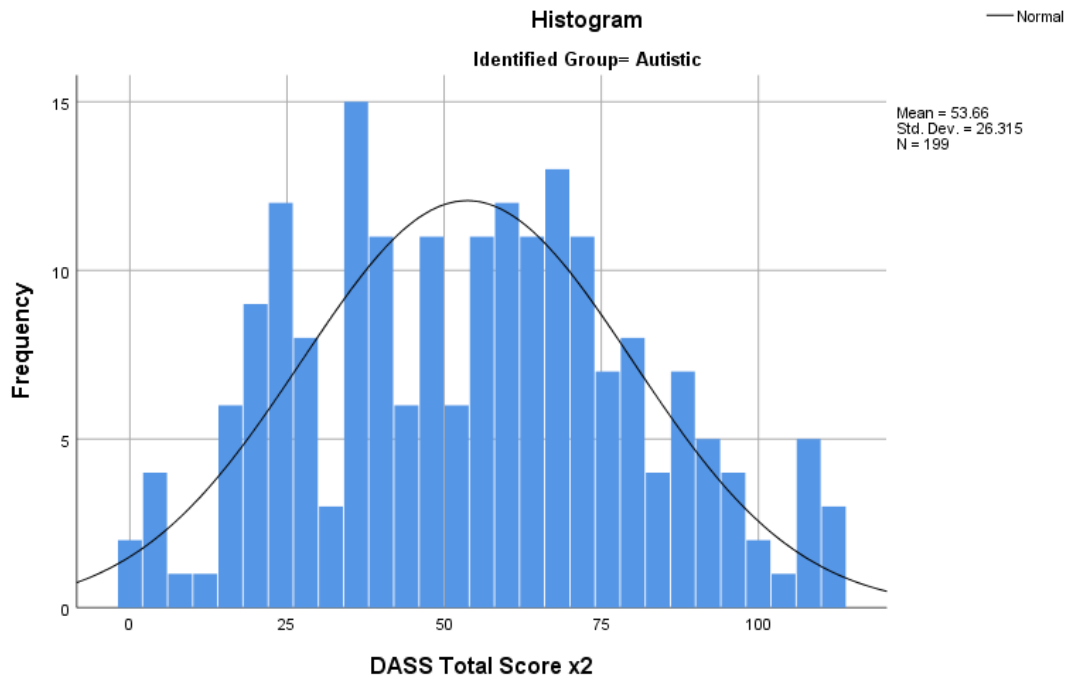


DASS-21 Total Score

Neurotypical Sample

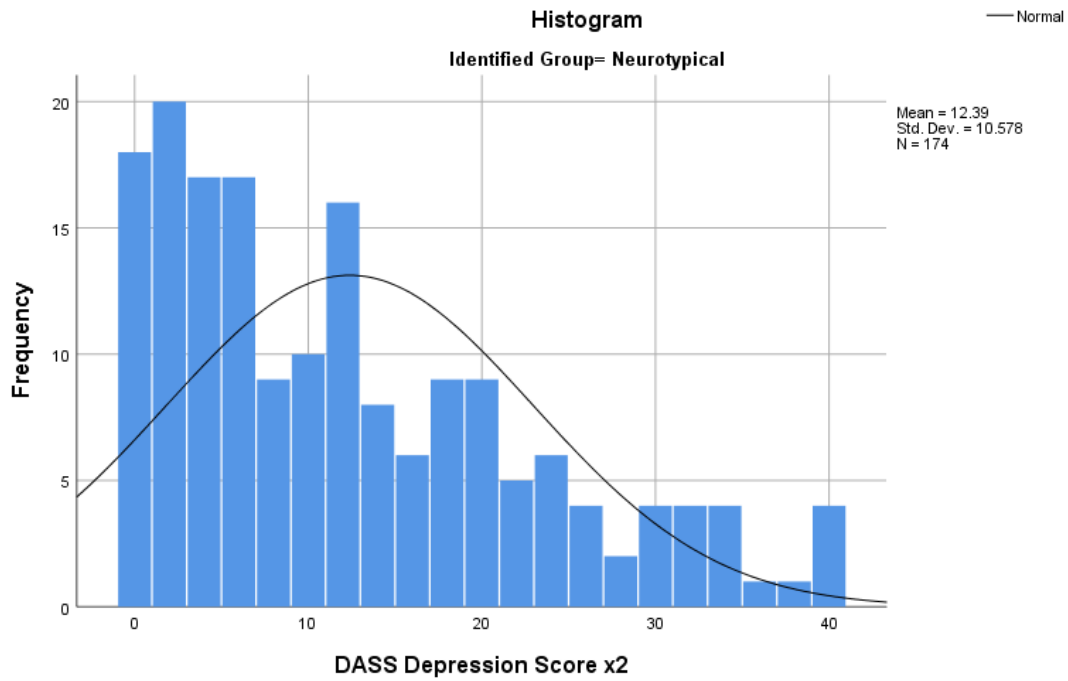


ASD Sample

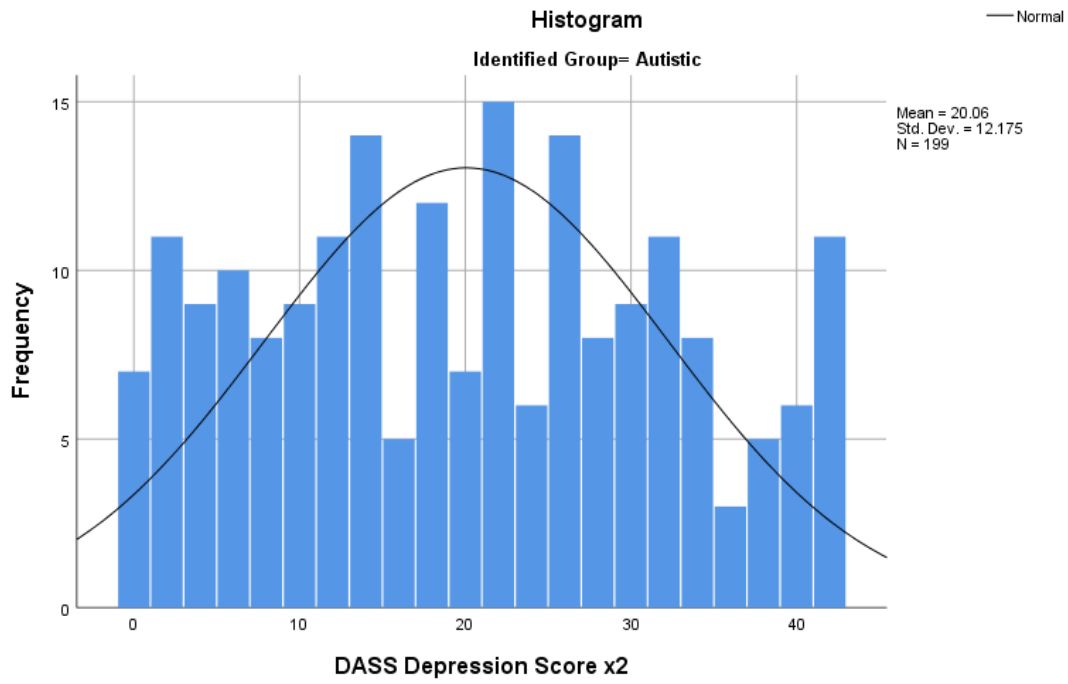


DASS- Depression Score

Neurotypical Sample

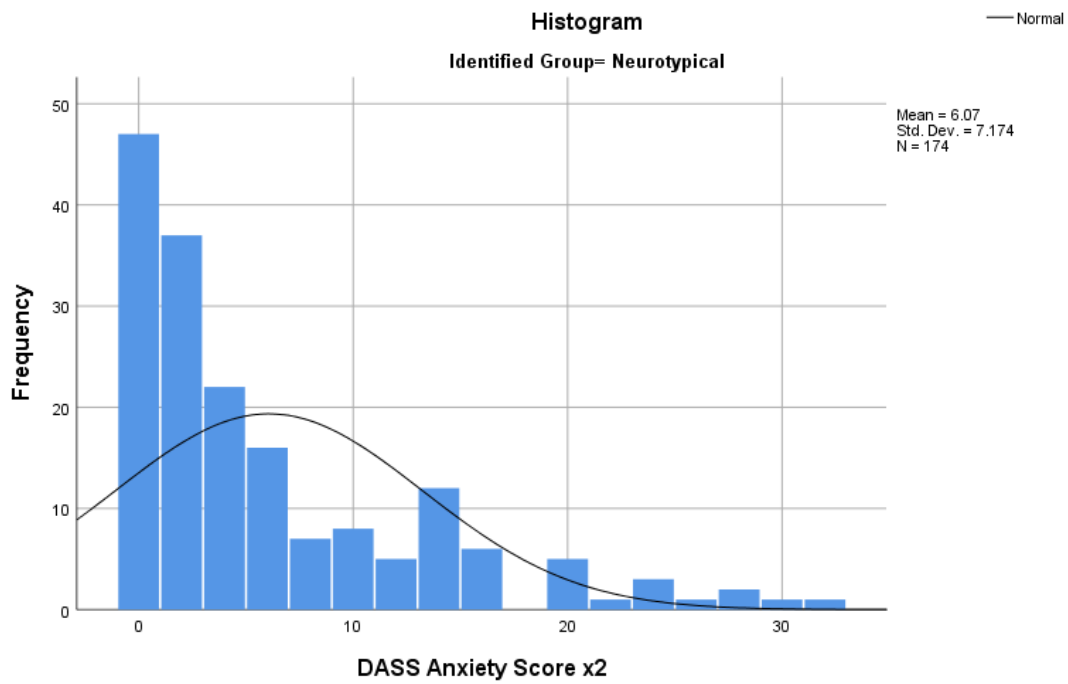


ASD Sample

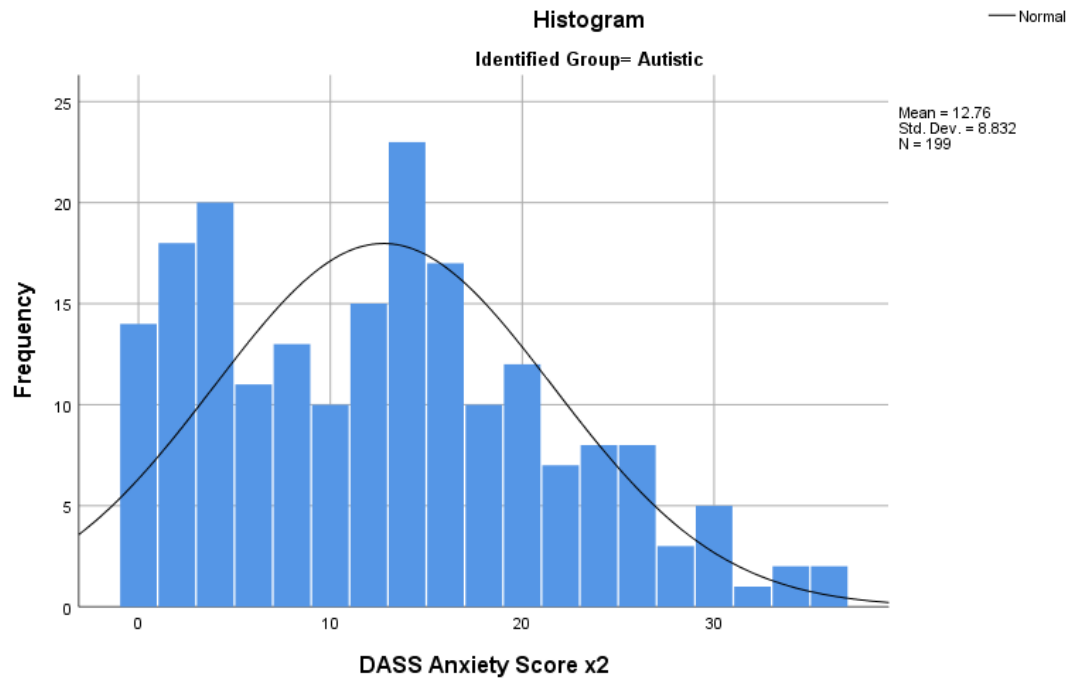


DASS-21 Anxiety Score

Neurotypical Sample

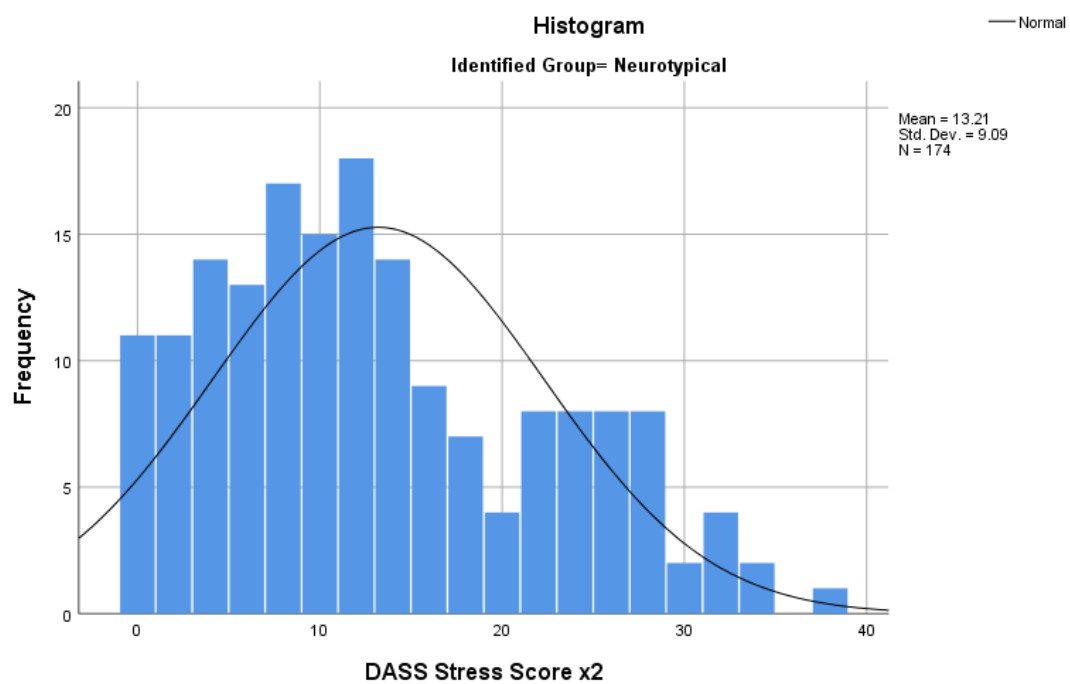


ASD Sample



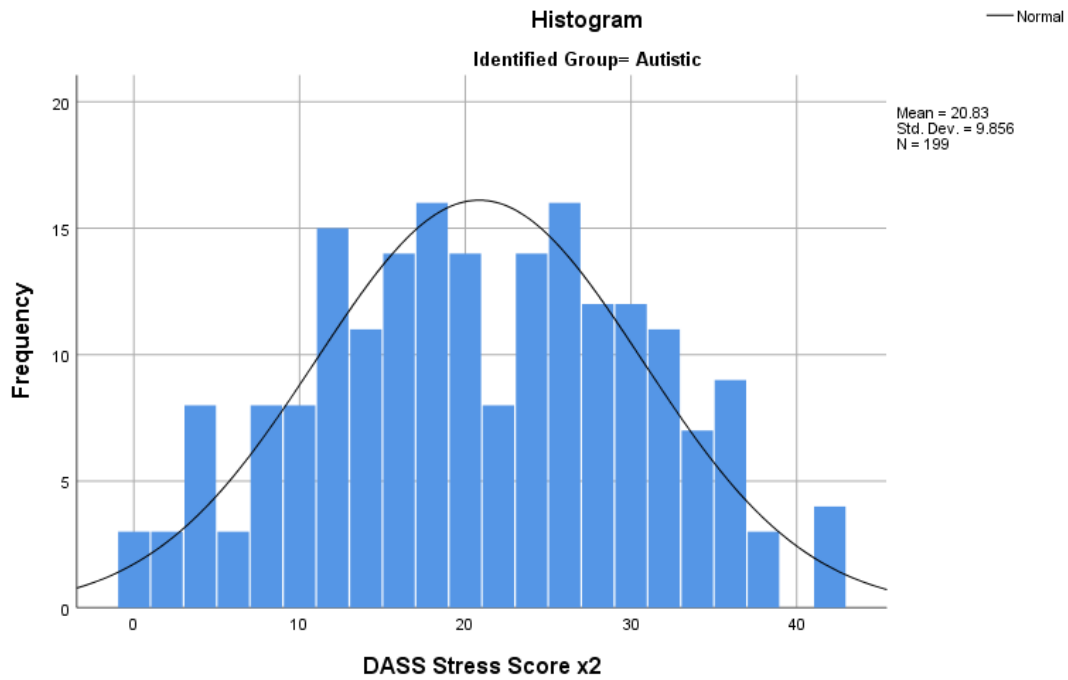
DASS-21 Stress Score

Neurotypical Sample



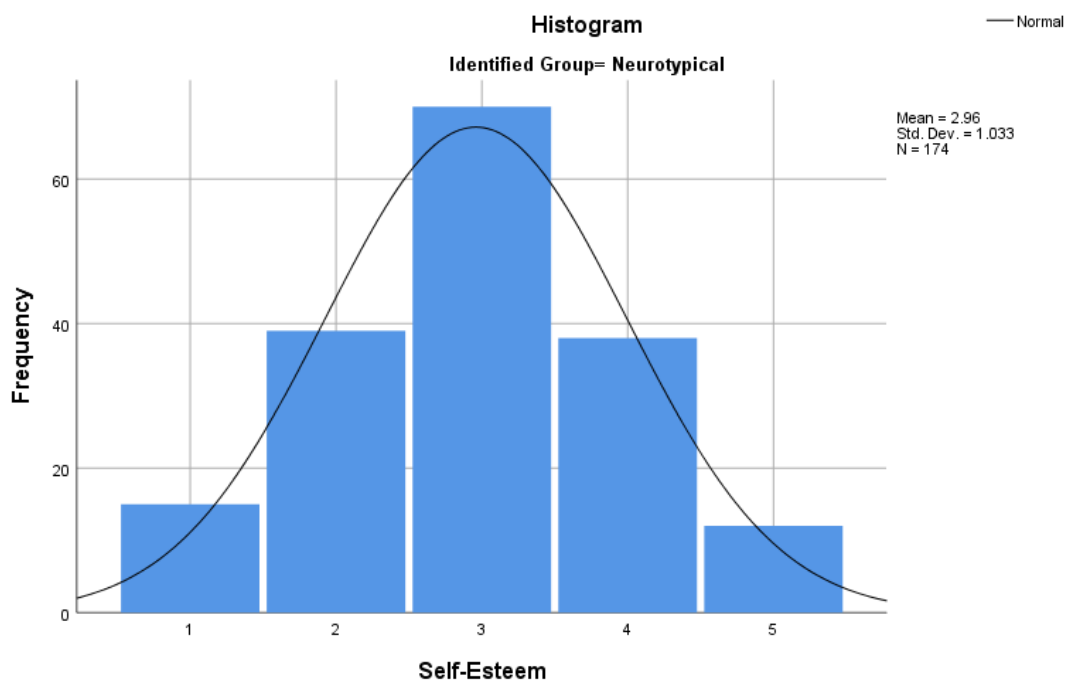


ASD Sample

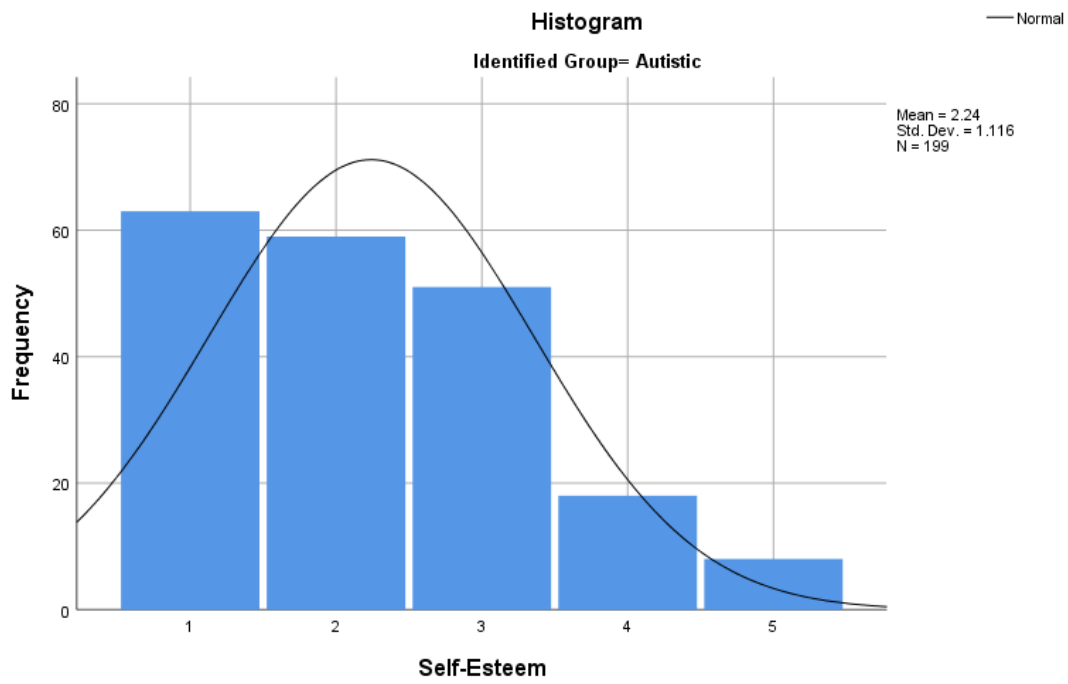


Self-Esteem

Neurotypical Sample

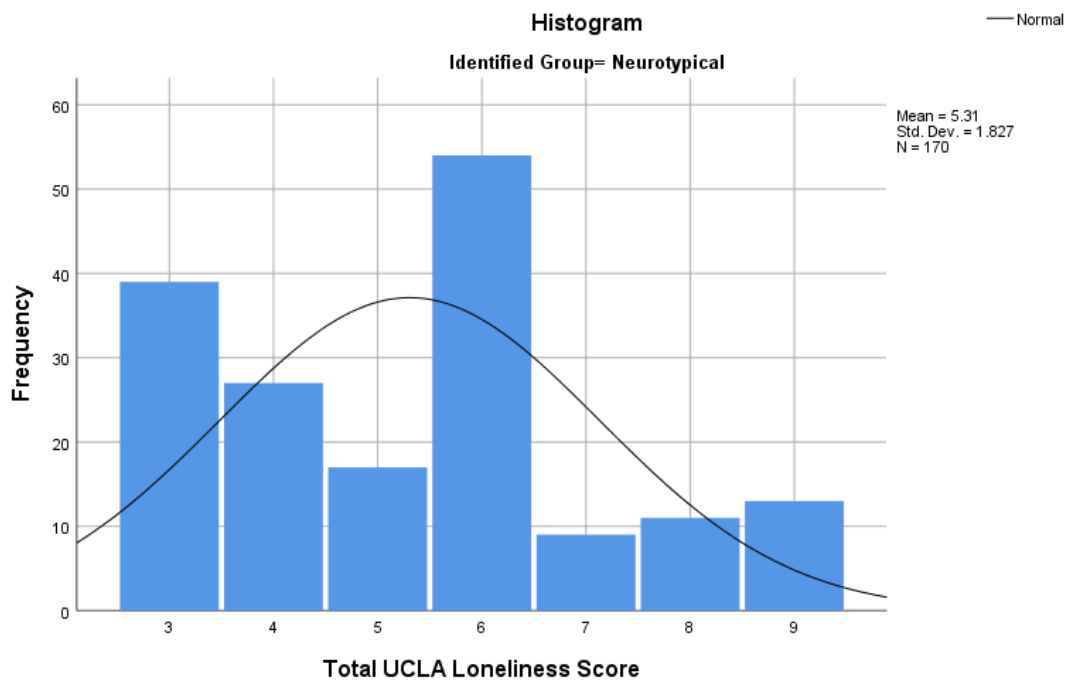


ASD Sample

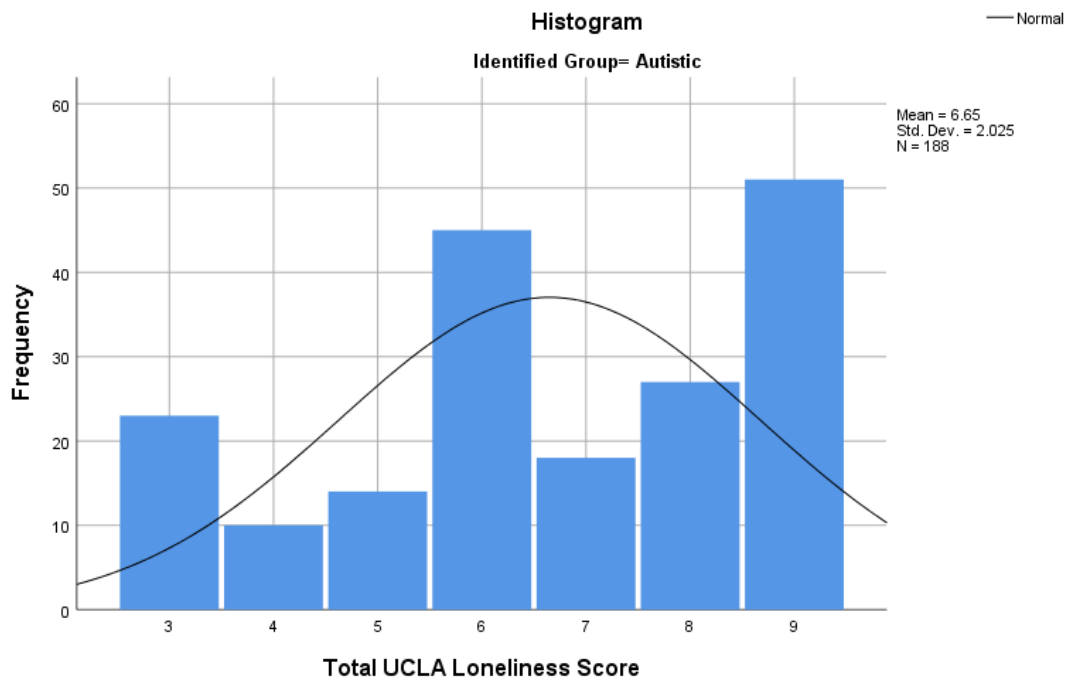


Loneliness

Neurotypical Sample

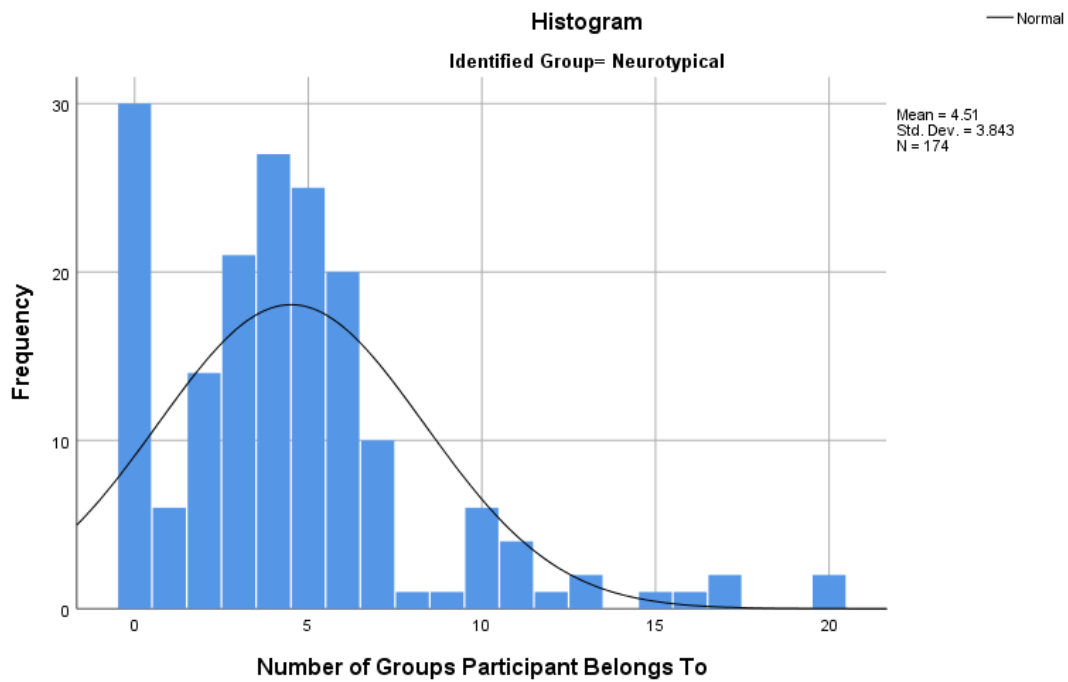


ASD Sample

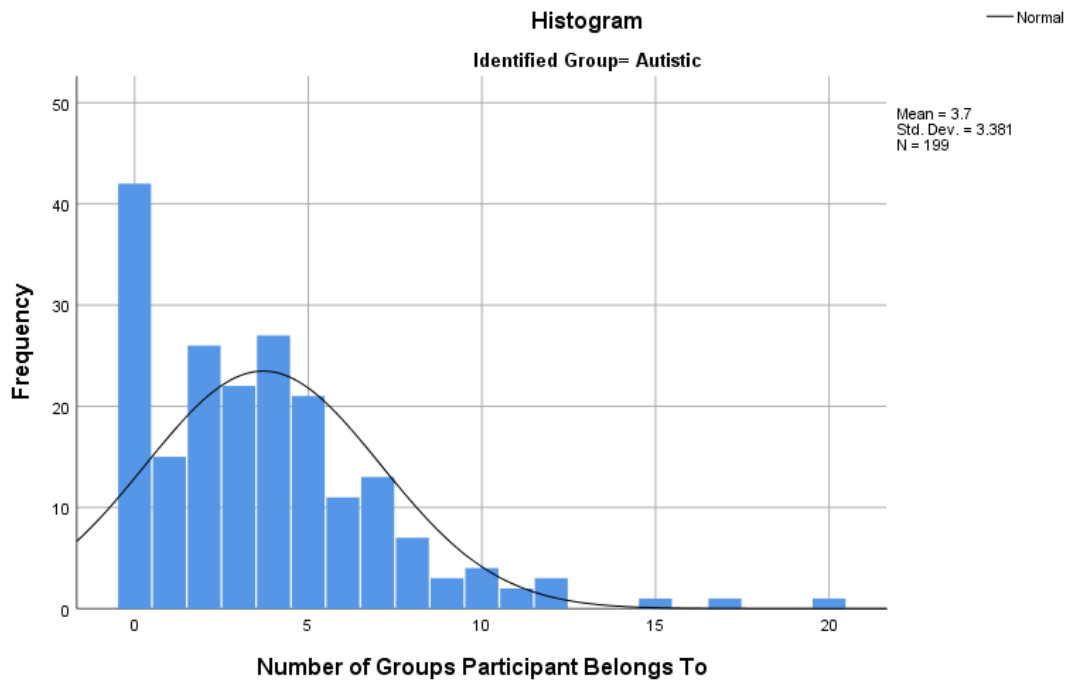


Number of Groups

Neurotypical Sample

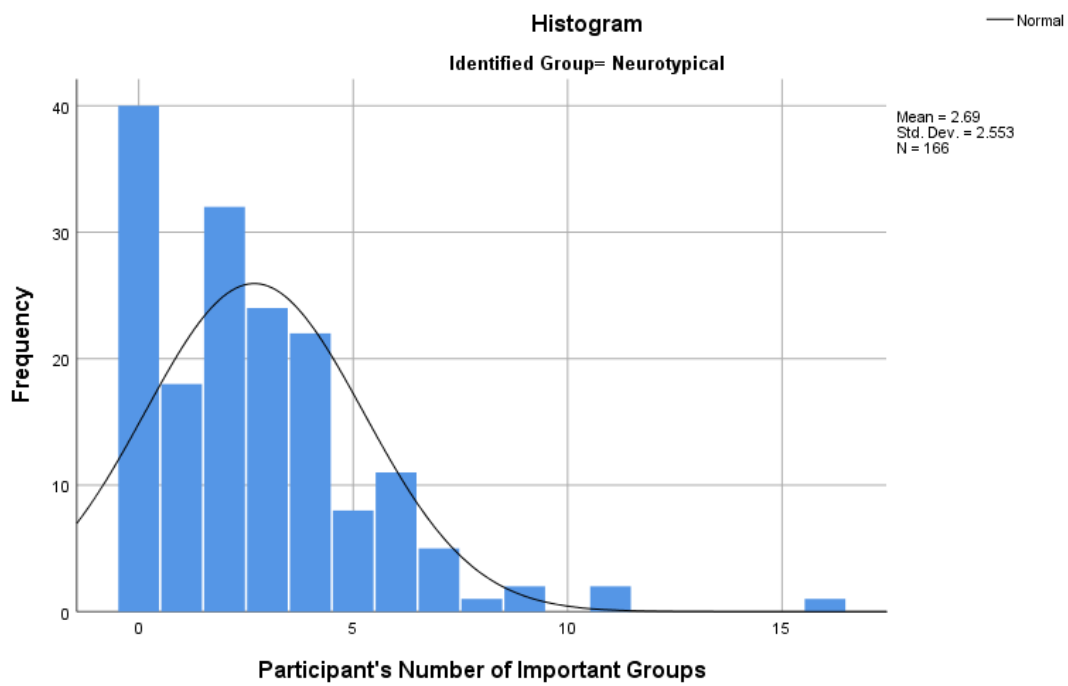


ASD Sample

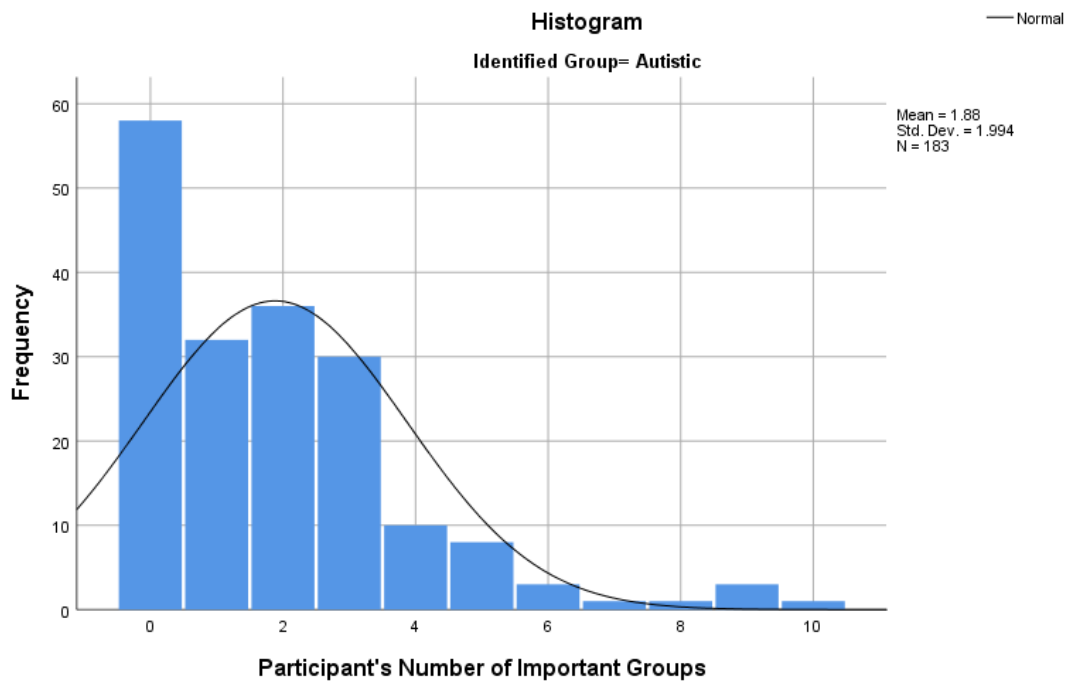


Number of Important Groups

Neurotypical Sample

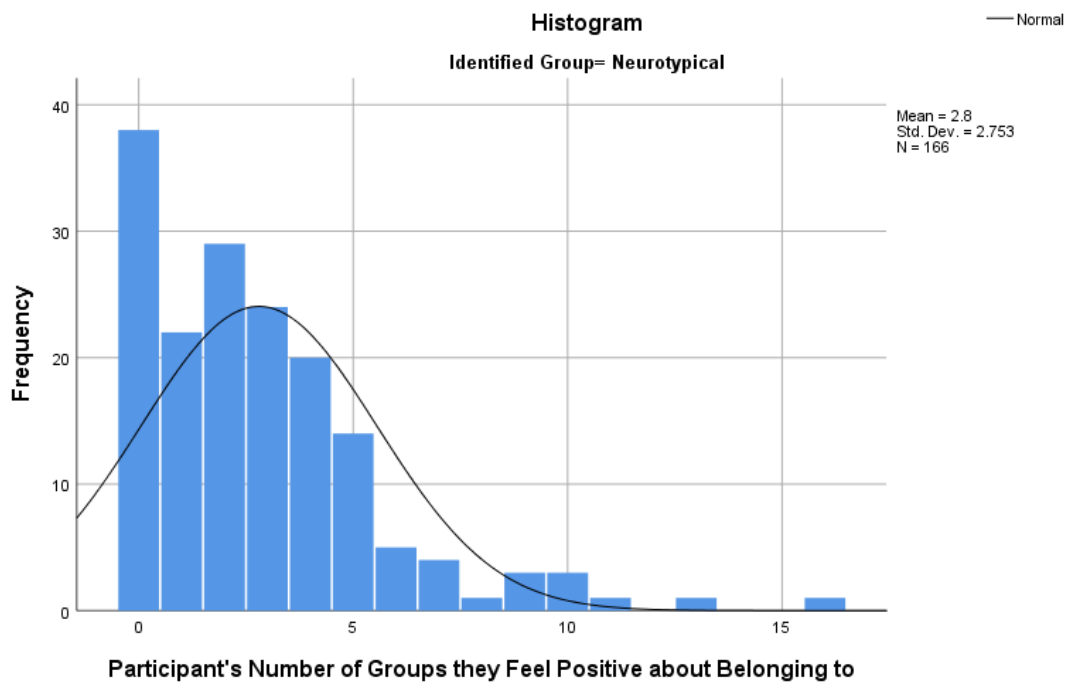


ASD Sample

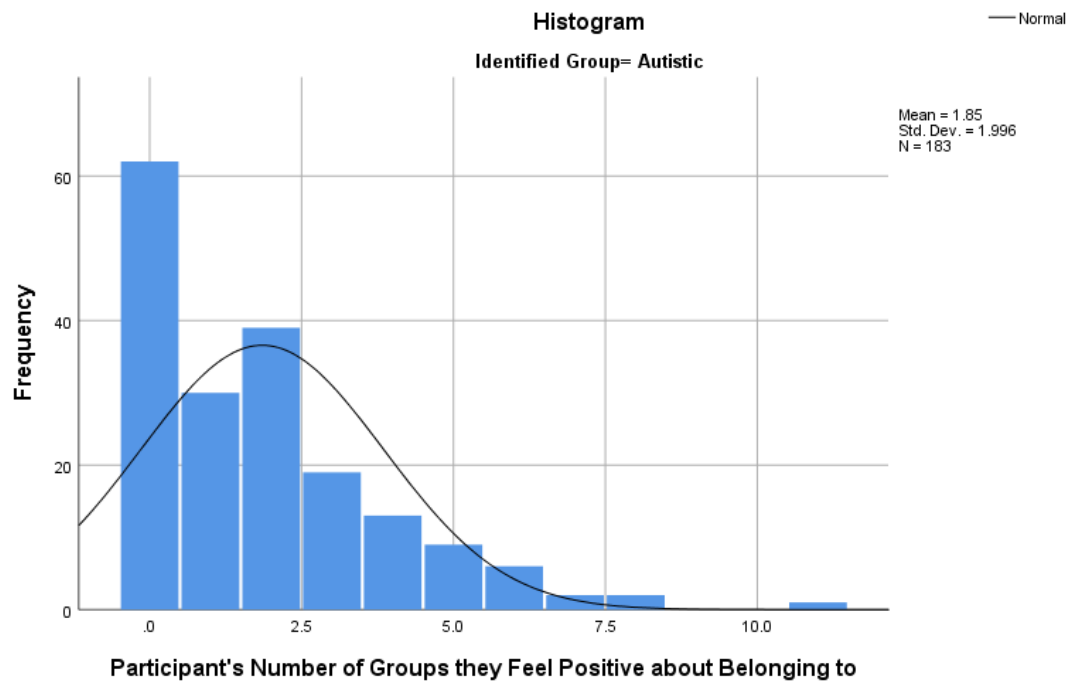


Number of Positive Groups

Neurotypical Sample



## ASD Sample



**Appendix P****Table P1**

*Sample Demographics and Between-Group Differences for Diagnosed and Self-Identified Autistic Participants*

	Diagnosed Autistic Participants (n=167)		Self-Identified Autistic Participants (n=32)		Differences Between Groups	
	N	%	N	%		
<b>Sex</b>						
Male	71	42.5	10	31.3	NS	
Female	94	56.3	22	68.8		
Prefer not to Answer	2	1	-	-		
<b>Gender</b>						
Male	66	39.5	9	28.1	N/A	
Female	79	47.3	19	59.4		
Transgender Male	2	1.2	-	-		
Gender Variant/ Non-Conforming	9	5.4	4	12.5		
Other	11	6.6	-	-		
<b>Ethnicity N (%)</b>						
White					N/A	
English/Welsh/Scottish/Northern Irish	144	86.2	30	93.8		
White Irish	2	1.2	-	-		
Black African	-	-	-	-		
Black Caribbean	-	-	-	-		
Black British	-	-	-	-		
Mixed White and Black Caribbean	5	3	-	-		
Mixed White and Black African	2	1.2	-	-		
White and Asian	2	1.2	-	-		
Asian Indian	-	-	-	-		
Asian Pakistani	1	0.6	-	-		
Asian Bangladeshi	1	0.6	-	-		
Asian Chinese	-	-	-	-		
Other	10	6.0	2	6.2		
<b>Has one or more additional Psychiatric, Physical or Neurodevelopmental Conditions</b>						
	115	68.9	21	65.6		NS
<b>Highest Education Level</b>						
University (Undergraduate or Postgraduate Degree)	97	58.1	20	62.5	NS	
Sixth Form College, Secondary School or less.	70	41.9	12	37.5		
<b>Current Employment Status</b>						
Employed (Part or Full-time)	88	52.7	13	40.6	NS	

Unemployed, Student or Unable to Work	79	47.3	19	59.4	
<b>Change in Employment since Lockdown</b>					
No change in Employment Status or gained employment	155	92.8	30	93.8	NS
Was Employed but now Unemployed	12	7.2	2	6.2	
Living Alone	44	26.3	5	15.6	NS
Living with Children (<18 years)	28	16.8	7	21.9	NS
Had Covid-19 or Symptoms	24	14.4	6	18.8	NS
In Medium/High Covid-19 Risk Category	122	73.1	27	84.4	NS
	M (R)	SD	M(R)	SD	
Age	35.80 (18-69)	12.93	36.09 (18-65)	14.91	NS
SES (ASD: N=176; NT: N=157)	5.12 (1-10)	3.01	4.93 (1-10)	2.87	NS
Age of Autism Diagnosis	29.52 (3-64)	14.98	29.41 (4-63)	15.21	NS
RAADS-14	31.14 (0-42)	8.32	29.47 (13-40)	8.68	NS
WASA Total Score	18.25 (2-40)	8.19	19.53 (2-36)	9.44	NS

*Note.* Results are from the full sample size unless otherwise stated. M=Mean, R=Range, SD=Standard Deviation, NS=Non-Significant. NA=Not Applicable due to violated assumptions. \* $p < 0.05$ , \*\* $p < 0.01$ , \*\*\* $p < 0.001$ .

**Table P2**

*Sample Descriptive Statistics and Between-Group Differences for Diagnosed and Self-Identified Autistic Participants*

	Diagnosed Autistic Participants (n=167)		Self-Identified Autistic Participants (n=32)		Between-Group Difference
	Mean (Range)	Standard Deviation	Mean (Range)	Standard Deviation	
DASS-21 Total	53.49 (0-112)	26.24	54.56 (4-108)	27.10	NS
DASS Anxiety	12.61 (0-36)	8.87	13.56 (0-30)	8.74	NS
DASS Depression	20.14 (0-42)	12.27	19.63 (0-42)	11.86	NS



DASS Stress	20.73 (0-42)	9.99	21.37 (2-38)	9.26	NS
Self-Esteem (1-item)	2.23 (1-5)	1.09	2.28 (1-5)	1.28	NS
UCLA Total Loneliness (ASD: 188; NT: N=170)	6.70 (3-9)	1.99	6.34 (3-9)	2.19	NS
Number of Groups	3.75 (0-20)	3.48	3.44 (0-9)	2.85	NS
Number of Important Groups (ASD: N=183; NT: N=166)	1.93 (0-10)	2.05	1.62 (0-5)	1.66	NS
Number of Groups Feel Positive about Belonging to (ASD: N=183; NT: N=166)	1.89 (0-11)	2.04	1.66 (0-5)	1.74	NS

*Note:* Results are from the full sample size unless otherwise stated. \* $p < 0.05$ , \*\* $p < 0.01$ , \*\*\* $p < 0.001$ .