# An exploration of identity, loneliness, and psychosocial functioning in autistic people.

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# Contents

# Thesis Overview

Identity development and feelings of loneliness are two prominent themes throughout adolescence and young adulthood (Kaniušonytė et al., 2019). Identity development is understood to be embedded in social contexts (Crocetti et al., 2018), in that people develop a sense of who they are through their continuous interactions with others (e.g., family members, friends). Owing to differing communication styles, the social demands of interaction with non-autistic people has been found to offer particular challenges for autistic people, and some autistic people have reported poorer ratings of global self-worth, feelings of social incompetence and social exclusion (Jamison & Schuttler, 2015; Kwan et al., 2020; Chen et al., 2017). This is likely to impact negatively on an individual's self-concept and increase the risk of experiencing loneliness. Loneliness itself has been found to have a range of undesirable physical, cognitive and emotional outcomes for autistic people (e.g. White & Roberson-Nay, 2009; Hedley, Uljarevic, Foley, et al., 2018).

Research has found that for autistic adolescents, use of social media is extensive (Kuo et al., 2014). Concern about the impact of extensive social media use on young autistic people is widespread, given its links with social isolation and depression (O'Keeffe & Clarke-Pearson, 2011) and that autistic people are already at an increased risk of these negative factors compared to non-autistic people (Schroeder et al., 2014). However, online communication is argued to be less socially demanding (e.g., due to the absence of non-verbal signals) and to provide greater opportunities to find others with similar interests, and may therefore enable young autistic people to feel more socially competent and less excluded from interactions than they do during face-to-face interactions (Benford & Standen, 2009; Burke et al. 2010). If autistic people are able to form successful and meaningful connections with others online, and enjoy the benefits afforded by a sense of belonging/group membership, then engaging with the online world may have positive consequences for their identity development and psychological wellbeing, and protect against the negative consequences of marginalisation (Haslam et al., 2009).

The first chapter in this thesis systematically reviews the literature investigating the relationships between loneliness and psychosocial factors in autistic adults and adolescents. Although previous reviews in the autism literature have considered similar topics, such as social isolation in children with neurodevelopmental disabilities (Kwan et al., 2020) and whether factors including loneliness are associated with depression in autistic adults and adolescents (Smith & White, 2020), to our knowledge, this was the first review of its kind. Fifteen papers were identified, examining a combined total of 41 psychosocial factors. Overall, the quality of the studies was poor. Recommendations are made regarding the need for good quality research, including studies with a longitudinal design and involving autistic researchers on the research team.

The second chapter empirically explored the views of eight autistic people about their identity when they are interacting online and face-to-face, and whether/how this relates to their psychological wellbeing. Thematic analysis of the data identified four themes highlighting the centrality of autism to participants' identity, the importance of acceptance, the challenges autistic people face during face-to-face interactions, and the benefits they find in interacting online. The study indicates the need for more flexibility in how services are provided, including an option for services to be delivered online. It also presents an argument for considering more closely whether normative models of identity development can be applied to neurodiverse populations.

Both chapters will be submitted to *Autism* for publication and have been formatted in line with author guidelines (Appendix A). This journal was chosen as its focus is on improving the quality of life of autistic individuals by exploring areas including psychological processes and social needs. In its current form, this thesis submitted to the university exceeds the word limits allowed for the chosen journals. This enabled the inclusion of a more in-depth discussion of the findings and relevant research, as detailed in the University of Liverpool Doctorate in Clinical Psychology programme handbook. The word limits will be amended according to the journal requirements prior to submission.

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# Chapter One: Systematic Review

## Loneliness in autistic adults and adolescents: a systematic review.

### Abstract

Autistic people are at an increased risk of social exclusion, and therefore of experiencing loneliness, due to differences in social behaviours and communication style. Prolonged loneliness has been found to have various negative physical, emotional and cognitive consequences. This systematic review aimed to synthesise the existing literature on the psychosocial correlates of loneliness for autistic adults and adolescents. Fifteen articles were identified, which included seven case control and eight cross-sectional studies, exploring a total of 41 psychosocial factors. Loneliness was found to significantly increase along with many psychosocial factors, though anxiety and depression were the only factors to show significant associations across more than one study. Overall, the quality of the studies was poor, making it difficult to draw any evidence-based recommendations for practice. However, several recommendations can be made for future research, including for future studies to take a longitudinal approach to clarify directionality of relationships, and to ensure that research teams include autistic researchers. The need for good quality research in this area is also highlighted.

### Lay Abstract

Autistic people might be more likely to feel left out of social groups and to experience feeling lonely. Research in the past has shown that loneliness is linked to a range of health difficulties, such as sleep problems, feeling low in mood and feeling more stressed. This review searched for studies exploring the relationships between loneliness and psychosocial (a combination of psychological and social) factors for

autistic people and presents a summary of their findings. A total of 15 studies were identified, and the studies examined a total of 41 different psychosocial factors. Depression and anxiety stood out as factors that were related to loneliness. The studies were generally of low quality, and this makes it difficult to make recommendations about clinical practice based on the findings of this review. Recommendations are made about the focus and design of future autism research, including that research teams should include autistic people.

## Introduction

### *Loneliness*

Belongingness is a basic human need and a powerful motivator of human emotions, cognitions, and behaviour (Baumeister & Leary, 1995). As such, humans are driven to seek out social interactions that lead to social attachments. When interactions are lacking and the need to belong is not satisfied, feelings of loneliness may emerge (Heinrich & Gullone, 2006).

It is important to note the distinction made between loneliness and similar concepts such as solitude and social isolation, which are seen as an objective shortage of interactions with others. People can experience solitude without feeling lonely, and for some, periods of being alone may be necessary for their wellbeing (Perlman & Peplau, 1984). Alternatively, people can live a seemingly rich social life yet still feel lonely.

As a transient experience loneliness can be beneficial, serving as an adaptive function heeding the evolutionary need for strong attachments (Cacioppo et al., 2014). However, as a more prolonged experience, loneliness can have negative implications for health and wellbeing (Heinrich & Gullone, 2006; Holt-Lunstad et al., 2015). It is difficult to gain accurate estimates of the prevalence of loneliness due to fluctuations across the lifespan, gender differences, and variations in the measurement scales used within research. However, estimates have shown that loneliness is chronic for up to a third of the general population (Theeke, 2009; Heinrich & Gullone, 2006).

Reviews of the literature demonstrate that interventions aimed at alleviating loneliness in the general population have targeted four main areas: improving social skills, improving social support, expanding opportunities for social interaction, and changing ‘unhelpful’ social cognitions (e.g. Masi et al., 2011; Cattan et al., 2005). The reviews conclude that such interventions are generally successful, in particular those increasing opportunities for social interaction.

### ***Loneliness in the autistic population***

Research has shown that differences in the social behaviours and communication style of autistic people mean they are at an increased risk of social exclusion (Kwan et al., 2020; Chen et al., 2017), and therefore of experiencing loneliness (Deckers et al., 2017; Bauminger & Kasari, 2000).

It was previously assumed that autistic people have less desire for social interaction, and therefore may be less susceptible to experiencing loneliness (Chevallier et al., 2012). The social motivation hypothesis of autism (Dawson et al., 2004; Dawson et al., 2005) proposes that autistic individuals’ motivation for social interaction is limited due to a reduction in reward value assigned to social stimuli. This results in diminished gratification from social interaction and hence inhibits the development of social relationships. It has also been suggested that autistic people may be sheltered by a lack of awareness of their social problems (White & Robertson-Nay, 2009). However, others have proposed that many autistic people are ‘‘acutely aware of their difficulties with social integration'' (Attwood 2000, p. 97) and demonstrate higher rates of self-reported loneliness than their non-autistic peers (Bauminger & Kasari, 2000). Indeed, loneliness is a consistent theme across recent research into the wellbeing of autistic adults (Moseley & Sui, 2019; Hickey et al. 2018; Chen et al., 2017). Similarly, the prevalence of loneliness has been found to be higher in autistic children and adolescents relative to their non-autistic peers (Kalyva, 2010; van Asselt-Goverts et al., 2015).

Social needs models of loneliness posit that loneliness results from an objective shortage of social contacts (e.g. Weiss, 1973). Drawing on John Bowlby's attachment theory, such perspectives emphasise various social needs. These include social integration (for companionship, a sense of community, social engagement, etc.) and close relationships (for emotional security, intimacy, etc.), which, when left unmet due to the absence of interpersonal relationships, can result in loneliness (Shaver & Buhrmester, 1983). Studies have found that autistic people have fewer social opportunities and, in turn, fewer friends (e.g. Gurbuz et al., 2019) which may contribute in part to the increased prevalence of loneliness in the autistic population. Social needs models of loneliness have, however, been criticised for neglecting the role of individuals' cognitions and appraisals made in the experience of loneliness.

Despite the absence of a single agreed definition, there does seem to be a consensus that loneliness is a subjective and unwanted experience that arises from a discrepancy between the quantity and quality of social connections that people desire and those they perceive they have (Hawkley & Cacioppo, 2010; Fried et al., 2020). This cognitive discrepancy model suggests that it is an individual's subjective appraisal of, or dissatisfaction with, their social situation rather than the actual level of social contact itself that leads to loneliness. Given that autistic people have been shown to express more dissatisfaction with their social networks than non-autistic people (e.g. van Asselt-Goverts et al., 2015), this may also be a relevant factor.

Other cognitive models of loneliness (Cacioppo et al., 2006; Cacioppo & Hawkley, 2009) have emphasised the role of perceived social threat and unsafety that can result from feeling lonely. Such models posit that hypervigilance to social threat, which is often based on past experiences of mistreatment, gives rise to cognitive biases (e.g., viewing the social world as threatening) which can evoke responses from others that reinforce the individual’s expectations. It may be the case that if autistic people are more likely to experience loneliness, they are also more likely to experience this self-fulfilling prophecy, whereby the lonely individual actively distances themselves from others.

De Jong-Gierveld’s (1987) model of loneliness is one model that captures the perspectives of both social needs and cognitive models. This model suggests causal factors for loneliness present within four areas: social structures (age, gender, relationship status, living arrangement, and employment), social network characteristics (friends and contact), one’s cognitive appraisal/perception of their social network (self-evaluated satisfaction and support), and personality characteristics (concept of self, social anxiety, introversion/extraversion). This model was of particular interest in the current study given that it includes both social and individual/cognitive elements that may relate to the autistic experience as it is described in the literature. For example, previous research with autistic populations has found associations between loneliness and female gender (Kapp et al., 2013) relating to social structures, quantity of friendships (Autism Spectrum Australia, 2013) relating to social network characteristics, dissatisfaction with social support (Ee et al.,

2019) relating to cognitive appraisal/perception of one's social network, and anxiety (Ee et al., 2019) relating to personality characteristics.

There is emerging evidence to suggest that autistic people are better able to navigate social interactions with other autistic people than they are with non-autistic people, and similarly, that non-autistic people have more successful interactions with other non-autistic people than with autistic people (Sheppard et al., 2016). Such research indicates that it is the difficulty autistic people face in navigating the non-autistic social world that separates them from non-autistic people, rather than it being a disinterest in social relationships (Elmose, 2020; Causton-Theoharis et al. 2009). Deckers et al. (2014) found that autistic children demonstrate a wish for social interaction on an implicit level, but less so on an explicit level, suggesting that they may lack the skills and/or require specific circumstances to enable them to achieve their desired level of social interaction.

The social challenges autistic people face often become more pronounced as they develop into adolescence (Picci & Scherf, 2015). This period is characterised by increased autonomy and peer interactions. Social complexity and social demands rise and awareness of personal social competence increases (Schopler & Mesibov 1983; Tantam, 2003). Adolescents must also navigate the processes of pubertal maturation and identity formation (Laursen & Hartl, 2013). This period may therefore offer challenges for young autistic people in remaining involved with and accepted by their peers and subsequently, satisfying their need to belong.

Recent work has shown that, as with the non-autistic population (e.g. Luo et al., 2012; Hawkley & Cacioppo, 2010; Cacioppo et al., 2006; Gow et al., 2007), loneliness is associated with a range of undesirable cognitive and emotional outcomes for autistic people. These include a reduction in self-efficacy and increase in anxiety, depression, suicidal ideation and self-harm behaviours (White & Roberson-Nay, 2009; Hedley, Uljarevic, Foley, et al., 2018; Lasgaard et al., 2010; Mazurek, 2014). However, the direction of these associations is often unclear. Research exploring the relationships between these variables has found that by increasing the likelihood of depression, loneliness predicts self-harm and suicidal ideation (Hedley, Uljarevic, Wilmot, et al., 2018). Given that autistic people are at considerably higher risk of suicide than the general population (Cusack et al. 2016), the contribution of loneliness to the mental health and social functioning of autistic people is an essential focus for research and intervention. A synthesis of the available literature in this area would therefore be useful.

### ***The current review***

To the best of our knowledge, no systematic review exploring the effects of loneliness in autistic adults or adolescents currently exists, although some recent systematic reviews in the autism literature have included similar concepts. For example, Cresswell et al.'s (2019) review explored the rewards and challenges autistic adolescents face in their experience of peer relationships, Smith and White's (2020) review examined whether factors including loneliness were associated with depression in autistic adults and adolescents, and a scoping review by Kwan et al. (2020) explored loneliness and social isolation in children with neurodevelopmental disabilities.

This systematic review therefore aims to synthesise existing literature on the psychosocial correlates of loneliness for autistic people, and offer a more thorough understanding than that gained from considering single studies. This will not only serve to enhance understanding of the impact of loneliness on the mental health and social functioning of autistic people, but may also highlight areas for future research and offer a rationale for future interventions aimed at alleviating loneliness in this population. Given the research indicating that the prevalence of loneliness tends to increase from adolescence onwards, and that studies documenting elevated levels of loneliness in relation to autism tend to include adolescents rather than younger children, this review will include studies of autistic adolescents and adults. The review therefore aims to answer the following questions:

(1) What are the psychosocial correlates of loneliness for autistic adults and adolescents, based on the literature published between 2000 and 2020?

(2) What does this tell us about the impact of loneliness on the mental health and social functioning of autistic adults and adolescents?

## Method

The method of conducting and reporting this systematic review is largely in accordance with the Preferred Reporting Items of Systematic Reviews and Meta-analysis guidelines (Page et al., 2021), though these guidelines were primarily developed for reviews of interventions, rather than for reviews with other objectives such as, prevalence, risk factors etcetera (Liberati et al., 2009; Moher et al., 2009). The review protocol was registered at the International Prospective Register of Systematic Reviews (PROSPERO: CRD42020204350).

### ***Inclusion and exclusion criteria***

Criteria for inclusion in the review were as follows:

- Sample: Adults (aged over 18) and adolescents (aged over 10, in line with the World Health Organisation's definition of adolescence) who have received a formal diagnosis of an Autism Spectrum Disorder; Studies with a sample size of 15 or more.

- Design: Quantitative studies and quantitative data extracted from mixed-methods studies
- Outcomes: Self-reported loneliness; Self-reported psycho/social factors
- Publication language: English
- Publication date: after January 2000

Exclusion criteria were also applied as follows:

- Sample: Studies including people with Intellectual Disability; Studies that do not perform some form of check of ASD diagnosis (e.g. original documents obtained, official disability cards reviewed, psychometric tests for autistic traits administered as part of the research)
- Design: Qualitative studies

### *Search strategy*

Development of the search strategy was assisted by a librarian (EH). A search of online databases was undertaken on 19th November 2020 and was re-conducted on 16th June 2021 to check for any newly published articles. The following databases were searched: PsycINFO, PubMed, Web of Science and Cochrane databases, using a combination of four groups of keywords: 1) autism, 2) loneliness, 3) psychosocial factors, 4) adults and adolescents. Table 1 shows the terms included in the free-text search:

**Table 1**

*Free-text search terms*

| Keyword group | Free-text search terms |
|---|---|
| Autism | autis* *OR* asperger* *OR* "pervasive developmental disorder" *OR* ASD *OR* ASC *OR* PDD |
| | *AND* |
| Loneliness | lonel* OR isolat* *OR* alienat* *OR* connect* |

| | |
|---|---|
| | *AND* |
| Psychosocial factors | mental* *OR* social *OR* friend* *OR* peer* *OR* depress* *OR* anxi* *OR* schizo* *OR* bipolar *OR* psycho* *OR* "obsessive compulsive" *OR* mood *OR* stress *OR* panic *OR* "eating disorder" *OR* suicid* *OR* dissociat* |
| | *AND* |
| Adults and adolescents | adult* *OR* adolescen* *OR* teenage* *OR* "young people" *OR* youth* *OR* student* |

Table 2 shows MeSH terms used for the controlled language searches:

**Table 2**

*MeSH Terms used*

| **Keyword group** | **MeSH Terms** |
|---|---|
| Autism | AUTISM SPECTRUM DISORDER *OR* DEVELOPMENTAL DISORDERS, PERVASIVE |
| | *AND* |
| Loneliness | LONELINESS (supplemented with general terms: isolat* *OR* alienat* *OR* connect*) |
| | *AND* |
| Psychosocial factors | MENTAL HEALTH *OR* MENTAL DISORDERS *OR* EMOTIONS *OR* SOCIAL PROBLEMS *OR* SOCIAL ENVIRONMENT *OR* PEER GROUP *OR* INTERPERSONAL RELATIONS (supplemented with general terms: “psychological wellbeing” *OR* “psychological distress” *OR* depress* *OR* anxi* *OR* schizo* *OR* bipolar *OR* psycho* *OR* "obsessive compulsive" *OR* mood *OR* stress *OR* panic *OR* "eating disorder" *OR* suicid* *OR* "mental illness" *OR* dissociat* |
| | *AND* |
| Adults and adolescents | ADOLESCENT *OR* ADULT (supplemented with general terms: teenage* *OR* “young people” *OR* youth or student*) |

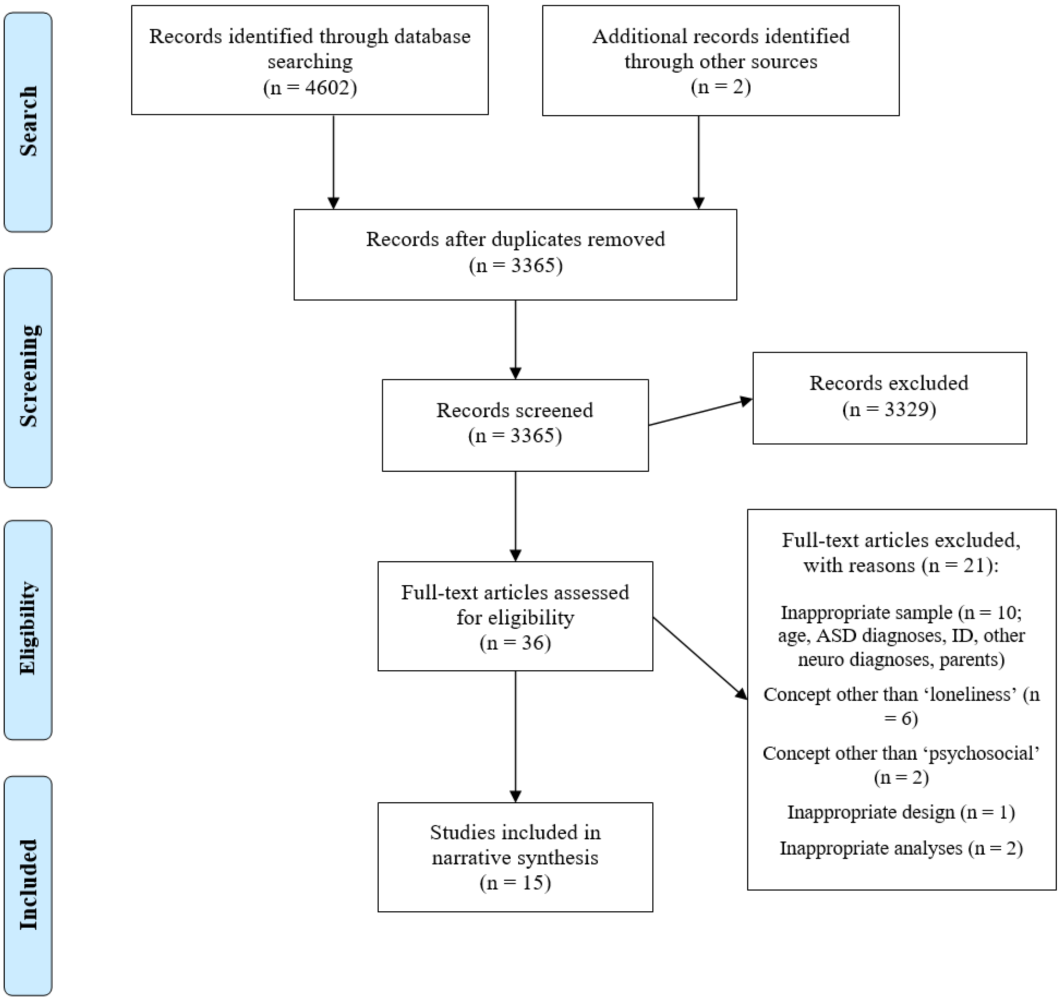
Two filters were applied to the search: the language the study was published in (English only) and the date it was published (between January 2000 and the date of the search). The bibliographic database searches were supplemented by scanning the reference lists of the included articles and other reviews of similar concepts, and field supervisors contacted colleagues to check for any additional studies meeting the review's inclusion criteria.

### *Selection of studies*

References were managed using EndNote X9, in which duplicates were removed. In the first stage of screening, titles and abstracts of identified articles were screened by the first author using a checklist determined by the inclusion and exclusion criteria detailed above (Appendix B). A sample was checked by a peer (JD) for accuracy, and studies not meeting the review's criteria were excluded. Stage two of screening involved evaluation of the full-texts of all studies included following Stage 1 screening (n = 36) by the first author. Again, a sample was checked by a peer (JD) and discrepancies were resolved through consultation with a research supervisor (KW, AF). The reasons for exclusion at this stage were recorded and are reported in Figure 1.

**Figure 1.**

*PRISMA 2009 Flow Diagram of Study Selection*



All studies exploring potential relationships between the variables of interest were included in the review; no restrictions were placed on the method of statistical analysis used. One of the exclusion criteria for this review was the inclusion of people with an ID. The review took an inclusive approach, in that studies were only excluded if they explicitly stated that people with an ID were included in their study. Where articles did not state whether people with ID were included in their sample or not, the article was included.

### *Quality assessment*

Quality assessment tools for systematic reviews tend to be developed for the evaluation of intervention studies and are therefore often unsuitable for observational studies (Jüni et al., 1999). In this review, study quality was assessed using the Newcastle Ottawa Scale (NOS) for case-control studies and a version of the NOS adapted for cross-sectional studies (see Appendix C and D respectively).

The initial plan was to exclude poor quality studies from the review, and therefore quality assessment was performed prior to data extraction in order to avoid bias with regard to the studies included in the review. The first author quality assessed each article, and a sample was discussed with the research supervisors (KW, AF) and an expert in systematic reviews (JG). Discrepancies were resolved by consensus.

### ***Data extraction***

Using a data extraction form developed by the research team (see a template in Appendix E), the primary author extracted relevant data from the articles. A sample was checked for accuracy by a peer (JD). Attempts were made to gain/ascertain missing information and data (for example, on recruitment, funding source, response rate) by contacting the authors of the articles. Tables 3 and 4 show data on study characteristics and participant characteristics, respectively. For ease of reporting, participant characteristics were separated into two tables, one for case-control studies (Table 4a) and one for cross-sectional studies (Table 4b).

Methodological information and study findings from the 15 included articles were summarised in a narrative analysis. For studies that included both children (aged under 10) and adolescents (aged over 10) in their sample, the adolescent data were extracted and included where possible. Where extraction of the adolescent data only was not possible (for example, if data had been combined with data for children for analysis), the study was excluded. The second of the two studies in Mahjouri’s (2011) paper was excluded for this reason. Similarly, if studies included both self- and other-

(for example, parent/teacher) reported data, the self-reported data were extracted and included in the review. Where this was not possible (such as, when parent and self-reported data were combined for further analysis due to a high correlation between the two reports) that part of the analysis was not included/report. Study results (all bivariate and/or multivariate associations between a psychosocial factor and loneliness examined in a study article) are listed in Table 5. The majority of studies used p>.01 or p>.05 as the level of statistical significance; this review used p>.05 throughout.

### ***Community Involvement***

As well as having had input in developing the review question, an Expert by Experience will be actively involved in the dissemination of the findings to participants and linked communities.

## **Results**

### ***Selection of studies***

The literature search yielded a total of 4604 citations, which after removing duplicates, left a total of 3365 studies for screening. Of those, 3329 were excluded after screening of titles and abstracts (stage 1 screening). Following closer inspection of the remaining 36 articles (stage 2 screening), a further 21 were excluded. This left a total of 15 articles to be included in the review. Figure 1 presents a flow chart of the study selection process.

### ***Study characteristics***

As shown in Table 3, publication dates for the 15 studies ranged between 2007 and 2019, though the majority (n = 11, 73%) were published in the last decade. The studies were conducted in various countries: a third (n = 5) were conducted in the

USA, and another study was conducted across the USA, Canada and the UK. Three studies were conducted in Australia, three in Taiwan, and a further study was conducted across both Australia and Taiwan. One study was conducted in Belgium, and one was conducted in Denmark. By way of study design, the included studies were a mix of seven (47%) case-control and eight (53%) cross-sectional studies. All studies employed a questionnaire survey approach using non-randomised sampling techniques. None of the studies indicated that they had an autistic researcher/advisor as part of the research team.

Over half of the studies (n = 8) included only adults, and a third (n = 5) included only adolescents. Two studies included both adult and adolescent participants. The psychosocial correlates under scrutiny varied across studies, but included depression, anxiety, quality of friendships, and perceived social support.

One of the inclusion criteria for the review was for studies to have performed some form of checks for autism; over half (n = 8) of the studies did this by administering an assessment for autistic traits as part of the research. The other seven studies gained confirmation through means such as checking official diagnosis and obtaining information that participants had received a formal diagnosis in order to be accepted into the organisation from which recruitment took place.

The source of funding for the study was acknowledged in nearly two thirds (n = 9) of the 15 studies: in three instances the studies had received grants from the Taiwan Ministry of Science and Technology and in two instances funding was received from DXC Technology and the Australian Government Department of Human Services and Department of Defence.

Nearly two thirds of the articles (n = 9) measured loneliness via a variation of the University of California Los Angeles Loneliness Scales: over one third (n = 6) used the UCLA Loneliness Scale-Short (ULS-8), two studies used the full UCLA Loneliness Scale-version 3 (ULS-3) and one study used the 3-item version. In the remaining articles (n = 6), a variety of measures were used, including the de Jong Gierveld Loneliness Scale, Asher, Hymel, and Renshaw's (1984) Loneliness Scale, and the Loneliness and Aloneness Scale for Children and Adolescents- Peers Scale- Short (LACA-P short). Two studies (Chen, 2016 and Merkler, 2007) included non-standardised measures of loneliness. A wide range of different outcome measures were used for the psychosocial factors.

**Table 3**

*Study Characteristics*

| Study | Country | Study Design | Study Population | How was ASC diagnosis established? | Recruitment Source | Variable of Interest (Outcome Measure) | Autism Advisor Involvement | Study Sponsorship / Funders |
|---|---|---|---|---|---|---|---|---|
| Bossaert, Colpin, Jan Pijl & Petry (2012) | Belgium | Case control | Students with SEN (ASD or motor/ sensory impairments) | Asked the school whether participants had a formal diagnosis of ASD and for details of their diagnosis e.g. autism classification | 7th grade classrooms across 53 schools | Number of best friends in class (P's asked to nominate best friends in class)<br>Quality of friendship with best friend (an instrument developed by Malcom, Jensen-Campbell, Rex-Lear, and Waldrip (2006)<br>Social self-concept (Social Description Questionnaire II-Short (SDQII-S)<br>Loneliness (Loneliness and Aloneness Scale for Children and Adolescents, Peers scale, short version; LACA-P short) | Not specified | Not specified |

| | | | | | | | | |
|---|---|---|---|---|---|---|---|---|
| Brooks (2016) | USA | Case control | Autistic adults | Parents had to provide details of their child’s ASD diagnosis e.g. date of diagnosis, type of clinician who made the diagnosis, etc. Participants also had to return a score of above 19 on the Autism Spectrum Screening Questionnaire-Revised Extended version (ASSQ-REV) to be included. | Community organisations and through the Aspirations Programme (a social and vocational support program) | Friendship quality (The Friendship Questionnaire; FQ)<br>Loneliness (The UCLA Loneliness Scale, version 3; ULS-3)<br>Positive/Negative Affect (The Positive and Negative Affect Schedule; PANAS)<br>Social relationships and activities engaged in with peers (Friendship Activity Report) | Not specified | The Organisation for Autism Research (OAR) graduate research grant program<br>The Coca-Cola Critical Difference for Women grants program<br>The Leadership Education in Neurodevelopmental and Related Disabilities Program (LEND) research trainee fund<br>The Ohio State University Nisonger Centre |

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|---|---|---|---|---|---|---|---|---|
| Chang, Chen, Huang & Lin (2019) | Taiwan | Case control | Autistic adults | Checked disability cards issued by a health agency of the Taiwanese government which confirmed they had been diagnosed using the DSM-5 by a psychiatrist | Flyers posted in mainstream high schools, clinics, local autism groups and public areas e.g. libraries. | Features of friendship (Friendship Qualities Scales; FQS)<br>Participation in activities (Child and Adolescent Scale of Participation; CASP – Chinese version)<br>Anxiety (Beck Anxiety Inventory; BAI – Chinese version)<br>Loneliness (The University of California Los Angeles Loneliness Scale- Short Form; ULS-8 – Chinese version) | Not specified | Grants from the Taiwan Ministry of Science and Technology. |
| Chen, Bundy, Cordier, Chien & Einfeld (2016) | Australia;<br>Taiwan | Cross-sectional | Autistic adolescents and adults (16-45) | Administered the Social Responsiveness Scale - all p's (both countries) had T-scores of >60 indicating they were in | Flyers circulated around Australia;<br>Through Autism Special clinics at the National | Participants' activities, social engagements and experience of loneliness (Experience Sampling Survey)<br>Social anxiety (Social Interaction | Not specified | Not specified |

| | | | | | | | | |
|---|---|---|---|---|---|---|---|---|
| | | | | the mild-moderate range of impairment | Taiwan University Hospital | Anxiety Scale; SIAS) | | |
| Hedley, Uljarević, Foley, Richdale and Trollor (2018) | Australia | Cross-sectional | Autistic adults and adolescents | Administered the AQ-Short. All participants were required to return a score >65, which indicates clinical significance for autistic traits | Australian Longitudinal Study of Adults with Autism (ALSAA) and Longitudinal Study of Australian School Leavers with Autism. Data presented here are from the first data point from both of the longitudinal studies | Loneliness (The University of California Los Angeles Loneliness Scale- Short Form; ULS-8)<br>Social support (The Social Support Questionnaire-Shortened Version; SSQ-6)<br>Depression (The Patient Health Questionnaire; PHQ) | Not specified | DXC Technology and the Australian Government Department of Human Services and Department of Defence |
| Hedley, Uljarević, Wilmot & Richdale (2018) | Australia | Cross-sectional | Autistic adults | Administered the AQ-Short. Also recruitment targeted people with ASD whose diagnostic | A supported employment programme;<br>Local ASD service providers or | Loneliness (The University of California Los Angeles Loneliness Scale- Short Form; ULS-8) | Not specified | DXC Technology and the Australian Government Department of Human Services and |

| | | | | | | | | |
|---|---|---|---|---|---|---|---|---|
| | | | | status was confirmed at the application stage through provision of a letter from a GP or a diagnostic report | support agencies | Depression (The Patient Health Questionnaire; PHQ) | | Department of Defence<br>Autism CRC post-doctoral fellowships |
| Jackson, Hart, Brown & Volkmar (2018) | USA, Canada, UK (Worldwide) | Cross-sectional | Autistic adults | Participants self-reported having a diagnosis of an ASD and reported the age at which they were diagnosed. The AQ-10 was administered to check they met the clinical cut off | Post-secondary academic institutions within the USA;<br>Advocacy/support groups in the US, Canada, and the UK;<br>Advertisements in ASD related academic journals | Loneliness (The 3-item University of California Los Angeles Loneliness Scale)<br>Friendships, romantic relationships and bullying (Social Experiences Scale)<br>Depression, anxiety and stress (Depression Anxiety and Stress Scale; DASS-21) | Not specified | No direct funding to report for this study, however, the position of one author was funded by the NIMH |
| Lasgaard, Nielsen, Eriksen & Goossens (2010) | Denmark | Case control | Autistic adolescent males | In order to be accepted into the schools, the boys had gone through | Two special education schools for students with ASD or | Loneliness (The University of California Los Angeles Loneliness | Not specified | Not specified |

| | | | | | | | | |
|---|---|---|---|---|---|---|---|---|
| | | | | assessment and diagnosis by experienced clinicians, using ICD-10 criteria and ADOS-Generic | severe ADHD. | Scale; ULS-3 – Danish version)<br>Perceived social support and positive regard from family and peers (The Social Support Scale for Children; SSSC) | | |
| Lin & Huang (2017) | Taiwan | Case control | Autistic adults | Checked disability cards issued by a health agency of the Taiwanese government which confirmed they had been diagnosed using the DSM-5 by a psychiatrist | Flyers at clinics and local autism groups | Quality of life (WHOQOL-Brief Taiwan version)<br>Loneliness (The University of California Los Angeles Loneliness Scale- Short Form; ULS-8) | Not specified | Grant from the Ministry of Science and Technology, Taiwan |
| Mahjouri (2011) – Study 1 | USA | Cross-sectional | Autistic adolescents | P's were enrolled in a larger school-based intervention study, in which all participants had met | Public and charter middle and high schools | Loneliness (Asher, Hymel & Renshaw's Loneliness Scale)<br>Anxiety (Multidimensional Anxiety Scale for Children; MASC) | Not specified | Not specified |

| | | | | | | | | |
|---|---|---|---|---|---|---|---|---|
| | | | | criteria for a research diagnosis of ASDs on the ADOS | | Social Anxiety Scale for Adolescents (SAS-A)<br>Depression (Children's Depression Inventory; CDI)<br>Number of friends (Kids in My Class Survey) | | |
| Mazurek (2014) | USA | Cross-sectional | Autistic adults | Participants were required to have a formal diagnosis of ASD and provide the ‘type’ of diagnosis. They administered the AQ-10 to check they reached the clinical cut off. | National open enrolment ASD registry, the Interactive Autism Network (IAN) Research Database at Kennedy Krieger Institute, and John Hopkins Medicine, Baltimore | Loneliness (The University of California Los Angeles Loneliness Scale- Short Form; ULS-8)<br>Friendship quality (Unidimensional Relationship Closeness Scale)<br>Life satisfaction (Satisfaction with Life Scale; SWLS)<br>Self-esteem (Rosenberg Self-Esteem Scale; RSE)<br>Depression (The Patient Health | Not specified | Supported by the University of Missouri School of Health Professionals Catalyst Award |

| | | | | | | | | |
|---|---|---|---|---|---|---|---|---|
| | | | | | | Questionnaire; PHQ) | | |
| Merkler (2007) | USA | Case control | Adults with HFASD | Participants were diagnosed by licensed psychologists un-associated with the current study and recruited through the Neurodevelopmental Disorders Research Centre Subject Registry Core. | The Neurodevelopmental Disorders Research Centre Subject Registry Core | Clinical symptomatology (The Brief Symptom Inventory; BSI)<br>Time spent with others/How much p's confide in others (the companionship and intimacy scales of the Network Relationships Inventory)<br>Positive/negative affect (The Positive and Negative Affective Schedule; PANAS)<br>Loneliness (The Social and Emotional Loneliness Scale for Adults; SELSA) | Not specified | Not specified |
| Storch, Ehrenreich-May, Jones, Lewin & | USA | Cross-sectional | Adolescents with ASD and co-occurring anxiety disorder | Administered the Autism Diagnostic Interview-Revised (ADI-R) and the | Participants were enrolled in a psychosocial treatment study for | Victimisation (Revised Peer Experiences Questionnaire; RPEQ) | Not specified | National Institute of Child Health and Human Development; |

| | | | | | | | | |
|---|---|---|---|---|---|---|---|---|
| Murphy (2012) | | | | ADOS administered by a certified rater. Only p's who met ASD diagnostic criteria with 100% certainty were included | anxiety with recruitment involving two sites | Loneliness (Asher Loneliness Scale; ALS) | | The All Children's Hospital Research Foundation;<br>The University of South Florida Office of Research and Innovation Established Researcher Grant Program |
| Syu & Lin (2018) | Taiwan | Cross-sectional | Autistic adults | Reviewed disability certificates issued by Taiwan Dept of Social Welfare to confirm diagnosis | Local autism groups and organisations | Anxiety (Beck Anxiety Inventory; BAI – Chinese version)<br>Loneliness (The University of California Los Angeles Loneliness Scale- Short Form; ULS-8) | Not specified | Grant from the Taiwan Ministry of Science and Technology |
| Whitehouse, Durkin, Jaquet & | Australia | Case control | Adolescents with Asperger | P's must have received a DSM-5 based diagnosis of AS by two | Mainstream secondary schools | Perception of friendships ( Friendship Quality Questionnaire; FQQ) | Not specified | Not specified |

| | | | | | |
|---|---|---|---|---|---|
| Ziatas (2009) | | | qualified staff. Diagnosis was confirmed in the study by the Childhood Asperger Syndrome Test (CAST) completed by the parent of each participant - only those with the recommended cut off of 15+ were included | Motivations for making friends (Friendship Motivation Questionnaire; FMQ)<br>Loneliness (De Jong-Gierveld Loneliness Scale)<br>Depression (Centre for Epidemiological Studies Depression Scale, Children's Version (CES-DC) | |

### ***Participant characteristics***

To summarise participants’ characteristics across the studies, the case-control and cross-sectional studies were included in separate tables for ease of reporting (see Table 4a and Table 4b).

#### ***Case-control (comparison) studies (n = 7).***

The total samples in the case-control studies ranged in size from *N* = 70 to *N* = 238. Of the seven case-control studies, all studies used ‘typically developing peers’ as a comparison group, and one study (Bossaert et al. 2012) added a second comparison group of participants with motor/sensory difficulties. Given that findings related to the comparison groups were not a focus of this review, participant characteristics of the comparison groups will not be reported here in the narrative synthesis but can be found in Table 4a.

The mean age of the participants varied between 14.2 years and 29.65 years for the ASD groups. Two studies (Bossaert et al., 2012 and Whitehouse et al., 2009) did not report a mean age. Three of the seven studies included adolescents only, three included adults only, and one study included both adults and adolescents. In five of the seven studies, the ASD group consisted of more males than females. Lasgaard et al. (2010) only included males, and Brooks (2016) had an equal gender split.

Ethnicity was reported in two of the seven case-control studies: White/Caucasian was the dominant ethnic group in both of these studies, with over 80% of participants recorded as being White/Caucasian. Diagnostic terminology varied, and included ASD, High Functioning Autism, Asperger Syndrome, PDD. One study did not specify participants’ autism diagnosis. Three studies provided details of participants' psychiatric diagnoses, which included mood disorders, anxiety disorders, and ADHD, whereas four did not specify whether participants had psychiatric diagnoses or not.

In four out of the seven studies, the authors confirmed participants did not have an ID (for example, by checking official documentation or administering a standardised measure of intelligence as part of the research process, such as the BETA-III).

### ***Cross-sectional studies (n = 8).***

The samples in the cross-sectional studies ranged in size from *N* = 18 to *N* = 185. The mean age of the participants varied between 12.2 years and 37.11 years. Three of the eight studies included adults only, two studies included adolescents only, and three studies included both adults and adolescents. Six of the eight cross-sectional studies included more males in their sample than any other gender identity. However, Hedley, Uljarević, Foley et al., (2018) had more females than any other gender identity, and in Jackson et al. (2018), there was an equal male/female split, with the remainder of their sample (7%) being non-binary.

Ethnicity was reported in six of the eight cross-sectional studies: White/Caucasian was the most dominant ethnic group in five of these studies, with over 50% of participants recorded as being White/Caucasian in each study. In Chen's (2016) study, the dominant ethnic group was Taiwanese (53%). As with the case-control studies, diagnostic terminology varied, and included ASD, High Functioning Autism, Asperger Syndrome, and PDD. Only two cross-sectional studies reported whether participants' had any psychiatric diagnoses. For participants in Chen's (2016) study, diagnoses included depression, anxiety, obsessive-compulsive disorder and

ADHD.  Syu and Lin (2018) does not provide details of the psychiatric diagnoses but indicated that 21% of their sample had at least one psychiatric diagnosis.

Half of the cross-sectional studies (n = 4) performed some form of screen for ID.  Three of these used a standardised measure of intelligence, whereas Syu and Lin (2018) used a non-standardised reading and word recall test.

**Table 4a**

*Participant Characteristics for Case-Control Studies*

| Study | Number of Participants | | Age<br>Mean (SD)<br>Range | | Sex/Gender (%) | | Recorded Ethnicity % | | ASD Diagnosis | Did the study confirm no LD? | Psychiatric Diagnoses % | |
|---|---|---|---|---|---|---|---|---|---|---|---|---|
| | **ASD group** | **Comparison group/s** | **ASD group** | **Comparison group/s** | **ASD group** | **Comparison group/s** | **ASD group** | **Comparison group** | | | **ASD group** | **Comparison group/s** |
| Bossaert, Colpin, Jan Pijl & Petry (2012) | 50 | *Motor/ sensory impair.*: 58<br>*TD*: 108 | Not specified<br>(not specified)<br>12-13 | M: not specified<br>SD: not specified<br>12-13 | M: 44 (89.66%)<br>F: 5 (10.34%) | *Motor/ sensory impairment*: M: 37 (64%)<br>F: 21 (36%)<br>*Non-autistic*: M: not specified<br>F: not specified | Not specified | Not specified | ASD | Not specified | Not specified | Not specified |
| Brooks (2016) | 56 | 56 | 26.3 (6.0) 18-40 | 26.4 (4.6) Range: not specified | M: 28 (50%)<br>F: 28 (50%) | M: 28 (50%)<br>F: 28 (50%) | Caucasian: 48 (85.7%)<br>African: 3 (5.35%) | Caucasian: 45 (80.35%)<br>African: 7 (12.5%) | HFASD | Yes | Mood disorder: 57%<br>Anxiety disorder: 23% | Mood disorder: 38%<br>Anxiety disorder: 7%<br>ADHD: 9% |

| | | | | | | | | | | | | |
|---|---|---|---|---|---|---|---|---|---|---|---|---|
| | | | | | | | Biracial: 5 (8.92%) | Biracial: 3 (5.35%)<br>Other: 1 (1.78%) | | | ADHD: 38%<br>Other: 5% | Other: 0% |
| Chang, Chen, Huang & Lin (2019) | 101 | 101 | | 15.6 (not specified) 10-19 | 16.1 (not specified) 10-19 | M: 84 (83.17%)<br>F: 17 (16.83%) | M: 53 (52.47%)<br>F: 48 (47.52%) | Not specified | Not specified | ASD | No, but parents reported FSIQ as part of exclusion criteria | Not specified | Not specified |
| Lasgaard, Nielsen, Eriksen & Goossens (2010) | 39 | 199 | | 14.2 (1.03) 13-17 | 14.1 (0.43) 13-16 | M: 39 (100%) | M: 199 (100%) | Not specified | Not specified | Atypical autism;<br>Asperger syndrome;<br>PDD | Not specified | ADHD: n/% not specified | Not specified |
| Lin & Huang (2017) | 66 | 85 | | 27.8 (5.2) 20-38 | 27.8 (4.3) 20-38 | M: 43 (65.2%)<br>F: 23 (34.8%) | M: 52 (61.2%)<br>F: 33 (38.8%) | Not specified | Not specified | ASD | No, but checked government issued disability cards | 22.7% | 0% |
| Merkler (2007) | 37 | 82 | | 29.65 (10.19) 18-52 | 18 (0.33) 17-19 | M: 30 (81.08%)<br>F: 7 (18.91%) | M: 26 (31.70%)<br>F: 56 (68.29%) | Caucasian: 89%; | Caucasian: 83%; | Not specified (refer to ‘autism’) | Yes using the BETA III | Not specified | Not specified |

| | | | | | | | | | | | | |
|---|---|---|---|---|---|---|---|---|---|---|---|---|
| | | | | | | | African American: 3%;<br>Asian: 3%;<br>Indian: 2% | African American: 10%;<br>Hispanic: 4%;<br>Asian: 5% | | | | |
| Whitehouse, Durkin, Jaquet & Ziatas (2009) | 35 | 35 | Not specified (not specified)<br>12-18 | Not specified (not specified)<br>13-17 | M: 28 (80%)<br>F: 7 (20%) | M: 29 (82.85%)<br>F: 6 (17.14%) | Not specified | Not specified | Asperger syndrome | Not specified | Not specified | Not specified |

**Table 4b**

*Participant Characteristics for Cross-Sectional Studies*

| **Study** | **Number of Participants (dropouts)** | **Age**<br>**M (SD)**<br>**Range** | **Sex (%)** | **Reported Ethnicity %** | **ASD Diagnosis** | **Did the study confirm no LD?** | **Psychiatric Diagnoses %** |
|---|---|---|---|---|---|---|---|
| Chen, Bundy, Cordier, Chien & Einfeld (2016) | 30 | *Australian*: 24.8 (9.0) 16–43 | M: 16 (53.33%)<br>F: 14 (46.66%) | *Australian*: 46.66%<br>*Taiwanese*: 53.33% | HFASD;<br>Asperger | Yes – by the Reading Comprehension Subtest of Woodcock Reading Test | ADHD: 10%;<br>Depression: 3.33%;<br>Anxiety: 3.33%; |

| | | | | | | | |
|---|---|---|---|---|---|---|---|
| | | *Taiwanese*:<br>27.8 (6.3)<br>19–45 | | | | (Australians) and WAIS-IV (Taiwanese) | Obsessive–compulsive disorder: 6.66% |
| Hedley, Uljarević, Foley, Richdale and Trollor (2018) | 185 | 37.11 (15.41)<br>14-80 | M: 83 (44.86%)<br>F: 92 (49.72%)<br>Other: 10 (5.4%) | Not specified | ASD;<br>HFASD;<br>Asperger Syndrome | Not specified | Not specified |
| Hedley, Uljarević, Wilmot & Richdale (2018) | 71 | 26.14 (8.20)<br>17–56 | M: 63 (88.73%)<br>F: 8 (11.26%) | Australian: 84.5%<br>Aboriginal or Torres Strait Islander: 1.4%<br>Other (Chinese, Salvadorian, British, North American): 8.5% | ASD;<br>HFASD;<br>Asperger Syndrome | Not specified | Not specified |
| Jackson, Hart, Brown & Volkmar (2018) | 56 | 22.98 (6.01)<br>18-57 | M: 26 (46.4%)<br>F: 26 (46.4%)<br>Non-binary: 4 (7.1%) | White: 80.4%<br>Hispanic: 3.6%<br>Black: 1.8%<br>Asian: 7.1%<br>Mixed/Other: 7.1% | Asperger Syndrome;<br>ASD;<br>HFA;<br>PDD-NOS | Not specified | Not specified |
| Mahjouri (2011) – study 1 | 18 | 15.1 (2.17)<br>12-18 | M: Not specified (86%) | Caucasian: 58.1%<br>Latino: 11.6% | ASD | Yes – by the Stanford-Binet (5th Edition) | Not specified |

| | | | | | | | |
|---|---|---|---|---|---|---|---|
| | | | F: Not specified (14%) | African American: 0.0%<br>Asian: 23.3%<br>Other: 7% | | | |
| Mazurek (2014) | 108 | 32.4 (12.5) 18-62 | M: 57 (52.8%)<br>F: 51 (47.2%) | Caucasian: 88.0%<br>Other: 12.0% | Autism;<br>Autistic disorder;<br>Asperger Syndrome;<br>PDD-NOS | Not specified | Not specified |
| Storch, Ehrenreich-May, Jones, Lewin & Murphy (2012) | 60 | 12.2 (1.1) 11-14 | M: 48 (80%)<br>F: 12 (20%) | Caucasian: 73.3%;<br>Hispanic/Latino: 8.3%;<br>Asian American: 5.0%;<br>African American: 3.3%;<br>Other/Mixed:10% | Autism;<br>Asperger Syndrome;<br>PDD | Yes – by a standardised measure of intellectual functioning | Not specified |
| Syu & Lin (2018) | 70 | 27.8 (5.0) 20-39 | M: 46 (65.7%)<br>F: 24 (34.3%) | Not specified | Autistic disorder;<br>Asperger Syndrome;<br>PDD-NOS;<br>ASD | Yes? – asked them to read a newspaper paragraph and then immediately write five of the | 21.4% |

| | | | | | | | |
|---|---|---|---|---|---|---|---|
| | | | | | | words they had read | |

### ***Quality appraisal***

A quality assessment was made of the 15 articles. The results from the quality assessment are reported here first, in order to allow for this to inform the reporting of the synthesised results. As shown in Table 6, the overall gradings for case-control studies were good (n = 0), fair (n = 0) or poor (n = 7). As shown in Table 7, the overall gradings for cross-sectional studies were very good (n = 0), good (n = 0), satisfactory (n = 3) or unsatisfactory (n = 5). The original plan was to exclude poor quality studies from the review, however this would have left only three studies for inclusion. All studies were therefore included in the review, but given that 80% of the studies were rated as ‘poor’ or ‘unsatisfactory’, caution should be taken when interpreting the results and drawing conclusions about the findings.

The three studies that achieved a rating of ‘satisfactory’ were Chen (2016), Hedley, Uljarević, Foley, et al. (2018) and Syu and Lin (2014). The synthesis of study results were weighted in accordance with these quality ratings (see page 45 for details).

**Table 6**

*Quality Assessment Ratings for Case-Control Studies*

| Study | Selection (max. 4 stars) | Comparability (max. 2 stars) | Exposure (max. 3 stars) | Total (max. 9 stars) | AHRQ standards (good / fair / poor quality) |
|---|---|---|---|---|---|
| Bossaert, Colpin, Jan Pijl & Petry (2012) | 2 | 2 | 1 | 5 | Poor |
| Brooks (2016) | 3 | 2 | 1 | 6 | Poor |
| Chang, Chen, Huang & Lin (2019) | 3 | 1 | 1 | 5 | Poor |
| Lasgaard, Nielsen, Eriksen & Goossens (2010) | 3 | 1 | 1 | 5 | Poor |
| Lin & Huang (2017) | 3 | 2 | 1 | 6 | Poor |
| Merkler (2007) | 1 | 1 | 1 | 3 | Poor |
| Whitehouse, Durkin, Jaquet & Ziatas (2009) | 3 | 2 | 1 | 6 | Poor |

**Table 7**

*Quality Assessment Ratings for Cross-Sectional Studies*

| Study | Selection (max. 5 stars) | Comparability (max. 2 stars) | Outcome (max. 3 stars) | Total | Herzog (2013) rating (very good, good, satisfactory, unsatisfactory) |
|---|---|---|---|---|---|
| Chen, Bundy, Cordier, Chien & Einfeld (2016) | 1 | 1 | 3 | 5 | Satisfactory |
| Hedley, Uljarević, Foley, Richdale and Trollor (2018) | 1 | 1 | 3 | 5 | Satisfactory |
| Hedley, Uljarević, Wilmot & Richdale (2018) | 1 | 0 | 3 | 4 | Unsatisfactory |
| Jackson, Hart, Brown & Volkmar (2018) | 1 | 1 | 2 | 4 | Unsatisfactory |
| Mahjouri (2011) – study 1 | 1 | 0 | 2 | 3 | Unsatisfactory |
| Mazurek (2014) | 1 | 1 | 2 | 4 | Unsatisfactory |
| Storch, Ehrenreich-May, Jones, Lewin & Murphy (2012) | 1 | 0 | 3 | 4 | Unsatisfactory |
| Syu & Lin (2018) | 2 | 1 | 2 | 5 | Satisfactory |

### *Study results*

In the 15 reviewed articles, 41 psychosocial factors were identified. To simplify the presentation, the psychosocial factors were grouped into three main categories: quantity of social contacts, quality of social contacts, and psychological factors. In order to allow quality assessment to inform the synthesis of the results, each of the three sections are structured around the results of the three studies that achieved a 'satisfactory' rating, with the results from poor quality studies presented after and in relation to the higher quality papers. The synthesis is also structured by age group (adult and adolescent) and study design (case-control or cross-sectional) to allow for a more detailed analysis and consideration to be given to factors potentially affecting inconsistencies across study results. Three studies included both adults and adolescents in their sample. This is referred to in the synthesis where relevant, however, all three of these studies are described under the 'Adults' headings. As none of the case-control studies achieved a quality rating of satisfactory or above, it was not possible to structure the synthesis of case control study results by quality assessment. The variable terms used in this report are the terms used by the original study (e.g. 'social supports', 'friends', 'close friends'). Given the heterogeneity of factors under study, as well as the overall poor quality and low number of studies included in the review, it was deemed inappropriate to conduct a meta-analysis (Deeks et al., 2021).

#### *Quantity of social contacts.*

Across all 16 studies, seven variables under the category of 'Quantity of Social Contacts' were identified. This category includes factors concerned with the *number* of social contacts participants report.

##### Adults.

Cross-sectional studies

Hedley, Uljarević, Foley, et al. (2018), whose sample included both adults and adolescents, found that the fewer *social supports* participants perceived they had, the more loneliness they reported. This finding is supported by two studies with an entirely adult population (that of Mazurek (2014) and Jackson et al. (2018), who found that greater loneliness was reported by participants who also reported fewer *friends* and *close friends*. Further analyses by Hedley, Uljarević, Foley, et al. (2018) found that *number of social supports* significantly predicted loneliness, and similarly, Mazurek (2014) found that *number of friends* provided significant main effects in predicting loneliness in adults, even after controlling for the effects of ASD symptoms. It is worthy of note that the study by Hedley, Uljarević, Foley, et al. (2018) achieved a ‘satisfactory’ quality rating, whereas the other studies did not.

Case-control studies

No studies examining quantity of social contacts in adults used a case-control design.

**Adolescents.**

Cross-sectional

In the one cross-sectional study that included adolescents only, the relationship between *number of friends* and loneliness was found it to be insignificant (Mahjouri, 2011). In terms of school involvement, greater *number of school friends* was significantly associated with lower levels of loneliness (Mahjouri, 2011), though this study was of poor methodological quality. Bivariate analyses were not reported for the relationship between loneliness and *number of friends outside of school* in this study.

Case-control studies

The relationship between *number of friends* and loneliness was also found it to be insignificant in the case-control study exploring this relationship (Bossaert et al., 2012). Further, *number of friends* did not significantly predict loneliness (Bossaert et al., 2012). In terms of school involvement, increased *school participation* (that is, active participation in school activities) was significantly associated with lower levels of loneliness (Chang et al., 2019). One study found the relationship between loneliness and the *amount of contact with peers outside school* to be insignificant, though they did not report the statistics of this analysis (Lasgaard et al., 2010). It is worthy of note that the study by Chang et al. (2019) received a 'satisfactory' quality rating, indicating that the results from this study are more reliable than those from studies, such as Lasgaard et al.'s (2010).

### ***Quality of social contacts.***

Across the 15 studies, 19 variables under the category of 'Quality of Social Contacts' were identified. This category includes factors concerned with the *perceived quality* of social relationships that participants report.

### **Adults.**

#### Cross-sectional

Hedley, Uljarević, Foley, et al. (2018) (mixed adult and adolescent sample) found that greater *satisfaction with social supports* was reported by participants who reported lower levels of loneliness, and that this factor emerged as a significant predictor of loneliness. The findings from this study, which received a 'satisfactory' quality rating, were supported by two poor quality studies. Jackson et al.'s (2018) study of adults only found that greater *satisfaction with close friends* was significantly associated with lower levels of loneliness. *Number of*, and *satisfaction with, romantic* *relationships* were not found to be associated with lower levels of loneliness (Jackson et al., 2018). A significant association was found between *closeness of the relationship with a best friend* and loneliness, though this did not significantly predict loneliness after controlling for the effects of ASD symptoms (Mazurek, 2014).

Case-control studies

In the studies using a case-control design, better *friendship quality* was found to be associated with lower levels of loneliness (Brooks, 2016). *Social network isolation* and *dyadic isolation* were both significant predictors of loneliness in adults (Merkler, 2007). This study also found that *social network isolation* predicted *social network distress*, and *dyadic (emotional) isolation* predicted *dyadic (emotional) distress*. The former relationship was found to be stronger than the latter, indicating that autistic adults are more distressed in the absence of social network relationships than they are in the absence of dyadic relationships (Merkler, 2007). Greater loneliness was found for those who reported lower *quality of life* in the *social relationships domain* (Lin & Huang, 2017). However, all of these studies lacked methodological quality and therefore the results should not be considered reliable.

### Adolescents.

Cross-sectional

One cross-sectional study found positive associations between loneliness and four types of victimisation in adolescents, though the relationships were only significant for *total peer victimisation* and *relational victimisation* (Storch et al., 2012). The associations between loneliness and *overt victimisation* and *reputational victimisation* were not found to be significant, nor was the association between loneliness and *prosocial receipt*.

Case control

Of the case-control studies, two found a significant relationship between *friendship quality* and loneliness (Bossaert et al., 2012; Chang et al., 2019). Further, the *conflict/betrayal* subscale of the Friendship Quality Questionnaire was identified as a significant predictor of loneliness in Whitehouse et al.'s (2009) study. The more *social support* adolescents felt they received from either a *school friend*, *classmates* or *parents*, the lower the level of loneliness they reported (Lasgaard et al., 2010). However, when *the effect of siblings* was controlled for, the relationship between loneliness and *perceived social support from a close friend* was no longer significant (Lasgaard et al., 2010). An increased risk of loneliness was found for participants who reported a lower *overall friendship score*, however this factor did not significantly predict loneliness itself (Whitehouse et al., 2009). All of the studies examining quality of social contacts in adolescents were of poor methodological quality.

### ***Psychological factors.***

Across the 15 studies, 15 variables under the category of 'Psychological Factors' were identified. This factor is concerned with individual-level processes and meanings that influence mental states.

### **Adults.**

Cross-sectional

Hedley, Uljarević, Foley, et al. (2018) (both adults and adolescents) found that as loneliness increases so does *depression*. The finding from this 'satisfactory' quality study was supported by two other poor quality studies quality that examined the relationship between loneliness and *depression*, one in a combined adult/adolescent sample (Hedley, Uljarević, Wilmot, et al., 2018) and the other in an adult sample

(Mazurek, 2014). Hedley, Uljarević, Foley, et al. (2018) also found that loneliness predicted depression, and Mazurek (2014) found this to be the case even after controlling for the effects of ASD symptoms. Further, *suicidal ideation* (Hedley, Uljarević, Foley, et al., 2018) and *thoughts of self-harm* (Hedley, Uljarević, Wilmot, et al., 2018) both increased with an increase in reported loneliness, and both of these relationships were mediated by depression.

Syu and Lin's (2014) study, which was of 'satisfactory' methodological quality, found a positive relationship between loneliness and *anxiety* in adults, and this finding was supported by another study examining this relationship (Mazurek, 2014). Mazurek (2014) also found that, after controlling for ASD symptoms, loneliness significantly predicted *anxiety*, and also *self-esteem*. Chen's (2016) study, which also achieved a 'satisfactory' quality rating for their study of a combined adult and adolescent sample, however, found that severe *social anxiety* was only weakly related to 'feeling lonely' whilst engaging in '*solitary/parallel leisure activities*' (as opposed to activities requiring social interaction).

Overall, loneliness provided significant main effects in predicting *satisfaction with life* after controlling for ASD symptoms (Mazurek, 2014). After controlling for age and gender, loneliness emerged as a significant predictor of *overall emotional distress* (Jackson, 2018). However, neither of these studies were of satisfactory methodological quality.

Case-control

In the studies using a case-control design, *positive affect* was found to be higher in adults who reported lower levels of loneliness, whereas *negative affect* was higher in those who reported greater loneliness (Brooks, 2016). Overall, loneliness provided significant main effects in predicting *quality of life* in the *psychological health domain* (Lin & Huang, 2017). However, both of these studies were of poor methodological quality and therefore the results cannot be considered reliable.

#### **Adolescents.**

Cross-sectional

Consistent with the findings of studies including adult and combined adult/adolescent samples, a significant relationship between loneliness and depression was found in an adolescent only sample (Mahjouri, 2011). Positive relationships were also found between loneliness and *social anxiety* for adolescents (Mahjouri, 2011). However, the relationship between *multi-dimensional anxiety* and loneliness was not found to be significant (Mahjouri, 2011).

Case-control

Whitehouse et al. (2009) found that loneliness was a significant mediator in the relationship between depressive symptoms and friendship quality in adolescents. Positive relationships were also found between loneliness and anxiety (Chang et al., 2019). Loneliness emerged as a mediator in the relationship between anxiety and friendship quality (Chang, 2019). *Social self-concept* in relation to *same sex* and *opposite sex* relationships were found to be higher in adolescents who reported lower levels of loneliness (Bossaert et al., 2012). *Same-sex social self-concept* was also found to predict loneliness, however *opposite-sex social self-concept* was not (Bossaert et al., 2012). Again, all of the studies examining psychological factors in an adolescent sample were of poor methodological quality and so their results cannot be considered reliable.

**Table 5**

### *Study Results*

| Study | Method of Analysis | Main Findings |
|---|---|---|
| Bossaert, Colpin, Jan Pijl & Petry (2012) | **Correlations** calculated to examine the links among friendships, social self-concept and loneliness. | *ASD group:*<br>Loneliness + number of friends -0.06<br>Loneliness + friendship quality -0.11<br>Loneliness + social self-concept (same sex) -0.65***<br>Loneliness + social self-concept (opposite sex) -0.49***<br>*** Beta coefficient (b) significant at p < .001. |
| | **Multiple regression analyses** | *ASD group:*<br>Same-sex social self-concept (and not opposite-sex social self-concept or number of friends) predicted loneliness (R2 = 0.48, F(5,48) = 9.00, p < .001).<br>Friendship quality did not have a significant effect on loneliness. |
| Brooks (2016) | **Pearson correlations** to explore the relationships among loneliness, friendship quality and emotions. | *HFASD group*:<br>Loneliness + positive affect scores -0.553**<br>Loneliness + negative affect scores 0.258*<br>Loneliness + friendship quality -0.467**<br>*Significant at the .05 level; **Significant at the .001 level |
| Chang, Chen, Huang & Lin (2019) | **Correlation** to explore relationships between loneliness and school participation, friendship quality and anxiety. | *ASD group*:<br>Loneliness + school participation -0.449***<br>Loneliness + friendship quality -0.229*<br>Loneliness + anxiety 0.442*** |

| | | |
|---|---|---|
| | | *p < .05. **p < .01. ***p < .001. |
| | **Mediation**<br>To examine whether loneliness was a mediator of the relationship between friendship quality and anxiety, a series of regression analyses were performed. | *ASD group:*<br>Loneliness mediated the relationship between friendship quality and anxiety, and based on analyses using Sobel's test [45], the mediation effect was found to be significant. |
| Chen, Bundy, Cordier, Chien & Einfeld (2016) | **Moderating** effects on the experience in everyday participation. | Severe social anxiety was only weakly related to ‘feeling lonely’ while engaging in ‘solitary/parallel leisure’ (β = -0.02, p = 0.01*)<br>* p<0.05; ** p<0.01 |
| Hedley, Uljarević, Foley, Richdale and Trollor (2018) | **Correlation** to explore the relationships between social support, depression and suicidal ideation. | Loneliness + Social Support Questionnaire Short Number (of supports) -.379**<br>Loneliness + Depression 0.437**<br>Loneliness + Social Support Questionnaire Short Satisfaction (with support) –0.558**<br>Loneliness + Suicidal ideation .284**<br>* P < .05, **P < .01 |
| | **Multiple regression** models exploring predictors depression. | The total model accounted for 29.1% of variance, F = 18.44, P < .001, with loneliness (t = 3.11, $\beta$ = .24, P = .002) emerging as a unique predictor of depression scores. |

| | | |
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| | **Path model** exploring the predictive roles that ASD traits, loneliness, the number of social supports, satisfaction with the available social support, and depressive symptoms, play in suicidal ideation. | Number of social supports predicted loneliness ($\beta$ = –.17, P = .009), and satisfaction with social support predicted loneliness ($\beta$ = –.47, P < .001).<br>Mediation analyses showed significant effects of loneliness (b = .04; BCa [.02, .06]) on suicidal ideation through depression, with depression accounting for 83.9 of the total effect. |
| Hedley, Uljarević, Wilmot & Richdale (2018) | **Correlations** exploring relationships between loneliness and depression and self-harm.<br>Two **exploratory mediation** analyses were performed to characterise the nature of the depression–loneliness– thoughts of self-harm interrelationship | Loneliness + depression 0.392*<br>Loneliness + thoughts of self-harm .338*<br>* p < .01. ** p < .001.<br>The mediation model exploring whether the relationship between loneliness and thoughts of self-harm was mediated by depression was supported, b = .011, BCa 95% CI [.004, .023], standardized effect size = .19, BCa [.09, .33]. The mediator accounted for 56.7% of the total effect, R2 = 30.9%, F = 15.46, p < .001. |
| Jackson, Hart, Brown & Volkmar (2018) | **Correlations** to explore the relationships between loneliness, close friends and romantic relationships.<br>**Hierarchical stepwise regression** analysis | Loneliness (M=6.52, SD=1.96) was found to be significantly associated with the number of close friends participants reported ($r_s$ (54)=−0.52, p<0.001) and how satisfied they were with how many close friends they had ($r_s$ (54)=−0.61, p<0.001), but was not found to be associated with number of or satisfaction with romantic relationships (0.36<*ps*<0.38).<br>Controlling for age and gender, overall loneliness emerged as a significant predictors of overall emotional distress. |

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| Lasgaard, Nielsen, Eriksen & Goossens (2010) | **Correlations** to explore relationships between loneliness and perceived social support from peers and parents. | Loneliness correlated negatively with perceived social support from classmates ($r = -0.52$, $p<0.005$), parents ($r = -.43$, $p<0.01$), and a school friend ($r = -.40$, $p<0.05$).<br>Moreover, no association was found between loneliness and the amount of contact with peers outside school. |
| | **Post hoc tests** | Controlling for the effect of siblings on correlations between the UCLA and the SSSC, using partial correlations, the moderate association between loneliness and perceived social support from a close friend no longer proved significant ($r = -0.24$, ns). |
| Lin & Huang (2017) | **Correlations** to explore relationships between loneliness and quality of life domains. | Loneliness ( $r= -0.378$, $p < 0.01$) was related to the psychological health domain.<br>Loneliness ($r = -0.404$, $p < 0.01$) was related to the social relationships domain. |
| | **Multivariate regression** analysis | Lower score for the psychological health domain ($R_2 = 0.516$, $p < 0.001$) was significantly predicted by more loneliness ($\beta= -0.271$, $p < 0.01$). |
| Mahjouri (2011) Study 1 | **Correlations** to explore relationships between loneliness, anxiety, depression and friendships. | Loneliness + social anxiety.503*<br>Loneliness + multidimensional anxiety .364<br>Loneliness + depression.683**<br>Loneliness + no. of friends in school -0.605**<br>Loneliness + no. friends identified -0.310<br>Loneliness + no. friends outside school *not specified*<br>* .05>p **.01>p |

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|---|---|---|
| Mazurek (2014) | **Correlations** to examine relationships between loneliness and each well-being variable (including friendships, life satisfaction, self-esteem, depression, and anxiety). | Loneliness was positively correlated with depression (r = .48, p < .001) and anxiety (r = .34, p = .001), and negatively correlated with both satisfaction with life (r = −.46, p < .001) and self-esteem (r = −.38, p < .001).<br>Number of friends was negatively correlated with loneliness (r = −.34, p = .001)<br>For those who reported having a best friend, the closeness of the friendship relationship was negatively correlated with loneliness (r = −.29, p = .02). |
| | **Regression analyses** | Loneliness provided significant main effects in the models predicting depression (β = .49, p < .001), anxiety (β = .32, p = .002), satisfaction with life (β = −.42, p < .001), and self-esteem (β = −.32, p = .001). In contrast, AQ did not contribute to the prediction of well-being in any model.<br>Number of friends provided significant main effects in predicting loneliness even after controlling for the effects of ASD symptoms (β = −.29, p = .007), whereas AQ was not a significant predictor.<br>Friendship closeness approached significance in predicting loneliness after controlling for the effects of ASD symptoms (β = −.23, p = .06). |
| Merkler (2007) | **Regression analyses** | Social network isolation was a significant predictor of social network distress (b = 2.531, p<.05) and dyadic (emotional) isolation was a significant predictor of dyadic distress (b = .965, p<.05). |

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| | | The relationship between social network isolation and social network distress was stronger than the relationship between dyadic isolation and dyadic distress, t = 2.57, p < .05.<br>Social network isolation was a significant predictor of all three individual emotion outcome variables (sadness, anger and loneliness).<br>Dyadic isolation was a significant predictor of all three individual emotion outcome variables (sadness, anger and loneliness). |
| Storch, Ehrenreich-May, Jones, Lewin & Murphy (2012) | **Correlations** between peer victimisation, social impairment, and loneliness. | Loneliness + Total Victimization .29*<br>Loneliness + Overt Victimisation .13<br>Loneliness + Relational Victimisation .30*<br>Loneliness + Reputational Victimisation .23<br>Loneliness + Prosocial Receipt -.01<br>*p≤.05; **p≤.01 |
| Syu & Lin (2018) | **Correlation** to evaluate relationships between loneliness and anxiety. | Loneliness + anxiety 0.501***<br>∗p < 0 05, ∗∗p < 0 01, and ∗∗∗p < 0 001 |
| Whitehouse, Durkin, Jaquet & Ziatas (2009) | **Correlation** to examine the relation between overall friendship score and loneliness. | *ASD group:*<br>Significant negative association between the overall friendship score and levels of loneliness (r(34) = -0.28, p = 0.04). |
| | **Regression** to examine whether overall friendship predicts loneliness. | *ASD group:*<br>Overall friendship score did not predict levels of loneliness ($R_2$ = 0.08, F(1,34) = 2.84, p = 0.1). |

| | | |
|---|---|---|
| | Separate **multiple regression** analyses to investigate whether scores on one or more of the FQQ subscales may be related to levels of loneliness. | *ASD group:*<br>The conflict/betrayal subscale of the FQQ was the only significant predictor of loneliness levels ($\beta = 0.54$, $t(31) = 3.14$, $p < 0.01$). |
| | **Mediation analysis** to determine whether feelings of loneliness mediated any association between friendship quality and levels of depressive symptoms. | Feelings of loneliness was a significant mediator in the association between friendship quality and levels of depressive symptoms ($p = 0.05$). |

## Discussion

### *Main findings*

Loneliness as a chronic state is a well-documented risk factor for negative health outcomes in the general population. Despite some research indicating that autistic people have less desire for social interaction (Chevallier et al., 2012), more recent research is challenging this assumption, indicating higher rates of self-reported loneliness in autistic adults and adolescents (Mazurek, 2014; Bauminger & Kasari, 2000, Lasgaard et al., 2010) than in their non-autistic peers.

Over the last decade, studies have begun to investigate the impact of loneliness on the wellbeing of autistic people. The aim of this review was therefore to synthesise the findings of existing research to understand the psychosocial factors that are associated with loneliness for autistic adults and adolescents. This was achieved via a systematic search of the literature published between January 2000 and 16th June 2021. A narrative synthesis of studies was provided. To our knowledge, this is the only systematic review of its kind. Given the clinical heterogeneity within studies, a meta-analysis was deemed inappropriate.

A total of 41 psychosocial factors were studied in the 15 articles included in this review. Many psychosocial factors were found to be significantly associated with loneliness, indicating that on the whole, lower levels of loneliness are found in participants who report a higher number of social contacts, greater quality of social contacts, and better psychological health/wellbeing. However, it is difficult to draw more specific conclusions about the findings given that only two factors were significantly associated with loneliness across more than one study; namely anxiety and depression. Across several studies, greater loneliness was associated with greater depression, and loneliness emerged as a predictor of depression even after controlling for ASD symptoms.  Similarly, greater loneliness was associated with greater anxiety across studies, and, after controlling ASD symptoms, loneliness was found to predict anxiety.  In addition, loneliness mediated the relationships between depression and friendship quality, and anxiety and friendship quality.  To allow for a more detailed analysis and consideration to be given to factors potentially affecting inconsistencies across study results, the synthesis was structured by age of the sample group (i.e., adults or adolescents) and study design (i.e., cross-sectional or case-control).  One tentative finding was revealed from this additional level of analysis, in that for adolescents, number of school relationships were associated with levels of loneliness when other/general relationships were not, whereas for adults, other/general relationships were associated with levels of loneliness.  No other notable differences between the adult/adolescent studies and the case-control/cross-sectional studies were apparent.  However, it is recognised that the lack of significant findings here may be due to methodological issues in the studies (such as, small sample sizes, differences in recruitment strategies, lack of clarity around age within samples).

It is important to note the overall low quality of studies in this review.  The inconsistency in findings across studies in relation to other psychosocial factors may be explained in part by the poor quality of studies, as weaknesses in the design and conduct of research may result in over- or under- estimation of the relationships under study (Whiting et al., 2004; Whiting et al., 2013).  Results should not be considered to be reliable and it would therefore be inappropriate to draw conclusions about specific targets for intervention.  This said, it is also important to acknowledge the limitations of the quality assessment tools used, as discussed in the section of this report pertaining to strengths and weaknesses of the review.

The findings of this review are consistent with the literature on loneliness in autistic children (Kwan et al., 2020), non-autistic adults (Cacioppo et al., 2006; Joiner et al., 2009) and non-autistic adolescents (Lasgaard et al., 2011) in showing the significant and wide ranging associations between loneliness and psychosocial outcomes. In line with the existing literature demonstrating the long lasting impact of loneliness on future mental health problems, such as the recent rapid review by Loades et al. (2020), this review indicated significant associations in both autistic adolescents and adults (total sample ranged between 10 years and 62 years), suggesting that loneliness is associated with negative psychosocial outcomes across the lifespan. The associations found can be understood within the context of de Jong-Gierveld’s model of loneliness (1987) with the majority of factors falling within the domains of social network characteristics, the cognitive appraisals one makes of their social network, and factors classified within the model as personality characteristics, such as, self-concept and social anxiety. However, as is the case within the general population literature (Groarke et al., 2020), the direction of many of the associations remain unclear. Given the distinction made in the literature between loneliness and associated concepts such as aloneness (Peplau & Perlman, 1982; Perlman & Peplau, 1981), it was anticipated that the relationships between loneliness and factors within the ‘Quantity of Social Contacts’ category may be weaker than those between loneliness and factors within the ‘Quality of Social Contacts’ category. However, this review has not found evidence to support this hypothesis.

Given the number and range of significant associations found between loneliness and the ‘Psychological Factors’ and the ‘Quality of Social Contacts’ factors in particular, there is evidence to suggest that loneliness has negative implications for the mental health and social functioning of autistic adults and adolescents. This contradicts traditional views assuming that autistic people have less desire for social relationships. Further, despite previous research suggesting that autistic individuals may want social interaction on an *implicit* level, but less so on an *explicit* level (for example, Deckers et al., 2014), the studies in this review suggest that autistic participants express a desire for social interaction on an explicit level (by way of self-report questionnaires) too.

### ***Strengths and limitations of the studies included***

As noted, the main limitation of the studies included in this review is their low quality, as only three of the 15 studies received ratings of ‘satisfactory’ rather than ‘poor’ or ‘unsatisfactory’. The lack of good quality research means that confidence in the results of the studies is limited. Only one study reported a justification for their sample size. Sample sizes were generally fairly small, and therefore associations with loneliness needed to be strong in order to yield significant results, and weaker associations may have been left undetected. No studies included a follow-up; longitudinal research would help to determine the causal relations among loneliness and psychosocial factors with more confidence. The majority of studies used convenience sampling, therefore the studies lack clear generalisability, and there is a potential for bias based on self-selection and the possibility of under- or over-representation of the population. Convenience sampling is the norm within developmental research as probability samples are costly and are often not best suited to developmental research questions (Jager et al., 2017). However, the implications for study findings should still be acknowledged, and efforts should be made to reduce the bias that this method of sampling risks. For the studies included in this review, inclusion of larger sample sizes, introduction of some probability sampling, and efforts to diversify samples by distributing questionnaires on various occasions, and at various times and recruitment sites, would have reduced the likelihood of bias in these samples. Identification of a core set of standardised outcome measures for the variables relevant to this field of research would be beneficial for comparing studies.

A further limitation of the studies included in this review is that none reported that their research team included an autistic researcher or ‘autistic advisor’. Inclusion of autistic people on research teams can improve the epistemological integrity of studies, improve ecological validity and embed findings within real-world contexts, and thus, strengthen the application of findings to practice (Fletcher-Watson et al., 2019; Carrington et al., 2016; Milton & Bracher, 2013).

### ***Generalisability***

An inclusion criterion of the review was that data were self-reported. Characteristics of individuals who self-select to research studies may be different to those who do not, and therefore the findings cannot be generalised to the autistic population as a whole. Over two thirds of studies were conducted in Western countries, and although ethnicity data were not consistently reported, where data were available it appears there is an over-representation of people who identify as White/Caucasian in the samples. There are cultural differences relevant to the variables under review, for example, that Western cultures tend to be characterised by individualism and independence, whereas non-Western cultures tend to favour interdependence and collectivism (emphasis on family and community relationships) (Özdemir & Tuncay, 2008). It is therefore unclear whether the conclusions drawn about the impact of loneliness in this review, based on mainly White/Western samples, would be valid for non-White/Western samples. In addition, the majority of samples in the included studies were dominated by individuals who identify as male and, given hypothesised sex-based differences in autistic presentations, it is not clear whether loneliness and other psychosocial factors in autistic females can be understood in the same way as in autistic males.

### ***Strengths and limitations of the systematic review***

A number of efforts were made to increase the robustness of this review. Firstly, trialling the search strategy and complementing the database search with manual searches of the reference lists of selected papers enables confidence that relevant research published within the specified timeframe was identified, and therefore, that conclusions drawn here consider available evidence. Secondly, a sample of the screening and selection, data extraction and quality assessment were all cross-checked by an independent reviewer to improve accuracy and objectivity. Thirdly, studies were only included in the review if they performed some form of check for ASD diagnosis.

Reviews of a similar nature have examined concepts closely related to loneliness, such as social isolation and alienation. However, research has made a clear distinction between being objectively socially isolated and feeling lonely (Perlman & Peplau, 1984; Leigh-Hunt et al., 2017). The more stringent criteria of this review in this regard therefore increases its robustness.

Quality assessment tools are generally designed for evaluating intervention studies and as such are not well-suited to a review of the types of studies included in this review (Jüni et al., 1999). The NOS was chosen for the current research as it is recommended as a valid tool for quality assessing observational/non-randomised studies by the Cochrane Collaboration (Higgins et al., 2019), and given that it has versions adapted for use with both cross-sectional and case-study designs. However, the tool still lacked relevance and sensitivity to the topic under study which rendered quality assessment challenging, introducing a degree of subjectivity in that quality assessment items needed to be amended to ensure that they were relevant. Even then, the quality assessment tool did not take account of issues currently relevant to research in the field of autism, for example, whether research teams included autistic researchers or whether studies used measures validated for use with an autistic population. However, item ratings were consistent across studies and this process allowed for quality to be taken into account when interpreting the results, improving the relevance and accuracy of conclusions drawn, as is advised by the Evidence-based Practice Centre Program of the Agency for Healthcare Research & Quality (AHRQ) and the Cochrane Collaboration. An example of reasoning behind the quality ratings are included in Appendix F.

However, there are limitations to the review. One of the review's exclusion criterion was inclusion of participants with an ID. However, it was not always clear whether participants with an ID were included in the sample or not. To avoid the inappropriate exclusion of articles, studies were included unless they specifically stated that their sample included individuals with an ID. This means it is not possible to draw conclusions about the findings being relevant to autistic people only, as opposed to people with an ID and/or autism and ID.

The broad age range may also be considered a limitation of this review. It has been argued that loneliness is a multi-faceted construct and that the different aspects of loneliness may present in different developmental stages (Heinrich & Gullone, 2006). The inconsistency in results may in part be explained by the broad age range within the sample, in that associations may be found for some age groups but not others.

This review was one of self-reported loneliness and self-reported psychosocial factors. Many studies also included data reported by important others (such as, parents or teachers), particularly of social factors. Where possible, the self-reported data were extracted. However, where self- and other- reported data were combined/collapsed for all or parts of the analysis in the published article, authors were contacted directly to request the self-report data only. No responses from authors were received however, meaning that whole articles (Bonhert et al., 2019) or parts of the analysis (e.g. in Storch et al., 2012) had to be excluded. This means that a small selection of self-reported data are missing from this review.

The seven case-control studies included in this review compared the relationships between loneliness and psychosocial factors for autistic participants and non-autistic participants (one study also included individuals with motor/sensory difficulties as a second comparison group). Results in relation to the comparison groups were not included in this review as it was not deemed to be relevant to the research question. However, on reflection this information could have been helpful by way of offering an insight into the psychosocial factors associated with loneliness that are specific to autistic people, for example, whether these associations exceed non-autistic population norms.

Further, as the review was aimed at psychosocial factors, studies/data on the relationship between loneliness and autistic traits were not included. It may be the case that risk and maintaining mechanisms for loneliness in autistic people partially reflect social communication differences, a tendency towards special/specific interests, or sensory sensitivity. A future review including exploration of traits commonly associated with autistic presentation and loneliness, and the potential for a mediating effect on these variables would therefore be helpful.

As mentioned previously, the majority of samples were drawn from White/Western populations, and this is a likely result of the search strategy being limited to articles published in the English language. The search and inclusion of papers published in languages other than English may have identified studies that include non-Western populations, thus increasing the generalisability of the findings to other populations.

### ***Implications and recommendations***

Several gaps in the literature are identified, many of which have been commented on in the section above. There is clearly a need for good quality research in this area; it is difficult to make any evidence-based recommendations for practice when the evidence is poor. The lack of longitudinal research means assessment of the direction of the relationships is limited, and identification of risk factors for loneliness is limited. Studies using a longitudinal design, particularly taking a developmental approach to research in this area, is therefore recommended. As the majority of samples in these studies were dominated by individuals who identify as male, it cannot be assumed that the findings are relevant for other gender identities. Research exploring these associations in other gender identities is therefore needed. There is also a need for researchers to involve autistic people in the design and conduct of studies, which is important to ensure research addresses the priorities of autistic people, and to help strengthen the application of findings to practice. Finally, there is a need to develop quality assessment tools that attend to aspects of study design that may require adapting for researching neurodiverse populations, such as, assessing whether studies used measures validated for use with an autistic population.

Holding the limitations discussed throughout this section in mind, there is tentative evidence to suggest potential value in exploring social relationships for both adults and adolescents referred to services for help with low mood and anxiety, with a particular focus on peers at school for young people. In addition, in relation to the growing area of mental health intervention in schools, the current findings suggest a benefit in ensuring that this provision does not rely on individualistic approaches alone but also incorporates ideas about social connectedness.

### *Conclusion*

It is difficult to draw conclusions from the studies about their findings because of the overall poor quality of studies included in this review. However, there is emerging evidence that loneliness has negative implications for the mental health and social functioning of autistic people, particularly in relation to increased depression and anxiety. There are indications that these associations are relevant across adolescence and adulthood. It is therefore important to consider interventions aimed specifically at decreasing loneliness for autistic people, which would likely improve aspects of their social and psychological health. There is also a need for better quality research involving autistic researchers.

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# Chapter Two: Empirical Paper

# The views of young autistic people on their identities online and offline: a qualitative study

## Abstract

Social interaction can be difficult for both individuals in a dyad if one is autistic and one is not autistic, due to differences in communication styles. Many autistic people find that interacting with non-autistic others has negative implications for their self-esteem, self-concept and self-worth, potentially leading to identity challenges. Given the reduced demands from non-verbal cues and increase in opportunities to find others with similar interests and experiences, the online world might provide autistic people with an opportunity to feel more socially competent and accepted. This qualitative research investigated the views of eight autistic people, aged 18-25, about their identity when interacting online and offline, and their perception of the relationship between their identity and psychological wellbeing. The data were collected via online semi-structured interviews during the COVID-19 pandemic. Four main themes were identified from the analysis of data: autism as an identity; acceptance is key to being one's true self; feeling different; and stigma and discrimination. Exploration of these themes identified benefits of online interaction, such as improving self-esteem and self-concept, highlighting the potential benefit of support services offering online options tailored to support the needs of autistic individuals.

## Lay Abstract

Social interaction between two people can be challenging if one person is autistic and the other person is not, because of differences in their communication styles. Research has suggested that how people interact with others can impact their

identity. Interacting online might be less challenging for autistic people than interacting face-to-face, because non-verbal signals are not used and there may be more opportunity to find others with similar interests and experiences. This research explored the views of eight autistic people, who were aged between 18 and 25, on their identity when they are interacting online and offline, and whether/how they think this relates to their wellbeing. We analysed the interviews and found four common themes in what participants said. Firstly, they talked about being autistic as a key part of their identity and how, therefore, this influences their interactions with others. Secondly, they felt that being accepted was important in being able to show their true self to others. Thirdly, people felt that the differences between how they communicate and how people who are not autistic communicate are biggest during face-to-face interactions, and that this often left them feeling different, as though they were not good enough, and as though they should try to 'blend in' with others. Fourthly, people felt that they still had to face stigma and discrimination from others and that the online world gave a chance to challenge some of that stigma. These findings suggest it would be a good idea to offer an online option in services to support autistic people's needs.

## Introduction

### *Autism*

Autism Spectrum Disorder (ASD) is a neurodevelopmental condition, experienced differently by different people. The Diagnostic and Statistical Manual of Mental Disorders 5th edition (DSM-5; American Psychiatric Association, 2013) describes ASD as characterised by difficulties with social communication, a tendency towards focused activities or interests, repetitive patterns of behaviour, and sensory sensitivities. Adolescence and early adulthood may be a particularly challenging time for autistic people, as social demands increase in frequency and complexity (Picci & Scherf, 2015; Rosenthal et al., 2013). Research has shown that an increase in desire for social connections is evident for autistic adolescents just as it is for non-autistic adolescents, however, this desire often goes unmet for autistic individuals due to differences in social cognition (Crompton et al., 2020; Carter et al., 2014). This discrepancy between social desires and experiences may mean young autistic people are faced with difficulty making sense of their place in society.

It is well documented within the literature that autistic people are at an increased risk of developing mental health difficulties such as anxiety, depression and Obsessive Compulsive Disorder, when compared with the general population (e.g. Lai et al., 2019), and that this heightened risk is particularly notable during adolescence and early adulthood (Mayes et al., 2011; Kusiko et al., 2008). As such, it is necessary to explore factors that might give rise to the development of these difficulties.

### ***Identity***

A major developmental task of adolescence and early adulthood is identity development, through which a person develops an awareness of themselves as an individual and within the context of their familial, cultural and social norms (Marcia, 1980). It has been suggested that an individual’s identity is successfully developed when they have gained a stable sense of their strengths, weaknesses, uniqueness and the values to which they are committed (Marcia, 1980). One of the earliest and most influential models of identity development is that proposed by Erikson (1983, 1968), which posits that this process is the primary psychosocial task of adolescence and exists as the fifth of eight stages of psychosocial development. According to Erikson, this identity development stage involves asking “Who am I now?” and “Who do I want to be?”, therefore bridging the gap between past/present and future ideas about the self. The model posits that successful completion of this identity development stage results in a healthy personality, allowing the individual to move on to subsequent stages, whereas failure to complete these tasks leads to ‘identity crisis’ and resulting feelings of inadequacy. Marcia (1980) described successful identity development as involving two processes: *exploration* (i.e. exploration and testing of options for who to ‘become’) and *commitment* (i.e. committing to and investing in chosen ideologies and occupations) (Kroger & Marcia, 2011). Drawing on ideas of Marcia (1980) and also Erikson (1968), a growing body of research demonstrates that the development of a synthesised identity is associated with better wellbeing (Sandhu et al., 2012; Waterman et al., 2010), fewer mental health difficulties (Crocetti et al., 2009; Ritchie et al., 2013) and less engagement in risk behaviours (Crocetti et al., 2013; Schwarts et al., 2009). However, these models have been criticised for their heavy focus on assumptions that the final identity is “fixed at the end of adolescence” (Erikson, 1968, p.161) and that the completion of one stage of development is a prerequisite for the next. There is evidence to suggest that identity development continues throughout the life course (Kroger, 2007) and that, particularly for autistic people, this is not a linear process given the range of factors likely to influence this process at different stages (e.g. age of autism diagnosis, opportunities for successful social interaction, etc.) (Riccio, 2020).

As well as considering identity from a developmental perspective, it is important to consider the role of identity in terms of individual functioning and at a sociological level. Social Identity Theory (SIT; Tajfel & Turner, 1979) suggests that social identity is an aspect of one’s self-concept that is defined by perceived membership within a social group. Research based on this approach has demonstrated that identification with a social group can facilitate wellbeing and self-esteem (Jetten et al., 2015;

Newman et al., 2007) and reduce difficulties such as depression (Sani, et al., 2012) and PTSD symptoms (Muldoon & Downes, 2007). There is growing recognition of the policy and practice implications of group identity processes for psychological health, and the extent to which they may form the basis for ‘social cures’ (Wakefield, et al., 2019). It is suggested, for example, that group identification provides access to important social and psychological resources, including a sense of meaning and purpose (Wegge, et al., 2006), a sense of control and agency (Hopkins et al., 2016), and social support (Avanzi et al., 2018). However, SIT has received some criticism, including that it fails to consider the possibility that there may be differences among group members in the centrality of the ingroup to their social identity (Brown, 2020), as if a social identity is either completely ‘on’ (or completely ‘off’) for all group members in any given situation. In addition, SIT has been criticised for assuming that identities are limited to one single group, whereas the likely reality is that identities are multi-faceted (Berry, 1997). Further, SIT assumes that the search for ‘positive distinctiveness’ is the only motive underlying group identification, neglecting the idea that people align themselves with groups for other reasons, including to reduce uncertainty about their social world (Hogg, 2007) and to gain self-insight and understanding (Deaux et al., 1999).

### ***Autism and identity***

Ratner and Berman (2015) note that “interpersonal functioning is at the cornerstone of both identity and autism” (p. 136), and in their study exploring the relationship between the two, found that the process of identity development can present particular challenges for autistic individuals. Young autistic people have reported poorer global self-worth, self-concept and self-esteem than their non-autistic peers, and are less likely to see themselves as holding social power or as socially competent (Nguyen et al., 2020; Jamison & Schuttler, 2015). Perceiving oneself as different and as stigmatised, often established through interacting with non-autistic others, may negatively impact on a person's wellbeing, self-concept and self-esteem (Morgades-Bamba et al., 2019; Moses 2009).

In relation to individuals with a disability, Goffman (1963) used the term 'undesired differentness' to define stigma, and suggested that stigma can result in a mismatch between an individual's personal and social identity. Despite research having traditionally focused on perceptions of individuals who are stigmatised, more recently, interest in the field has shifted to explore how those who are discriminated against or excluded on the basis of their group membership interpret, appraise, and cope with, stigma. Furthermore, there is evidence that membership in a group that is perceived to be stigmatised can affect an individual's engagement with and use of health care services (Haslam et al., 2018).

Indeed, autistic individuals must also consider their social identity, including the extent to which they align themselves with, and are influenced by, their minority group status (MacLeod et al., 2013; Turner 1999). In line with Goffman's work, studies have demonstrated that some young autistic people choose not to identify or engage with autism as a social identity due to concerns regarding associated stigma and not 'fitting in' with peers (Frost et al., 2019; MacLeod, 2013). Studies have shown that up to 70% of autistic people consistently mask or 'camouflage' (use strategies, either consciously or unconsciously, to supress autistic characteristics during social settings) in attempts to fit in and avoid mistreatment from others (Cage & Troxell-Whitman, 2019; Hull et al., 2017). A number of negatives were found to be associated with camouflaging. These included physical and emotional exhaustion, difficulty accessing a diagnosis, and significantly, challenges around identity. Other research, however, has shown that some young autistic people feel proud that they are autistic (e.g. Cooper et al., 2021; Cage et al., 2016). Baxter (2018) found that identifying as autistic can yield a sense of shared identity and belonging, subsequently reducing social anxiety, and increasing social opportunities. Similarly, Cooper et al. (2017) found that identifying as autistic was associated with increased personal self-esteem and reduced anxiety and depression, and that these relationships were mediated by collective self-esteem (i.e., perceived positivity of autism identity). In line with Social Identity Theory, these findings propose that a positive autistic identity may serve as a protective factor against psychological difficulties.

### ***Social media use***

Social media are “internet-based channels that allow users to opportunistically interact and selectively self-present” (Carr et al., 2015, p.49) and can include Facebook, Instagram, Twitter, gaming sites and blogs. Social media use amongst young autistic people is common (Hassrick et al., 2021), and research has shown that young autistic people spend more of their free time online than their non-autistic peers do (Mazurek et al., 2012).

A key feature of social media is the ability to create a personal profile. This, as well as being able to form new social connections, may afford individuals an opportunity to present an image of themselves based on how they would want to be seen by others (Williams & Merten, 2008). However, there is evidence that autistic people are at an increased risk of many negative factors linked to frequent internet use (such as social isolation and depression) when compared to non-autistic people (Schroeder et al., 2014). Social media use and identity formation in young autistic people is therefore a much-needed area of research.

### *Autism, identity and online interaction*

Online communication is argued to be in some respects less socially demanding than offline communication (Benford & Standen, 2009), and may therefore provide an opportunity for young autistic people to feel more socially competent and less excluded than they do during face-to-face interactions. Indeed, in Burke et al.'s (2010) study, autistic adults reported that interacting online brought benefits such as providing opportunities to find others with similar interests, whilst the demands to interpret non-verbal signals were reduced. In addition, the literature suggests that impression management is particularly pertinent to the online world, as the option to remain anonymous allows choice over what version of themselves people present, and the public nature of social media increases motivation to present themselves in a positive light (Leary & Kowalski, 1990). Studies have also shown that self-esteem can determine the nature of the self that is presented online (Pringle, 2015). It is important to bear in mind, therefore, that online identities may be idealised self-representations.

There is a limited but growing body of research into online identity for young autistic people. Parsloe (2015) analysed discussions within one online community and discovered that members managed to recover a positive autistic identity with regard to normalcy, symptoms and agency. Discussions centred around the socially constructed nature of 'normal' and perceptions that autistic ('abnormal') identity is often seen as inferior. Members rejected these representations, and viewed their autistic 'symptoms' as positive aspects of their identities and saw themselves as advocates. In another study, Seidmann (2018) explored the role that online blogging plays in the construction of autistic identity and found that three constructs emerged: autism diagnosis, autistic agency and normality. Individuals again rejected the perception of 'normality' as non-autistic, and saw a sense of agency as central to autistic identity. They also saw autistic diagnosis as a formative construct for autistic identity. Both of these studies begin to shed light on the role of social media in shaping autistic identity in terms of both personal and social identity.

Given the links between difficulties with identity development and mental health, if identity brings particular challenges for autistic individuals, then it is important to explore how this may differ across different settings (such as, in the online world), and the factors contributing to this. Despite some recent advancements in research in this area, there remains a lack of understanding around the role of online and face-to-face communication in autistic people's identity development, the extent to which autistic people align themselves with autistic and non-autistic culture when interacting online and face-to-face, and the impact of these issues on mental health and wellbeing. If the online world is particularly facilitative of positive identity development, clinical approaches should aim to encourage and incorporate these ideas.

### ***Aims and research questions***

Drawing upon Social Identity Theory, this research project aims to explore the views of young autistic people on their personal and social identities, and how they identify with and align themselves to autistic and non-autistic culture, when they are online and offline. It also aims to explore how young autistic people perceive that these aspects of their identity relate to their psychological wellbeing. There is very little known about how the recent loss of opportunities for offline interaction and the likely increase in online communication due to the COVID-19 lockdown measures is impacting on young autistic people's identities, and therefore, exploration of this will be incorporated in the research. Findings aim to add to current theory on identity development for young autistic people and inform clinical approaches for working with autistic individuals who face identity challenges.

The research questions for this project, therefore, are:

- How do young autistic people perceive their personal and social identities when interacting online and offline?
- To what extent do young autistic people perceive that they identify with autistic and non-autistic culture when online and offline?
- How do young autistic people perceive that their online and offline identities relate to their psychological wellbeing and/or to psychological difficulty?
- Has the decrease in opportunities for offline interaction and increase in online interaction during the COVID-19 lockdown period impacted on young autistic people's identities? If so, how?

## Methodology

### ***Theoretical and philosophical underpinnings of the research***

The theoretical framework upon which this research is based is Social Identity Theory (Tajfel & Turner, 1979). This theory considers how an individual's self-concept is influenced positively or negatively by their group membership and by the perceived status of those groups (Turner, 1999). Further, it assumes that individuals seek to have a positive and distinct self-concept, and will adapt their behaviour and allegiances to achieve this (Crisp et al., 2006).

The research is approached from within the Social Constructivist paradigm, assuming that knowledge is constructed through interaction with others (Vygotsky, 1978). It is accepted that a 'reality' may exist (Duffy & Jonassen, 1992), however all that can be known of this reality is an interpretation of information (von Glasersfield, 1995; O'Donoghue, 2006), and therefore all knowledge and understanding is relative to interpretations made of experiences with others and the world around us (Guba & Lincoln, 2001). The ontological and epistemological assumptions are that a true 'reality' cannot be discovered (Kukla, 2013; Bahari, 2012), and that all knowledge is socially and culturally constructed (Ernest, 1999; Prawat & Floden, 1994; Berlin, 1987). The aim of inquiry within this research is therefore to gain an understanding of the constructions that individuals form from their experiences of interacting online and offline, and how they perceive this to relate to their identity and psychological wellbeing.

### *Methodological approach*

The methodological approach is guided by these assumptions. As the purpose of this research is to explore views and experiences of autistic individuals, the use of qualitative methods is considered appropriate, as it provides an opportunity to gain an in-depth, more explanatory understanding of how and why such patterns and relationships exist (Willig, 2012). Qualitative methods also permit an understanding of how participants interpret and construct meaning through their experiences (Silverman, 2013). Thematic analysis was chosen to allow consideration of patterns of meaning across the dataset as a whole (Braun & Clarke, 2020), and the reflexive and interpretive approach to analysis will allow consideration of how the researcher's own beliefs and judgements may have influenced the research process (Finlay, 1998).

### *Method*

In order to gain a rich understanding of the subjective experiences of individuals, semi-structured interviews (either by telephone, video call or online instant messenger) were conducted. This was intended to allow for specific topics of interest to be discussed, whilst giving participants the freedom to describe and expand on their experiences from their own point of view. It is argued that in this way, qualitative research enables a more equal 'researcher–participant' relationship to develop, allowing participants some freedom over the topics generated in discussion (Babbie et al., 1998).

### *Eligibility criteria*

Despite earlier models suggesting that identity formation occurs between the ages of 12 and 18 (Erikson, 1963, 1968), more recent literature suggests that this process continues into early adulthood (Kroger et al., 2010). This research therefore recruited participants aged between 16 and 25 (Kroger et al., 2010).

Although there is no universally accepted term, the terms ‘autism’, ‘autistic’ and ‘on the autism spectrum’ are used in this manuscript as umbrella terms given that they are terms preferred by people who are autistic (Kenny et al., 2016). Diagnostic terminology has changed over the years (National Autistic Society, 2016), differing according to both the diagnostic framework and the time the assessment was completed. Participants were eligible to take part in the research if they had one of the following diagnoses: Asperger Syndrome or High Functioning Autism (diagnosed using the DSM-IV criteria), Autistic Spectrum Disorder without accompanying intellectual impairment (diagnosed using the DSM-V criteria) or Pervasive Developmental Disorder (diagnosed using the ICD-10 criteria). As the literature suggests that the concept of identity differs across cultures (Schwartz et al., 2012), only individuals living in the UK were eligible to take part. Participants were also required to be fluent speakers of English.

### *Community involvement*

As well as having had input into the development of the research questions, an Expert by Experience was involved in designing all of the study materials. Particular attention was paid to potential communication differences in the design of the PIS and consent form. During background research prior to conducting the interviews, a number of topics were identified as significant areas of interest. These were discussed with the Expert by Experience and, thus, a framework of questions was collaboratively prepared in the form of an interview schedule (Appendix G). During the main study, respondent validation was used so that previously unanticipated topics could be added to the interview schedule and discussed with participants as interviewing and analyses progressed (Bloor, 1978). The Expert by Experience on the research team will also be actively involved in the dissemination of the findings to participants and linked communities.

### ***Pilot study***

A pilot interview was undertaken with an individual who met the study's eligibility criteria (not a member of the participant group or the research team) to trial and provide clarification in three main areas. Firstly, to trial the draft interview schedule regarding the extent to which it would successfully target the desired research areas. Secondly to indicate how long the interviews were likely to take, in order to inform potential participants prior to their consenting to the research. Thirdly, to consider the extent to which the wording of questions and interview techniques used would encourage as much discussion and open response from participants as possible. This involved active feedback from the pilot study participant.

The pilot interview ran as a formal research interview, and then a discussion was held between the interviewer and pilot interviewee about the number, suitability and wording of questions. This feedback and subsequently amended version of the interview guide was then discussed with the Expert by Experience, who assisted with further clarification of the wording of some questions and also with refining the questions included to ensure the interviews were not overlong.

Feedback from the pilot interview was generally that most questions were clear and relevant but that some were ambiguous and likely to be interpreted differently by different participants (with some responses not relevant to the research questions). Ideas were shared around making the wording of these questions more specific, however it was agreed that in some cases, this meant the question became lengthier, more complex, and in turn, less clear. Where it was not possible for these questions to be re-worded, consideration was given to their necessity in relation to other similar questions, and where appropriate, some questions were omitted. The pilot interviewee also made suggestions for new questions to be included, in the hope of generating interesting and relevant data not already covered by the existing questions. The decision was also made at this point to clarify a definition of identity at the beginning of the interviews in order to ensure a shared understanding of the concept prior to the remainder of the interview.

Given the complex and abstract nature of the research topic, the pilot study process, and particularly, the feedback from the pilot interviewee was extremely valuable in helping to ensure that the interviews were conducted meaningfully, ethically and sensitively. The first and final versions of the interview schedules, with notes from the pilot study interviewee’s feedback, are included in Appendix G. The data generated from the pilot interview was not included in the analysis.

## ***Participants and Recruitment Strategy***

### ***Recruitment.***

The study recruited participants through a mixture of volunteer sampling and purposive sampling.

*Strategy one:* The research team posted the research advert (Appendix H) to online autism/Asperger forums and autism/Asperger groups on social media sites (e.g. Facebook, Twitter) and on the social media sites of local, non-NHS support organisations asking people who met the inclusion criteria to take part in the research. Where permission to join a group was required, the named administrator for the group was contacted with an explanation behind the request to join the group. The research advert provided a description of the research aims and procedure and asked people to register their interest by contacting the researcher.

*Strategy two:* The second source of recruitment involved the Expert by Experience on the research team sending the research advertisement directly to eligible individuals. This group was selected from a database held by the University of individuals who had previously participated in autism-related research and indicated that they would be interested in taking part in future research.

### ***Sample size.***

As argued by Braun and Clarke (2021), given the reflexive, interpretive approach of this research, it was felt that ‘data saturation’ may not be a particularly helpful criterion for establishing adequate sample size. Other aspects such as the scope and purpose of the research, the diversity of the participants, the data’s complexity and relevance to the research question, and pragmatic constraints of the project in determining when to cease recruitment, were all considered more relevant to recruitment. Malterud et al.’s (2016) concept of ‘information power’, that is, that the more relevant information the sample boasts, the fewer participants required, was also used to guide sample size. The decision to stop interviewing was therefore made by reviewing data quality throughout the data collection process.

### *Managing some common communication difficulties.*

Participants had the choice between completing their interviews via telephone, videocall or via online instant messenger. This was to encourage those who may struggle with the additional social demands of a spoken interview to participate. It also met the social distancing requirements caused by the global pandemic. Interview schedules were sent to participants prior to commencement of the interviews, to allow participants time to familiarise themselves with the questions and to consider their answers. Given that the focus of the interview (i.e. identity) may have brought some specific demands for participants who have difficulty with inference (Pijnacker et al., 2009), variations in wording of questions were made available. A 15-minute break was offered to participants half-way through the interviews. All written materials were presented in a dyslexia-friendly font.

## *Data collection*

The primary researcher responded by email to requests to participate and conducted a screening questionnaire (Appendix I) to check eligibility (including diagnosis) and sample characteristics. Participants were asked to indicate whether they preferred the interview to take place via telephone, videocall or via an instant messaging platform, such as Skype. Once informed consent was provided, a time and date for the interview was arranged. Individuals who did not meet the eligibility criteria were thanked for their contribution and took no further part in the study.

Four interviews were held by telephone, three by videocall and one via instant messenger. Data was collected over a three month period (April to June 2021). Interviews lasted between 60 and 90 minutes (mean length = 81 minutes) and were undertaken and audio-recorded by the primary researcher. The recordings were later transcribed by the primary researcher and a University approved paid transcriber. All transcripts were reviewed and anonymised by the primary researcher.

### *Ethical considerations*

This research conforms to the British Psychological Society's Code of Ethics and Conduct (2018). The research proposal was approved by the University of Liverpool's Central Research Ethics Committee in November 2021 (see Appendix J for letter of ethical approval).

#### *Informed consent.*

Once it had been established that participants met eligibility criteria for taking part in the research, a participant information sheet (PIS; Appendix K) and consent form (Appendix L) was sent by email. The PIS detailed the purpose of the research, the methods involved (including the required setting for the interviews to take place, for example, alone in a quiet, private room where privacy could be maintained), information about data storage and use (particularly, that all data and information would be anonymised at the point of being transcribed), dissemination of the results, information about participants' voluntary rights and contact details for the primary researcher and supervisor. It also included details of a protocol for managing risk and safeguarding concerns, and of a distress protocol (Appendix M). This included plans for terminating the interview early if necessary. Consent forms asked participants to confirm that they were over the age of 16, and to indicate informed consent to participate, to have debrief information sent to an email or postal address they provided, to have their interviews audio recorded (if they chose a telephone or videocall interview), and to have their data analysed, reported and stored. Consent forms also asked participants to indicate that they understood their voluntary rights including the right to withdraw their information until data analysis commences. A separate, shorter version of the PIS (Appendix N) and consent form (Appendix O), including the same information but developed in line with the NHS Health Research Authority guidance on developing PISs and consent forms for children and young people, was developed for participants aged between 16-18. However, all individuals who expressed an interest in taking part in the study were over 18.

#### *Interview conduct and debrief.*

Participants were invited to ask any questions either via email in the weeks prior to their interview, or at the beginning of the telephone/video call or instant messaging chat before the interview began. Consent and the PIS were also revisited and understanding was checked before the interviews began. Careful consideration was given to the sensitive issues raised in interviews; interviews were semi-structured yet conducted in a flexible manner to enable the interviewer to change topic if it appeared that any level of distress was being caused.

Each participant was debriefed at the end of their interview and offered the opportunity to ask any further questions. Participants were also signposted at this point to relevant support services. A debriefing document (Appendix P) was sent to participants by email at the end of the interview, which reminded them of the contact details of the researchers in case questions arose at a later date, of the contact details of relevant bodies in case of any problems, and of support providers in case of any distress caused as a result of the study. The debriefing document also reminded participants that they would receive a £15 Amazon Gift Card by email to thank them for their contribution.

#### *Confidentiality, data storage and consent withdrawal.*

Names and email addresses were collected from participants; these details were used to arrange interviews and to send copies of the PIS, consent form and study findings (if participants requested a copy). As the interviews were completed, telephone and videocall interviews were transcribed and online instant messenger interviews were extracted from the online platform. Interviews were anonymised at the point of transcription or data extraction from the online messaging platform. All data were stored on a password-protected computer; participant identifiers were used to protect participants' identities whilst allowing experiences to be conveyed effectively and the individuality of accounts to be maintained. Consent forms, which include participants' email addresses, have been stored separately. In line with research ethics committee requirements, all files bearing participant identifiers (e.g. contact details) will be destroyed at the end of the study and only participants' consent forms will be retained for audit purposes.

Participation was voluntary and participants were able to withdraw until the point that data analysis began. The PIS made clear that participants were able to do this without giving reason by contacting the main researcher or primary supervisor by email; participants were reminded of this at the start of their interview.

### *Data analysis*

Following Braun and Clarke's (2006) step-by-step guide (see Table 2 below), as the study progressed the anonymised interview transcripts were analysed using an interpretive thematic analysis approach to allow the organisation, description and interpretation of patterns of similarity within the dataset (Braun & Clarke, 2006). The analysis was inductive and iterative, allowing the developing coding framework to be data-driven (Braun & Clarke, 2006). Analysing the data on a semantic and latent level, the current research aimed to uncover the prominent and recurrent themes within participants' experiences, searching, where appropriate, beyond the surface observations to explore potential sources and implications of the observed themes, thus providing a more insightful analysis. QSR NVivo software was used to assist in the organisation and indexing of qualitative data. An example of the coding structure, with illustrative quotations, can be found in Appendix Q.

**Table 1**

*Braun and Clarke's 'Step-by-step Guide' to Reflexive Thematic Analysis. (Table adapted from Braun and Clarke, 2006: 86-93)*

| **Phase** | | **Description of the process** |
|---|---|---|
| 1 | Familiarising yourself with the data | Verbal data were transcribed verbatim by the primary researcher and a University approved transcriber. Transcripts were reviewed and anonymised by the primary researcher. The data were read and re-read by the primary researcher in an *active* way, noting down initial ideas for codes. |
| 2 | Generating initial codes | The primary researcher worked systematically through the entire dataset to identify as many initial 'codes of interest' from the data as possible, and organised the data into meaningful groups. Surrounding contextual data were retained. |
| 3 | Searching for themes | The primary researcher re-focused the analysis at the broader level of themes. Codes were sorted into potential overarching themes, with consideration given to the relationships between and within codes and themes e.g. main overarching themes, sub-themes, etc. Any unique/ "theme-less" codes at this stage were kept. |
| 4 | Reviewing themes | Themes were revised, separated, and collapsed. Level one: collated extracts for each theme were reviewed, and |

| | | |
|---|---|---|
| | | coherent patterns were explored using a ‘thematic map’. Level two: ‘accuracy’ of the thematic map was reviewed and re-coded as necessary. |
| 5 | Defining and naming the themes | Themes and sub-themes were defined and refined further: the focus was on determining the precise nature of each theme and establishing the facet of the data that each theme embodied. The content of each theme and sub-theme was analysed: the focus here was on identifying the ‘story’ that each theme told, and how it related to the research question. The research team reflected on themes/sub-themes to ensure clarity and appropriateness of the analytic claims. The primary researcher noted down ideas for ‘concise, punchy’ theme names. |
| 6 | Producing the report | The primary researcher developed the manuscript, ensuring key findings and recommendations went *beyond* description, making an *argument* in relation to the research question. A focus was on ensuring the write-up included evidence of themes via ‘vivid’ and ‘compelling’ data extracts, embedded within an analytic narrative. |

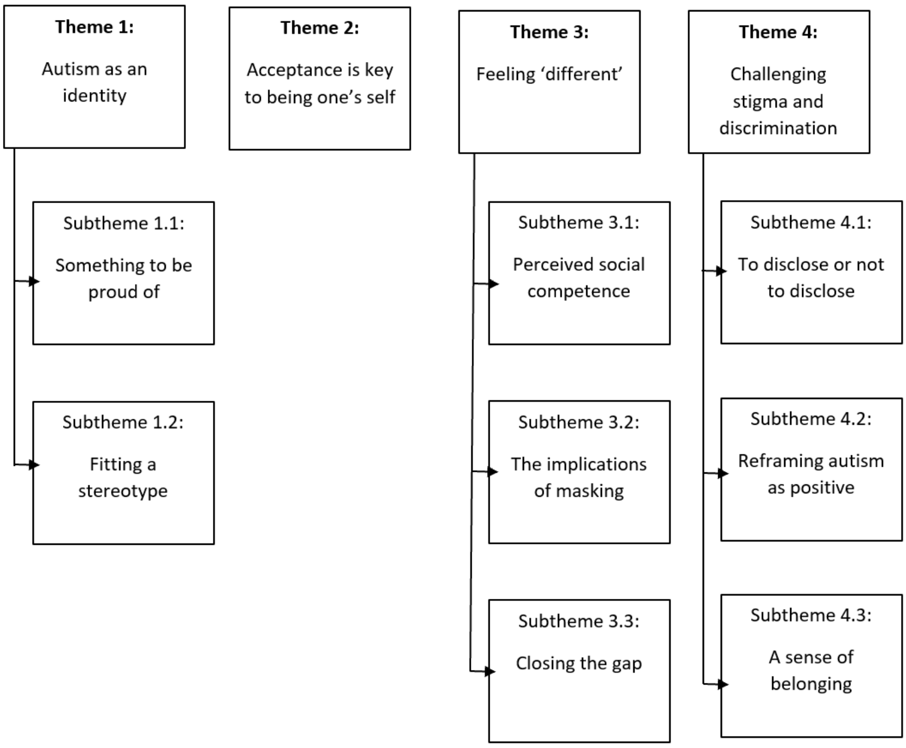
## Analysis and Results

Eight individual semi-structured interviewers were conducted. Participants’ ages ranged from 18 to 25. Participants reported using social media between 10 and 100 hours (mean time = 35 hours) per week, and five participants also played online video games (for up to 50 hours per week).

Analysis of findings suggests that whilst there were variances between participants’ views and experiences, the overall interpretations of and views towards how online and face-to-face interaction influenced their identity and their psychological wellbeing were generally similar across the eight participants' narratives. Four themes were identified within the data: (1*) autism as an identity*; (2) *acceptance is key to being one's true self*; (3) *feeling different*, and (4) *stigma and discrimination*. Figure 1 shows the structure of themes and the subthemes within them. This analysis seeks to provide a genuine picture of these recurrent themes, in order to present an accurate representation of the views and experiences of eight young autistic people in relation to their identity and interacting in the online and offline world. Words in square brackets were added by the transcriber for detail and clarification.

**Figure 1.**

*Structure of themes and subthemes*



### *Theme 1. Autism as an identity: "It's everything about who I am isn't it, there's no part of me that isn't autistic" (Participant 8)*

For participants in this research, there was sense across their narratives that autism was an integral part of their identity and the majority chose to use identity-first language to reflect that. There is debate in the literature around the use of identity-first (‘autistic person’) versus person-first (‘person with autism’) language. In terms of the language that is most preferred by autistic people in general, there is no clear consensus. However, some have argued that there is consensus around the least preferred, this being person-first language (Vivanti, 2020; Botha et al., 2021; Anderson-Chavarria, 2021). One participant explained how she felt that being autistic was inherent to her whole self, whereas, person-first language made it feel as though being autistic was an adjunct:

> “*You can't take the autism away from someone. It is part of the person. That's why I hate it when people say, people* with *autism, it's not something they have with them and can be taken away or added on.*” (Participant 2)

In this way, participants felt that being autistic was an aspect of their identity that was both important and relevant to their interactions, as it influences how they understand, process and respond to social and environmental information:

> “*Being autistic is most important to every single interaction I have, because yes it plays the biggest role in who I am and how I behave and how I er, understand and process everything that's going on and happening in an interaction*.” (Participant 3)

#### ***i) Something to be proud of***

In discussing how they felt about being autistic, some participants talked about some of the challenges they had faced, living in a predominantly non-autistic world, and how they felt a sense of pride at having developed the skills and characteristics required to cope with these difficulties:

> “*I’m proud of being autistic because I think there are some wonderful skills and talents and ways of perceiving the world that come with it. But I’m also proud of*

> *my perseverance and resilience that's needed to get through things that autistic people tend to find challenging*." (Participant 6)

Other studies exploring the attributes that autistic people associate with, have similarly shown that autistic people often feel pride in their autism (Cooper et al., 2021). One participant in the current study spoke about the pride they felt specifically in relation to 'getting through' a face-to-face interaction, given that this is something she found particularly challenging. Indeed, the literature shows the additional complexities and demands autistic people face when interacting with non-autistic people face-to-face (Crompton et al., 2020; Morrison et al., 2019).

> "*After having a face-to-face conversation with someone (particularly if I'm not that close to them) I am proud of myself as a whole to have been able to get through it because I'm autistic and it is something that I really struggle with*." (Participant 6)

However, other participants felt that because being autistic was so integral to their identity, as something they were born "as" rather than born "with", this meant that by default it was not something they could be proud of, "*it's like having ten fingers and ten toes, it's just a part of me like everything else*" (Participant 5).

### *ii) Fitting a stereotype*

Participants expressed the view that not only must they consider their own thoughts about themselves, but also others' perspective of them and of autism. Some suggested that forming and understanding their autistic identity involved navigating how they perceive themselves to fit (or not) with existing stereotypes associated with autism, and figuring out their own autistic identity by filtering out what, of the available information, is relevant for them. This suggests that for some autistic people, there is an element of personal/individual identity that is important to autistic identity as well as it the collective/group identity:

> "*when you get told you're autistic you feel like all the stereotypes associated with autism have to apply to you … but you have to kind of work to get to that point of recognising that just 'cause that's what is said about autism … that doesn't necessarily mean you'll struggle with that area or whatever. So it's difficult, you really have to work hard to figure it out and be okay with it*." (Participant 8)

One participant offered that the extent to which one aligns themselves with autistic identity is to do with the experiences they have had and the extent to which they were made to feel different to others. She described how her experiences of attending a small school where little attention was paid to difference, meant that growing up, she felt less of a need to identify as something different to that of her peers:

> "*in my class everyone played together, I wasn't excluded from a group so I couldn't really be left out … so I didn't have the same sort of hardships that most autistic people have, so maybe that's also why I haven't had so much of the struggles of autism built into my identity*" (Participant 7)

She also highlighted that from her perspective, identity labels are all socially constructed and therefore only have relevance and meaning in the context of interacting with other people:

> "*don't any identity labels exist just for the sake of explaining your place in society or other people doing that for you? … I believe all of them are created for you, and, by society or by other people … I believe all aspects of one's identity are … socially constructed … so by default it's only really relevant when there are others around you.*" (Participant 7)

In summary, participants felt that being autistic was a core part of their identity, as something that was integral to who they were and therefore something that influenced how they interact with others. It was suggested that the extent to which someone adopts an autistic identity relates to how much they have struggled as a result of being autistic. Developing an autistic identity that felt relevant and meaningful for participants seemed important, as they felt they had come to reject many of the stereotypes often associated with autism that were initially ‘put upon’ them. Many participants felt a sense of pride in being autistic and were proud of the resilience and perseverance they had come to develop.

### *Theme 2. Acceptance is key to being one’s true self:* **“*I can be myself when I am accepted … for who I am*” *(Participant 2)***

Throughout interviews, participants referred to the importance of feeling accepted as being key to their being able to be their true selves when interacting with others. This referred to feeling accepted by others, as well as coming to a point of acceptance in/of themselves. Several participants gave examples of what ‘acceptance’ meant for them, and accounts generally centred around feeling comfortable and safe from judgement or questioning from others, and feeling at peace with the different (good and bad) aspects of their own identity.

> “*if I know the other person, er, accepts me for me and if that's in whatever shape or form I come, without judging or questioning me then I, then I can be myself and feel comfortable er, it allows you to accept yourself too, in whatever shape or form too*” (Participant 1).

There was also a sense that reaching acceptance meant that participants were able to understand and prioritise their needs better. They described how accepting themselves as autistic unlocked a new understanding of their needs and gave them permission to attend to self-care strategies, without feeling pressured to engage in behaviours that did not feel natural to them:

> “*It's important, knowing that I'm autistic and coming to accept that, cos now I have I can understand myself better, I can, give myself allowances for the way I am and I can, do self-care like, I can choose when I shut myself off from*

> *people, and I can choose, like how I communicate with somebody or how often I meet up with someone, like I know I don't have to force myself anymore*" (Participant 2)

One participant explained that learning to accept herself allowed her to be less critical of herself, and that receiving a diagnosis facilitated that acceptance. She felt this process enabled her to better understand and accept her difficulties and, in turn, to find ways to invest in her wellbeing:

> "*After years of believing I might be, to have the validation that comes along with a professional diagnosis made me more accepting of myself and less critical of the aspects of myself that I didn't like … before being formally diagnosed … I felt very confused about who I was… and when you don't understand yourself properly it's hard to prioritise what you need … so you're just struggling all the time*." (Participant 6)

In summary, finding acceptance (both self-acceptance and feeling accepted by others) seemed key in order for participants to feel comfortable and confident to express their true selves. Acceptance also seemed central to facilitating participants' understanding of themselves and their needs, and therefore being able to prioritise their needs and wellbeing accordingly.

### ***Theme 3. Feeling 'different': I feel very much on the periphery, outside the majority. Knowing you're different … to the majority is what drives you to try to … fit in"* (Participant 6)**

Participants described a range of challenges associated with interacting with non-autistic people, these generally relating to the additional demands placed upon them during face-to-face interactions as a result of differing communication styles. For these participants, aspects of communication required active effort rather than feeling natural, and included making small talk, using 'appropriate' non-verbal cues to accompany their speech, and managing being frequently misunderstood.

> "*you've got to think about so much … like getting your face and eye contact right and saying hi and bye and all that extra stuff it's … hard work and … I think people don't understand me a lot or I don't understand them*." (Participant 4)

The ease of interacting with autistic people in comparison to interacting with non-autistic people face-to-face was also described, however, with participants highlighting a sense of 'unspoken understanding' that comes with having more similar communication styles to other autistic people:

> "*with my autistic friends … we understand each other, it's really weird, because, we don't have to fake anything … there's no need to, try and decipher what people are saying*." (Participant 2)

Indeed, previous research has indicated that autistic people find interacting with other autistic people easier, more comfortable and more successful than interacting with non-autistic people (Crompton et al., 2020).

Within this theme, three sub-themes were identified from participants responses relating to the impact of differing communication styles on feelings of social competence, attempts people make to reduce perceived differences between themselves and non-autistic others, and the implications of masking behaviours.

### ***i) Perceived social competence***

Participants spoke of the various consequences that result from being made to feel different to the non-autistic majority during face-to-face interactions ("*offline you get knackered and all sorts of things happen like burnouts, which make you feel bad about yourself";* participant 7). The effort that interacting face-to-face required was echoed across participants' accounts and seemed to leave them with a sense of incompetence and pressure to 'be better' ("*I don't think I'm the best at them, to be* *honest…I have to make a bit more effort*” Participant 1; “*I'm always trying to be better at this stuff*” Participant 4). For most, awareness of being different left them feeling as though they did not fit in, as though they were existing on the edge of society:

> “*I'd never be involved. I'd just be, essentially, a convenient, person lying on the edge … if you imagine a number of … concentric circles I'm on the outside*.” (Participant 5)

Some participants described a general sense of questioning themselves as “*right or wrong as a person*” (participant 7), wondering whether the problem was inherent to themselves and who they are. Others discussed ruminating over the specifics of their behaviour after a face-to-face interaction, and experiencing guilt and shame around their (in)ability to communicate in a way that seemed acceptable to non-autistic others, and a sense of wanting to escape themselves to become someone/something different. Reflecting on this, one participant described experiencing trauma-like symptoms, such as flashbacks and self-blame (Unthank, 2019):

> “*After finishing a face-to-face interaction I can often be left questioning everything I did or said, this leads me to panic and sometimes I can have almost flashback to the incidents … I beat myself up for it and I pick myself apart to the point that I don't really know what is me and what is mirrored behaviour. It really knocks my confidence, even makes me dislike myself or want to be someone else*.” (Participant 6)

In contrast to the clinical characterisation of autism as a condition inhibiting the desire for social connections (Chevallier et al., 2012), participants in this study spoke of wanting social relationships but finding that the impact that having to manage different styles of communication has on them (lack of confidence, anxiety, exhaustion, etc.) serves as a barrier to achieving their social aims:

> "*I do have emotional needs that could be satisfied through face-to-face social interaction … but then social interaction's a double-edged sword, because, if I interact with others, it's exhausting and tiring, and, takes up a lot of energy and it doesn't guarantee success.*" (Participant 5)

> "*there's part of me who wants to have more friends … but because of how anxious I get I feel like I can't*." (Participant 6)

Participants' reflections indicate the implications that differences in communication styles, and the efforts that autistic people must go to manage these differences, can have on the mental health and self-concept of autistic people. It is also indicated that these implications seem particularly relevant to face-to-face interactions with non-autistic people, and that some of these challenges may be mitigated when interacting online.

### ***ii) The implications of masking***

Participants shared that as their 'true self' often seemed both different and unacceptable to others, they felt a need to mask, or suppress naturally autistic behaviours, in face-to-face interactions in order to present a version of themselves that they perceived would be more socially acceptable ("*when they do see me when I'm autistic, when I'm not masking, I'm not accepted, so I have to mask*"; participant 2). Indeed, the literature suggests that up to 70% of autistic people consistently mask in social settings (Cage & Troxwell-Whitman, 2019). Participants spoke of having to make a conscious effort to ensure their behaviour was in line with the expectations of non-autistic people ("*the pressure to be liked means you're always trying to be what someone else would approve of, and as everyone is different, that could be a variety of different things*"; participant 6). This included playing down their own social and sensory needs, forcing themselves to engage in non-autistic norms of behaviour and communication styles (for example, giving eye contact, making small talk) and to stay in environments they find uncomfortable; essentially having to "*put up and shut up*" (participant 5).

Research has begun to explore the variety of consequences of masking for autistic people, and studies have shown that masking is often challenging to one's identity, as people lose track of their authentic selves, due to playing many different roles (Bargiela et al., 2016; Hull et al., 2017). Participants spoke about themselves and other autistic people they know as struggling to hold on to their true self, feeling confused and conflicted, struggling to separate who they really are from what they present:

> "*When you're trying to be so many different things at once it really leaves you feeling conflicted and uncertain … I felt very confused about who I was, separate to the things I was trying/pretending to be*" (Participant 6)

> "*He's had to over mask and try to, meet the social needs of other people, to the point where he doesn't know who he is. And I think for me, I'd say I don't really know who I am, myself*" (Participant 5)

### ***iii) Closing the gap***

Throughout participants' narratives, they described how interacting online was generally more successful than interacting face-to-face. In line with previous research highlighting the benefits of online communication for autistic people (Burke et al., 2010), participants identified advantages including having time to process information before responding to messages, being able to re-read and amend what they say, the absence of non-verbal information and availability of emojis to convey tone and feeling, and the opportunity to control their sensory environment. Participants described how this went some way to closing the gap between their perception of their own success in interactions and that of the non-autistics they interacted with, which allowed them to feel more relaxed and less anxious:

> "*I think having the ability to wait and think during messaging online is vital to me preferring online communication methods rather than face-to-face. I feel a lot more relaxed during online interactions for this reason as well, which means I don't have to worry about coming across how I want to come across"* (Participant 6)

Interestingly, one participant's view was that the more someone has struggled in face-to-face interactions, the more likely they are to seek solace online. She (and others) felt that the opportunity to have successful interactions and develop positive relationships with both autistic and non-autistic people online helped to reverse some of the impact that difficult face-to-face interactions had had on them:

> "*People who have struggled more in that way offline might be more inclined to find online interacting much better in that sense, because of all the hardship that's come from interacting in real life and the impact that has over years on how you see yourself, whereas online sort of gives you that chance to feel like you can be sociable, you can interact, you can have friends, like others do, so you learn to like yourself more I think*" (Participant 7)

However, this participant also felt that as online interaction affords less feedback from the other person about how the interaction is going, she can be left with feelings of uncertainty around the success of the interaction ("*online you just don't get that feedback … so you're left with … feeling unsure about yourself which isn't good for self-esteem or your sense of self*"; participant 7).

In the main, participants felt that the reduced social demands and more successful online interaction provided them with an opportunity to feel more competent, and to close the gap between the version of themselves that they present and their true self. They described how this reduced the negative influence that interactions had on them, improving their self-concept. One participant referred to it as a self-fulfilling prophecy:

> "*That also translates to how you feel about yourself too – so face-to-face I'm aware that I come across as anxious and unsure of myself, so I probably do even more so … Online I know I'll probably seem pretty well functioning, which I think probably means that's how I come across. It's a self-fulfilling prophecy, you could say*." (Participant 6)

> "*You can preserve your energy much easier [online] which makes you feel you can stay true to who you are easier, I think, and you feel better about yourself*" (Participant 7)

This appeared relevant to the ongoing COVID-19 pandemic, in that participants expressed a sense of relief as they explained how they felt there is normally an expectation from others to socialise face-to-face, and that being in an imposed lockdown served to justify their use of online platforms, again minimising the perceived difference between themselves and others:

> "*everyone's interacting online because they have to so people don't ask why you haven't got offline friends or why you don't want to go out to socialise*." (Participant 8)

In contrast to recent research indicating that social media was not useful for autistic people during the COVID-19 lockdown period (Parlangeli et al., 2021), the consensus from participants in this research was that they enjoyed connecting with others via the internet, as being able to interact online in keeping with the norm of the majority at the time, without having to justify their choice even seemed to have an impact on how participants viewed themselves:

> "*because I know that everyone else is now interacting online it makes me feel less weird/different for that being the case for me … because I can pretend to myself that I'm interacting online because that's what everyone does, rather than just because I'm autistic … My behaviour and ways of communicating are less dictated by who I am and more about the situation we all find ourselves in*." (Participant 6)

> "*I'm normal for once [laughs]*". (Participant 8)

Perhaps unsurprisingly then, participants expressed some concern over the lifting of lockdown restrictions and returning to increased face-to-face interaction. These concerns centred around issues such as having to re-learn the social skills lost during the lockdown period and whether the support networks participants had built up online over lockdown would still be available to them:

> *"I feel even more anxious about going back to any kind of face-to-face interactions now, and I feel less sure of myself. I feel like I've got to re-learn something I was never very good at. That really knocks your confidence*." (Participant 6)

> *"In the lockdown … I've had much more time, to … communicat[e] with people. So … I've just felt better in myself … now that it's coming to an end … I'm just thinking, is it gonna be the same now, with the support group I've er, accessed or, are the people still gonna be there?*" (Participant 3)

***Theme 4. Challenging stigma and discrimination: "there's a real positive atmosphere around being autistic online at the moment … there's opportunities to see the good side of being autistic whereas … offline it's all doom and gloom deficits stuff that makes you think you're it's bad to be autistic."* (Participant 8).**

Throughout participants' narratives, it was apparent that people often felt faced with challenges associated with stigma and discrimination linked to common misconceptions about autism. They felt that the lack of understanding around autism amongst non-autistic people meant that autistic people were often subjected to negative stereotyping and structural discrimination by the majority non-autistic group:

> "*I think there is a societal misconception of what autism is … my dad he thought autism meant that … they'd essentially be a knife wielding psychopath … people have their own perceptions of what autism is, and try and apply that, to every autistic person*" (Participant 5)

> "*I don't really share … my autistic identity with people … because, people may judge me, people may feel like, there's something wrong***,** *there's some problem*" (Participant 3)

> "*offline you're made to feel like being autistic is a bad thing, it's all deficit this deficit that*" (Participant 8)

Some participants described how this motivated them to challenge these stereotypes and promote awareness of autism, which they hoped would improve other autistic people's experiences:

> "*a key part of who I am is trying to make things better so other autistic people don't have to suffer like I did … Because they're linked, being autistic is the reason I suffered*" (Participant 7)

Three sub-themes were identified within this theme, which reflect participants' experiences of facing a dilemma about whether/when to disclose their autism diagnosis, the emphasis within the online world on reframing autism as positive, and the protective effects that belonging to a community can have against stigma and discrimination.

### *i) To disclose or not to disclose: "I wouldn't necessarily feel comfortable sharing that I'm autistic because people might judge you badly for it" (Participant 8)*

Throughout their accounts, participants referred to frequently being faced with a dilemma regarding whether or not to disclose their autism diagnosis, citing their concern over stigma and judgement as reasons to avoid doing so. The literature on how disclosure of an autism diagnosis affects stigmatisation is mixed. Some studies (e.g., Jones, et al., 2015; Humphrey & Lewis, 2008), have demonstrated that autistic people feel that revealing their diagnosis changes how they are perceived by others and makes it harder to fit in, lending support to ideas of labelling theory (Scheff, 1966) and Goffman’s (1963) ideas about undesired differentness. Indeed, participants in this study described a reluctance to share that they are autistic due to fear of stigma and judgement that result from society misconceptions about autism:

> “*I feel that would be something that I feel people could use against me, and that's why I don't think I'd be comfortable with disclosing it*” (Participant 1)

> “*There's still stigma, there's still judgement, there's still discrimination, there's still inequality … I've learnt, why disclose or why come to an extent where you're justifying it with people, because there's no point*.” (Participant 3)

Other studies (e.g., Calzada, et al., 2012), however, have found that autistic people see disclosing their diagnosis as a way to improve non-autistic others’ understanding of autism-related difficulties and stop them attributing blame to autistic individuals for displaying behaviours that deviate from non-autistic norms, in support of attribution theory (Weiner, 1993). In the current study, participants reported finding it necessary and/or helpful to disclose being autistic for two main reasons. The first relates to face-to-face interactions, as participants described occasions whereby they feel a need to explain themselves or to justify their behaviours, for example, if they are struggling with environmental conditions and/or engaging in self-soothing behaviours:

> “*I do feel like I have to explain … that I’m autistic and that’s why I’m behaving the way I am. It does feel like having to justify your existence sometimes ... When you know you’re a minority of some sort amongst a majority, you can’t just exist without explaining ... I think society doesn’t like not having all the answers*” (Participant 6)

The second reason participants gave for disclosing their autism diagnosis was as a way of increasing awareness and challenge common misconceptions about autism in order to educate others:

> “*I am more than happy to mention my autism diagnosis ... it’s important to talk about to reduce stigma*” (Participant 6)

> "*I feel the need to improve things for the next generation by educating people and spreading acceptance as I feel it's my duty to the autistic children who are born after me so they won't have such a hard time … I'm quite comfortable talking about … the fact that I'm autistic to help with that purpose*". (Participant 7)

As demonstrated by this participant, however, some felt that this was easier to do online than it was to do offline: "*I wouldn't do it so much offline ... I don't have the opportunity, maybe the confidence to do so*" (Participant 7).

Participants also referred to their perceived social competence and lack of obvious difference when interacting online meaning that they had more choice about whether to disclose being autistic, and that they could go 'undetected' if they so wished. Some participants reported wanting to ignore parts of, or escape from, their true self and that the online world provided an opportunity to do that:

> "*If there's a part of me I want to ignore for whatever reason then I can escape that for a short while … it feels as though there's more choice about who you are online.*" (Participant 7)

However, one participant reflected that although he knew other autistic people did this, he himself struggled with the idea of presenting an alternative version of himself:

> "*Friends who do have, like, online friends and that like, they're usually trying to escape their 'in person' self in a way, but, I know I just can't do that because it's … hard to separate … despite having let's say a different name to what's presented, I'm still talking as myself, I am the person I am not like someone else and, that's … confusing*" (Participant 4)

In line with Marcia's (1980) theory of the two processes of identity development, another participant described using the freedom brought by the online world to test out ways of interacting ('exploration' of options for who to be) in a way that felt safe, before doing so in the offline world (‘commitment’ to the chosen identity). She (and others) referred to there being less risk online, for example by being able to shut the conversation down when needed and not having to make an excuse to leave, which meant she felt more comfortable and confident interacting in ways she might not initially in face-to-face interactions:

> “*I sort of use it as a trial run sometimes like to see how people react to stuff in real life … if it’s not received well then I’ll know not to say it … in real life. And I can just close the conversation and be out of it, I don’t have to make an excuse to leave. So I can use it like a practice almost cause I’m more comfortable online, there’s less risk.*” (Participant 8)

### *ii) Reframing autism as positive online*

Participants who considered themselves to be part of an online autism community spoke of their experience of online spaces as providing an opportunity to learn about autism and share resources, and that the traits associated with autism were framed in a positive light. In line with previous research indicating that framing autistic traits as positive can protect against psychological difficulties (Cooper et al., 2021; Parsloe, 2015), for participants in this study, this served to boost their self-esteem as well as reversing some of the dominant (and negative) discourses around autism that participants felt existed, particularly in the offline world:

> “*online there’s acceptance and positivity in a collective sense around being autistic, but in face-to-face you’re pretty much on your own, which makes it feel quite negative*” (Participant 6)

> “*in face-to-face you’re constantly reminded of someone’s supposed deficits … whereas online you’re more proud*” (Participant 7)

> “*offline you’re made to feel like being autistic is a bad thing, it’s all deficit this deficit that, whereas online well in the autistic community at least you’re made*

> *to feel it's a good thing … or at least a normal thing … how I experience online makes me feel good about who I am.*" (Participant 8)

The latter participant expressed their hopes that future generations will benefit from the advocacy of the autistic community, in changing perceptions of autism by educating people and promoting the view that autistic people and other neurodiverse groups are simply people with normal variations in behaviour:

> "*maybe people who are autistic in the future will have a better experience in society because people are learning about autism online and there's opportunities to see the good side of being autistic whereas you don't get that in offline*" (Participant 8)

### ***iii) A sense of belonging***

Many participants spoke of the sense of belonging that involvement in online autism communities brought for them, which seemed to offer a protective effect against the impact of stigma. This sense of belonging appeared driven by understanding and acceptance within the community. Meeting others with similar experiences, for example, in relation to their journey to receiving an autism diagnosis, or facing stigma and discrimination, enhanced this sense of understanding and connection. One participant commented on how she felt protected by the online autism community as people "*who have [her] back*" (participant 2) and that this helped her to be more confident in challenging prejudice and discrimination when she witnessed it. Others described the protective effect that 'belonging' online had against the negative impact of not fitting in in the offline world:

> "*The good relationships and the solidarity you have with the autism community also means when face-to-face interactions go wrong, I don't quite care… it's not the same as before I found the autistic community when I thought it was just me on my own, at least now I'm like, well I have got friends and people that like me so it's fine*" (Participant 8)

Previous research has shown that feeling a sense of belongingness can protect against the negative impact of stigmatisation and marginalisation (Haslam et al., 2009). One participant in this study went on to explain how, for her, the sense of validation and acceptance gained from the autistic community online even "heals" the damage caused by the negative experiences she had had offline:

> "*being part of something allows you to feel accepted, approved of, and gives you a sense of belonging and as though your existence is validated … when you haven't had that before (from mostly face-to-face interacting) that's a really powerful and healing feeling … healing from the damage caused by not feeling accepted, approved of*" (Participant 6)

In summary, participants felt that there are societal misconceptions about autism that mean autistic people are often faced with stigma and discrimination, the effects of which are particularly relevant to face-to-face interactions. Participants generally felt that online interaction provided an opportunity to escape the effects of stigma and discrimination that they often experienced in face-to-face interactions. They also valued a sense of belonging that came with the social relationships they developed online, particularly in being part of the online autism community, in which the positives of autism could be celebrated. Indeed, research has shown that the social support brought by the autism community on social media has benefits such as improved wellbeing, improved self-concept and self-esteem (Hassrick et al., 2021; Saha & Agarwal, 2016).

## Discussion

### ***Main findings***

This qualitative study aimed to explore how young autistic people view their personal and social identities when interacting online and offline, how they identify with and align themselves to autistic and non-autistic culture when they are online and offline, and the extent to which these issues impact on their mental health and wellbeing. The analysis revealed four key themes: autism as an identity, acceptance is key to being one's true self, feeling different, and stigma and discrimination. Participants saw being autistic as an integral part of their identity, which they felt influenced the way they interact with others whilst being viewed largely as negative by society. Participants suggested that the additional demands placed upon them that result from differing communication styles between them and non-autistic people, were higher in face-to-face interactions than in online interactions, and this had negative implications for their mental health, self-esteem and self-concept. Participants spoke of how, in order to feel more socially competent, they would attempt to mask these difficulties, but that this brought about its own challenges for their identity. They spoke of attempts made to 'close the gap' or minimise the differences between themselves and their non-autistic peers, and how the reduced social demands required for interacting online facilitated this. They also referred to the stigma and discrimination they face, and the opportunities afforded by the online world to challenge some of the negative discourses around autism by focusing on the positives of their autistic identity and enabling them to feel a sense of belonging to a community. Participants felt this had positive implications for their self-esteem and self-concept. Participants also described how they had enjoyed the lockdown period due to reduced expectations for them to interact face-to-face and they expressed anxieties around returning to increased face-to-face interactions.

This is not the first study to highlight that autistic people see autism as a key part of their identity, and one which is stigmatised (Bury et al., 2020). Further, previous research has demonstrated that autistic people see autistic suffering as a product of existing as an identity-based minority group in a majority non-autistic world (rather than their suffering being inherent to autism itself) and that this dynamic means they are subject to minority stress (Botha & Frost, 2020; Sasson et al., 2017). In line with the literature, participants in this study described the range of challenges presented to their self-concept, self-esteem, and overall wellbeing as a result.

Social Identity Theory (Tajfel & Turner, 1979) posits that when a social group is stigmatised, members of the group attempt to elevate their social status and recover a positive identity using both individualistic and collective strategies. Individualistic strategies entail distancing oneself from their in-group (such as, the autistic community) in order to align themselves with a more highly regarded out-group (such as, non-autistic communities). Participants in this study reported that during face-to-face interactions they often felt required to mask or suppress their naturally autistic behaviours in order to ‘fit in’ with the social expectations of non-autistic people and avoid negative judgement from others. The literature on masking highlights the relationship between perceived autism-related stigma and masking, and the various identity challenges that consistent masking can present (Perry et al., 2021; Bargiela et al., 2016; Hull et al., 2017). Collective strategies, on the other hand, strive to reconceive the in-group positively and thus elevate its status. Previous studies (e.g. Botha et al., 2020) have found that autistic people employ collective strategies such as reframing traditional, deficit-based perspectives of autism into more positive perspectives, and reclaiming language (Brontsema, 2004) by refusing to accept labels that non-autistic people put upon them. Similarly, in the current study, participants spoke of benefits of interacting online, including opportunities to have their own perspectives of autism that they had internalised/inherited from society positively reframed, and how this had a favourable impact on their self-concept and self-esteem.

Also in line with Social Identity Theory, participants spoke of the protective effect that feeling a sense of belonging and affiliation gained in online communities afforded them, as going some way to reverse the negative impact that stigmatisation and marginalisation had had on their identity (Haslam et al., 2009). Given the increase in availability of autism specific forums, chatrooms and social media groups, it may be the case that the online world provides a platform for autistic community and culture to grow, in turn promoting a sense of shared identity and protecting against the negative implications associated with offline interactions.

### ***Strengths and limitations***

To the authors' knowledge, this research is the first examination of the relationships between identity development and social media use in young autistic people. The autistic community has identified the importance of researching factors that may influence the developmental trajectory of autistic people such as social learning opportunities (Roche et al., 2021; Fletcher-Watson et al., 2017). The current study makes a useful contribution to the literature here.

During interviews, participants often spoke about their autistic identity in general terms, providing an insight into how they conceptualise their identity. This presented a dilemma in terms of whether to include information that did not relate directly to the research question. However, the research aimed to be data-driven and remain true to what was important to our participants, rather than being constrained by the specific research questions. It was therefore important to include what participants felt was important contextual information as well as the subthemes that related more specifically to offline and online interaction.

Research influenced by, and developed with, autistic people is becoming increasingly acknowledged as an essential component of the research process (Roche et al., 2021). As well as having had input in developing the research proposal, an adult Expert by Experience was actively involved in the design of the study, including development of the materials and discussing implications of the findings for future research and clinical practice. However, as noted by Fletcher-Watson et al. (2019), there is clearly a broad range of views among autistic people and it is important to acknowledge that receiving consultation from one autistic individual is unlikely to provide access to a consistent, ‘community’ view. Conducting a pilot study enabled valuable feedback to be gained regarding the interview process, materials used and interviewer’s style and approach. In addition, each participant was invited to provide feedback on the same at the end of their interview, and this feedback was used to inform/shape future interviews.

A further strength of the study was the option to take part in the study via telephone, videocall and instant messaging as opposed to face-to-face, and this degree of inclusivity served to enhance the diversity of the participant sample and enabled the study to proceed during the Covid-19 pandemic. The option of taking part via instant messaging service was also well-matched to the topic under study.

However, there were some limitations to the study. This discussion is not concerned with the general critiques associated with qualitative research, such as lack of generalisability due to a small sample size, as this was not the intention of the research. It must be made clear however, that the findings reported in this manuscript are specific to the particular participants studied.

This aside, there are some methodological limitations remaining that should be considered. The first refers to the sample and inclusion criteria. Participants with an intellectual disability (and those who are non-speaking or unable to use the internet independently) were excluded from the research, adding to the selection bias against people with intellectual disability in autism research (Russell et al., 2019). People who were self-diagnosed as autistic were also excluded. To have included self-diagnosed individuals may have enhanced understanding of whether the experiences of identity development for this cohort differ from those with a formal diagnosis. Participants were not asked to disclose co-morbidities, however the experiences of autistic individuals who also have health difficulties may be more complex. Most of the sample were male, and given the gender differences in autism presentation (such as increased use of camouflaging by autistic women; Lai et al., 2017) and the different social expectations of women in the United Kingdom, the impact of social interactions on self-esteem and self-concept may differ by gender. Social norms and expectations also differ cross-culturally. Diverse British cultures (including those of participants in this study) may affect how self-identity is perceived. It would be helpful for future research to consider autistic people's experiences of identity development and social media cross-culturally. Specific data on race/ethnicity and socioeconomic status for participants in this study were not recorded.

The second refers to the interview approach. Asking participants to answer questions about their identity in a study that required them to be autistic as part of the inclusion criteria, may have influenced the extent to which participants discussed autism in favour of other aspects of their identity. Although many questions were broad (i.e. not specific to autism) participants may have placed more emphasis on autism than other aspects of their identity and collective groups, such as those of race, religion, nationality, etc.

The third refers to the flexibility of thematic analysis as an analytic tool in this research. Due to the subjective nature of interpretation, the themes generated from this research are, on the whole, dependent on the individual researcher and may therefore attract the ‘anything goes’ critique of thematic analysis (Braun & Clarke, 2006). It is therefore important to acknowledge the individuality of interpretation, as that of a different researcher may have generated different themes and conclusions. Involving multiple researchers to analyse and code simultaneously may have increased the credibility and dependability of this analysis, prompting greater confidence in the findings. KW second coded 10% of the transcripts and regular meetings were held to discuss and develop the coding framework. The flexibility of thematic analysis in this research has been extremely beneficial, as it has allowed themes to be discovered within each individual’s experiences as well as themes shared across the group of participants. This is compatible with idiosyncratic research assumptions, exploring the themes arising from the interviews with each individual participant, whilst also allowing identification of any nomothetic themes that are shared across the participant group to come to light during the analysis.

### *Reflexivity*

In qualitative research it is important to acknowledge the researcher’s (my) role as a thinker and writer, particularly the extent to which my assumptions, understandings and interpretations may have influenced the research, and the processes that I have been involved in intentionally and unintentionally, consciously and subconsciously. Mauthner and Doucet (2003) note the range of influences that a researcher can have on their research, and thus, in the following section, some of my personal, interpersonal theoretical, epistemological and ontological influences on the research are explored.

Firstly, it is important to consider my own position as an individual belonging to minoritised groups and how this has shaped my assumptions about identity development for minoritised individuals. It is likely that my own experiences in this regard have influenced my motivation to produce a research paper that may be regarded as taking a political standpoint. Consideration must also be given to my role as a Clinical Psychology trainee, having spent considerable time familiarising myself with the identity literature. Thus, it was inevitable that I would approach the research with a number of assumptions about what I was likely to find. For example, my knowledge of the principles of Social Identity Theory influenced the design of the study and particularly, the interview schedule. As with those stemming from own minority statuses, it is important to acknowledge these assumptions and expectations, and to pay equal attention to all frames of reference, constructions, codes, themes and discussion topics.

Other considerations relate to the interview process, such as the extent to which my immediate (subconscious) emotional reactions may have influenced the direction of participants' responses. As there was no real time delay between questions posed and the answer given (and vice versa) in the interviews conducted via videocall and telephone, it is inevitable that participants may have picked up on my (unintentional and/or subconscious) non-verbal reactions to their answers or interjections/minimal responses, which has the potential to have influenced the extent to which they discussed certain topics further.

Finding the topic under study to be somewhat abstract, I began by being over-cautious about 'creating' meaning from participants' responses. This hesitation resulted in my initial analysis lacking in explanatory depth or understanding to the data. I then placed all emphasis on interpreting and finding 'new meaning' in data in order to resolve this, and found I was tending to over-interpret in order to uncover interesting and abstract patterns and themes. This in turn led to my themes becoming vague, obscure, and over-complicated. It was a challenge, therefore, to find a balance between the two in order to achieve a level of satisfaction that I had conducted a successful analysis and gained a genuine picture of the experiences of my participants.

### ***Implications and recommendations***

Given the finding that for some autistic people, interacting online affords an opportunity to feel more comfortable as well as more socially competent, it would be helpful for mental health services to offer services online, for example, online assessment sessions and online therapeutic interventions. This may be particularly beneficial for group interventions. This recommendation could be extended to wider health and social care services in offering online options wherever people are required to interact (interviews, meetings, etc.) to support autistic people to access services, avoiding the additional stressors and demands associated with face-to-face interactions.

Since for some autistic people it appears to be the mode of interaction that results in negative outcomes for their self-esteem and self-concept, rather than the interacting itself, it is likely that this reflects the socio-cultural environment within which they interact**,** rather than indicating underlying pathology of a ‘disorder’. This lends support to the social model of disability. Consequently, researchers and clinicians should attend to the social, cultural and political systems that can empower or disempower autistic people. Future research should explore the part to be played by psychology in reconceiving autism and supporting the neurodivergent community.

Although the purpose of the study was not to explore stigma explicitly, the data generated clearly communicate how significant stigma (as both experienced by the individual, and as a driver of decision making) plays a role in the lives of autistic people. This emphasises the need for ongoing research into how best to target stigma (for example, ongoing discussions and consultation with the autistic community around the least stigmatising language/preferred terminology, and efforts to increase awareness and education) as well as clinical interventions to support autistic people and their families when faced with stigma (for example, increasing self-esteem and self-compassion skills, and support around/preparedness for responding to instances of stigma from the public, other family members, and/or professionals).

The data generated also suggest that online interactions play an important role in identity development for autistic individuals. It is argued, therefore, that developmental theories of identity have the potential of furthering understanding of the meaning of online contexts in identity development and, equally important, research on identity development should take online contexts into account in order to grasp the whole story of adolescents’ identity development in contemporary society.

## ***Conclusion***

In sum, this study aimed to investigate how autistic people view their identity when interacting online and offline, and found that generally, differences in communication styles leave autistic people questioning their social competence and finding it more difficult to present their true/authentic selves in offline interactions, due to a fear of being stigmatised and unaccepted. Our findings suggest this leads people to mask naturally autistic behaviours during face-to-face interactions, which can result in identity challenges and mental health difficulties. In general, participants felt that autism was an integral part of their identity and that the benefits afforded by online interaction (including reduced social demands from the absence of non-verbal cues, ability to control one's sensory environment, increased control and personal safety, and access to autism communities in which autism is celebrated) had more positive implications for their self-esteem and self-concept than offline interactions. This research has implications for societal awareness and responses to autism, particularly, illustrating the importance of offering as standard varied methods communication across a range of services.

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The author(s) declared no potential conflicts of interest with respect to the research, authorship, and/or publication of this article.

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All procedures performed in studies involving human participants were in accordance with the ethical standards of the University of Liverpool's Central University Research Ethics Committee, from which ethical approval for this project was obtained (8123).

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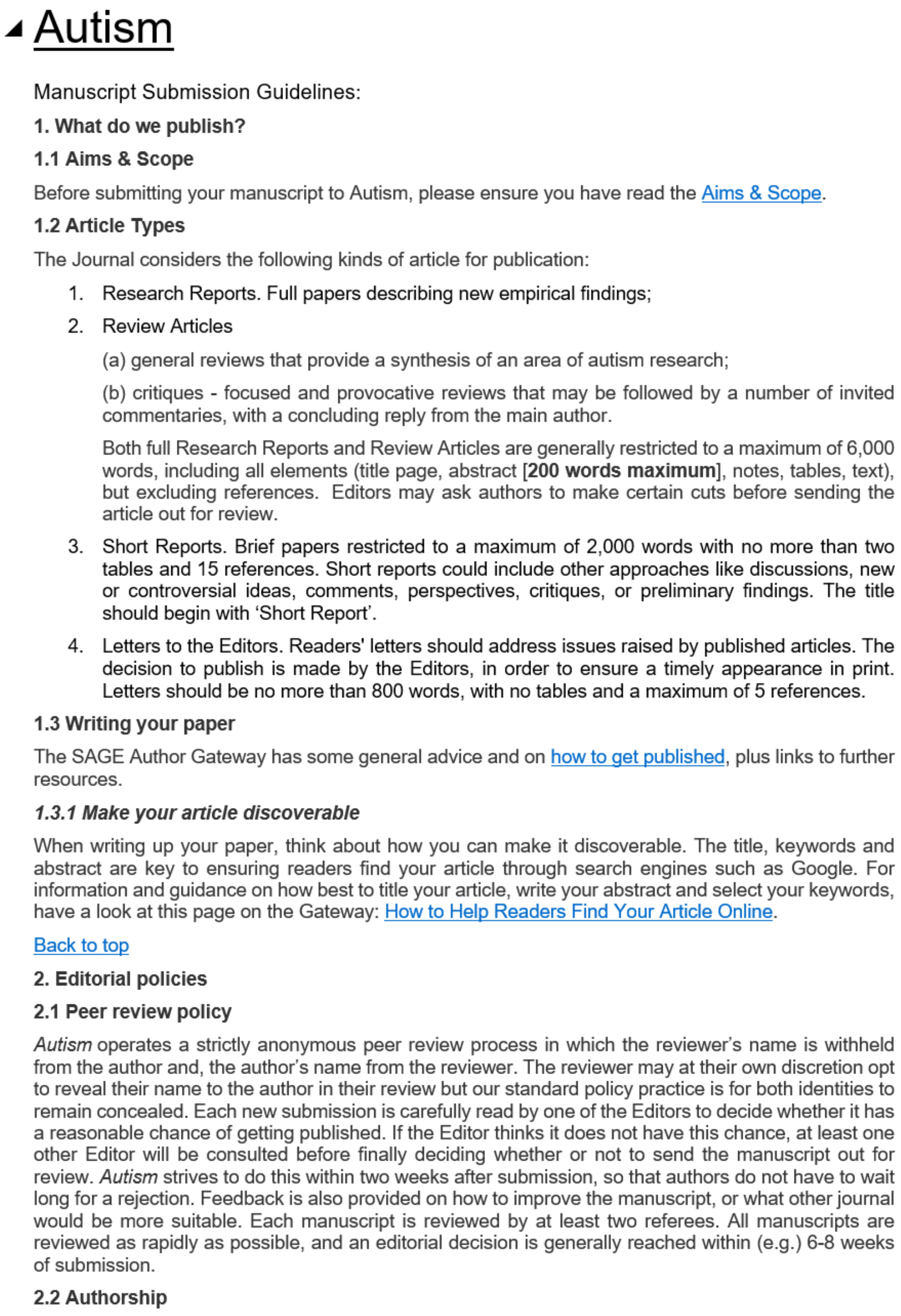
# Appendices

List of Appendices:

# Appendix A: Summary of Submission Guidelines for Target Journal



## Autism

Manuscript Submission Guidelines:

**1. What do we publish?**

**1.1 Aims & Scope**

Before submitting your manuscript to Autism, please ensure you have read the Aims & Scope.

**1.2 Article Types**

The Journal considers the following kinds of article for publication:

1. Research Reports. Full papers describing new empirical findings;
2. Review Articles

   (a) general reviews that provide a synthesis of an area of autism research;

   (b) critiques - focused and provocative reviews that may be followed by a number of invited commentaries, with a concluding reply from the main author.

   Both full Research Reports and Review Articles are generally restricted to a maximum of 6,000 words, including all elements (title page, abstract [**200 words maximum**], notes, tables, text), but excluding references. Editors may ask authors to make certain cuts before sending the article out for review.
3. Short Reports. Brief papers restricted to a maximum of 2,000 words with no more than two tables and 15 references. Short reports could include other approaches like discussions, new or controversial ideas, comments, perspectives, critiques, or preliminary findings. The title should begin with 'Short Report'.
4. Letters to the Editors. Readers' letters should address issues raised by published articles. The decision to publish is made by the Editors, in order to ensure a timely appearance in print. Letters should be no more than 800 words, with no tables and a maximum of 5 references.

**1.3 Writing your paper**

The SAGE Author Gateway has some general advice and on how to get published, plus links to further resources.

***1.3.1 Make your article discoverable***

When writing up your paper, think about how you can make it discoverable. The title, keywords and abstract are key to ensuring readers find your article through search engines such as Google. For information and guidance on how best to title your article, write your abstract and select your keywords, have a look at this page on the Gateway: How to Help Readers Find Your Article Online.

Back to top

**2. Editorial policies**

**2.1 Peer review policy**

*Autism* operates a strictly anonymous peer review process in which the reviewer's name is withheld from the author and, the author's name from the reviewer. The reviewer may at their own discretion opt to reveal their name to the author in their review but our standard policy practice is for both identities to remain concealed. Each new submission is carefully read by one of the Editors to decide whether it has a reasonable chance of getting published. If the Editor thinks it does not have this chance, at least one other Editor will be consulted before finally deciding whether or not to send the manuscript out for review. *Autism* strives to do this within two weeks after submission, so that authors do not have to wait long for a rejection. Feedback is also provided on how to improve the manuscript, or what other journal would be more suitable. Each manuscript is reviewed by at least two referees. All manuscripts are reviewed as rapidly as possible, and an editorial decision is generally reached within (e.g.) 6-8 weeks of submission.

**2.2 Authorship**

All parties who have made a substantive contribution to the article should be listed as authors. Principal authorship, authorship order, and other publication credits should be based on the relative scientific or professional contributions of the individuals involved, regardless of their status. A student is usually listed as principal author on any multiple-authored publication that substantially derives from the student's dissertation or thesis.

### 2.3 Acknowledgements

All contributors who do not meet the criteria for authorship should be listed in an Acknowledgements section. Examples of those who might be acknowledged include a person who provided purely technical help, or a department chair who provided only general support.

Please supply any personal acknowledgements separately to the main text to facilitate anonymous peer review.

#### *2.3.1 Third party submissions*

Where an individual who is not listed as an author submits a manuscript on behalf of the author(s), a statement must be included in the Acknowledgements section of the manuscript and in the accompanying cover letter. The statements must:

- Disclose this type of editorial assistance – including the individual's name, company and level of input
- Identify any entities that paid for this assistance
- Confirm that the listed authors have authorized the submission of their manuscript via third party and approved any statements or declarations, e.g. conflicting interests, funding, etc.

Where appropriate, SAGE reserves the right to deny consideration to manuscripts submitted by a third party rather than by the authors themselves.

### 2.4 Funding

Autism requires all authors to acknowledge their funding in a consistent fashion under a separate heading. Please visit the Funding Acknowledgements page on the SAGE Journal Author Gateway to confirm the format of the acknowledgment text in the event of funding, or state that: This research received no specific grant from any funding agency in the public, commercial, or not-for-profit sectors.

**Important note:** If you have any concerns that the provision of this information may compromise your anonymity, you should withhold this information until you submit your final accepted manuscript.

#### 2.4.1 National Institutes of Health (NIH) funded articles

If you have received NIH funding for your research, please state this in your submission and if your paper is accepted by *Autism* an electronic version of the paper will automatically be sent to be indexed with the National Library of Medicine's PubMed Central as stipulated in the NIH policy.

### 2.5 Declaration of conflicting interests

Autism encourages authors to include a declaration of any conflicting interests and recommends you review the good practice guidelines on the SAGE Journal Author Gateway. In particular, for working reporting on the development or evaluation of interventions the ICJME Conflict of Interest form provides an excellent template for considering a range of potential sources of conflict, and this can be uploaded and submitted with your manuscript if relevant.

Where an Editor of Autism is a lead or contributing author to a paper submitted to publication, the paper is always handled through the peer review process by another member of the Editor team and three reviews are obtained in each case. A statement is also published on each article where this occurs.

### 2.6 Research ethics and patient consent

Medical research involving human subjects must be conducted according to the World Medical Association Declaration of Helsinki

Submitted manuscripts should conform to the ICMJE Recommendations for the Conduct, Reporting, Editing, and Publication of Scholarly Work in Medical Journals, and all papers reporting animal and/or human studies must state in the methods section that the relevant Ethics Committee or Institutional Review Board provided (or waived) approval. Please ensure that you have provided the full name and institution of the review committee, in addition to the approval number.

For research articles, authors are also required to state in the methods section whether participants provided informed consent and whether the consent was written or verbal.

Information on informed consent to report individual cases or case series should be included in the manuscript text. A statement is required regarding whether written informed consent for patient information and images to be published was provided by the patient(s) or a legally authorized representative.

Please also refer to the ICMJE Recommendations for the Protection of Research Participants

### 2.7 Clinical trials

Autism conforms to the ICMJE requirement that clinical trials are registered in a WHO-approved public trials registry at or before the time of first patient enrolment as a condition of consideration for publication. The trial registry name and URL, and registration number must be included at the end of the abstract.

### 2.8 Reporting guidelines

#### 2.8.1 Transparent reporting of trials

The relevant EQUATOR Network reporting guidelines should be followed depending on the type of study. For example, all randomized controlled trials submitted for publication should include a completed CONSORT flow chart as a cited figure and the completed CONSORT checklist should be uploaded with your submission as a supplementary file. Systematic reviews and meta-analyses should include the completed PRISMA flow chart as a cited figure and the completed PRISMA checklist should be uploaded with your submission as a supplementary file. The EQUATOR wizard can help you identify the appropriate guideline.

The What Works Clearinghouse (WWC) guidelines should be followed when submitting in single-case design (SCD) and meet the standards outlined for internal validity of the SCD.

Other resources can be found at NLM's Research Reporting Guidelines and Initiatives

#### 2.8.2 Sample selection and demographic characteristics

*Autism* now requires authors to report the following information for all Research Reports (including systematic reviews):

i. procedures for sample selection and recruitment; and
ii. major demographic characteristics, including age, gender, race/ethnicity and socioeconomic status.

Including this information will provide greater clarity regarding sample characteristics and generalisability of the findings, even when such characteristics are not used in the analysis (although we encourage investigation of subgroup differences, where possible). It should also encourage researchers to consider the way in which context and culture contribute to their findings.

If authors are unable to report some or all of this information, its absence must be acknowledged with a clear statement of explanation (e.g., "specific data on socioeconomic status and educational attainment levels were not recorded"). Manuscripts that contain neither the required information nor an appropriate statement will be returned prior to consideration by the editors.

#### 2.8.3 Community involvement

Autism encourages research that is actively carried out 'with' or 'by' members of the Autistic and autism communities (rather than 'to', 'about', or 'for' them), often referred to as 'co-production', 'participatory research', 'patient and public involvement' or 'integrated knowledge translation'.

We therefore now require authors to include a community involvement statement at the end of the Methods section for Research Reports, outlining whether autistic people or family members, community providers, policy makers, agency leaders or other community stakeholders were involved in developing the research question, study design, measures, implementation, or interpretation and dissemination of the findings. Community members should be duly acknowledged – as authors or in the acknowledgements section – depending on the extent and nature of their contribution. We recommend that authors follow the BMJ's editorial guidelines for documenting how community stakeholders were involved in their research.

If community members were not involved in the study, authors should state this.

For more details about the reasoning behind this journal requirement, and editorial expectations of authors, please download this FAQs document.

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### 2.9 Data Policy Statement

*Autism* supports open research practices and FAIR principles. As such encourages authors to share their data wherever possible and submit their data (or a link to it) and where applicable, their syntax/command files for the analyses presented in the contribution. Authors can make data available through a third party data repository or on the journal website as a supplementary data file.

If cited data is restricted (e.g. classified, require confidentiality protections, were obtained under a non-disclosure agreement, or have inherent logistical constraints), authors should notify the editor at the time of submission. The editor shall have full discretion to follow their journal's policy on restricted data, including declining to review the manuscript or granting an exemption with or without conditions. The editor shall inform the author of this decision prior to review.

Where data is sensitive and cannot be shared in an open forum, authors are encouraged to share metadata and provide a contact for requesting access if the raw data itself cannot be made available.

Data can be submitted with your article and hosted on the SAGE *Autism* website where we work with Figshare to host data content. Authors can use a recognised third party data repository service to host their data such as Open Science framework. Authors may use their institution's data sharing repository.

*Autism* also encourages authors to delineate clearly the analytic procedures upon which their published claims rely, and where possible provide access to all relevant analytic materials. If such materials are not published with the article, we encourage authors to share to the greatest extent possible through a digital repository (above).

*Autism* encourages authors to use data citation practices that identify a dataset's author(s), title, date, version, and a persistent identifier. In sum, data should be referenced and cited, where possible, as an intellectual product of value.

Back to top

## 3. Publishing Policies

### 3.1 Publication ethics

SAGE is committed to upholding the integrity of the academic record. We encourage authors to refer to the Committee on Publication Ethics' International Standards for Authors and view the Publication Ethics page on the SAGE Author Gateway.

#### 3.1.1 Plagiarism

Autism and SAGE take issues of copyright infringement, plagiarism or other breaches of best practice in publication very seriously. We seek to protect the rights of our authors and we always investigate claims of plagiarism or misuse of published articles. Equally, we seek to protect the reputation of the journal against malpractice. Submitted articles may be checked with duplication-checking software. Where an article, for example, is found to have plagiarised other work or included third-party copyright material without permission or with insufficient acknowledgement, or where the authorship of the article is contested, we reserve the right to take action including, but not limited to: publishing an erratum or corrigendum (correction); retracting the article; taking up the matter with the head of department or dean of the author's institution and/or relevant academic bodies or societies; or taking appropriate legal action.

#### 3.1.2 Prior publication

If material has been previously published it is not generally acceptable for publication in a SAGE journal. However, there are certain circumstances where previously published material can be considered for publication. Please refer to the guidance on the SAGE Author Gateway or if in doubt, contact the Editor at the address given below.

### 3.2 Contributor's publishing agreement

Before publication, SAGE requires the author as the rights holder to sign a Journal Contributor's Publishing Agreement. SAGE's Journal Contributor's Publishing Agreement is an exclusive licence agreement which means that the author retains copyright in the work but grants SAGE the sole and exclusive right and licence to publish for the full legal term of copyright. Exceptions may exist where an assignment of copyright is required or preferred by a proprietor other than SAGE. In this case copyright in the work will be assigned from the author to the society. For more information please visit the SAGE Author Gateway.

### 3.3 Open access and author archiving

Autism offers optional open access publishing via the SAGE Choice programme. For more information on Open Access publishing options at SAGE please visit SAGE Open Access. For information on funding body compliance, and depositing your article in repositories, please visit SAGE's Author Archiving and Re-Use Guidelines and Publishing Policies.

Back to top

## 4. Preparing your manuscript for submission

### 4.1 Formatting

Autism asks that authors use the APA style for formatting. The APA Guide for New Authors can be found on the APA website, as can more general advice for authors.

### 4.2 Artwork, figures and other graphics

For guidance on the preparation of illustrations, pictures and graphs in electronic format, please visit SAGE's Manuscript Submission Guidelines.

Figures supplied in colour will appear in colour online regardless of whether or not these illustrations are reproduced in colour in the printed version. For specifically requested colour reproduction in print, you will receive information regarding the costs from SAGE after receipt of your accepted article.

### 4.3 Supplementary material

This journal is able to host additional materials online (e.g. datasets, podcasts, videos, images etc) alongside the full-text of the article. For more information please refer to our guidelines on submitting supplementary files.

### 4.4 Terminology

#### 4.4.1 Terminology about autism and autistic people

*Autism* has researched and produced its own guidance on terminology and language used in autism research. Please consult the guide here: autism terminology guidelines.

#### 4.4.2 Language used to discuss race and ethnicity

Likewise, *Autism* has also produced the following guidance to be considered when writing about race and ethnicity. Please consult the guide here: race and ethnicity language guidelines.

### 4.5 Reference style

Autism adheres to the APA reference style. View the APA guidelines to ensure your manuscript conforms to this reference style.

### 4.6 English language editing services

Authors seeking assistance with English language editing, translation, or figure and manuscript formatting to fit the journal's specifications should consider using SAGE Language Services. Visit SAGE Language Services on our Journal Author Gateway for further information.

Back to top

## 5. Submitting your manuscript

Autism is hosted on SAGE Track, a web based online submission and peer review system powered by ScholarOne™ Manuscripts. Visit http://mc.manuscriptcentral.com/autism to login and submit your article online.

IMPORTANT: Please check whether you already have an account in the system before trying to create a new one. If you have reviewed or authored for the journal in the past year it is likely that you will have had an account created. For further guidance on submitting your manuscript online please visit ScholarOne Online Help.

### 5.1 ORCID

As part of our commitment to ensuring an ethical, transparent and fair peer review process SAGE is a supporting member of ORCID, the Open Researcher and Contributor ID. ORCID provides a unique and persistent digital identifier that distinguishes researchers from every other researcher, even those who share the same name, and, through integration in key research workflows such as manuscript and grant submission, supports automated linkages between researchers and their professional activities, ensuring that their work is recognized.

The collection of ORCID iDs from corresponding authors is now part of the submission process of this journal. If you already have an ORCID iD you will be asked to associate that to your submission during the online submission process. We also strongly encourage all co-authors to link their ORCID ID to their accounts in our online peer review platforms. It takes seconds to do: click the link when prompted, sign into your ORCID account and our systems are automatically updated. Your ORCID iD will become part of your accepted publication's metadata, making your work attributable to you and only you. Your ORCID iD is published with your article so that fellow researchers reading your work can link to your ORCID profile and from there link to your other publications.

If you do not already have an ORCID iD please follow this link to create one or visit our ORCID homepage to learn more.

### 5.2 Information required for completing your submission

You will be asked to provide contact details and academic affiliations for all co-authors via the submission system and identify who is to be the corresponding author. These details must match what appears on your manuscript. At this stage please ensure you have included all the required statements and declarations and uploaded any additional supplementary files (including reporting guidelines where relevant).

### 5.3 Lay Abstracts

As part of your submission you will be asked to provide a lay abstract of your article. Lay abstracts are a brief (max 250 words) description of the paper that is easily understandable. These abstracts will be made widely available (to the general public, and particularly to autistic people and their families). As such, lay abstracts should avoid both technical terminology and the reporting of statistics. Examples of lay abstracts are provided in recent issues of the journal.

Authors may consider the following questions when composing their lay abstract.
a. What is already known about the topic?
b. What this paper adds?
c. Implications for practice, research or policy

Authors may also find the following resources helpful on this topic:

- How to write a summary paragraph
- Self Advocacy Resource and Technical Assistance Center (SARTAC): Plain Language
- Center for Plain Langauage: Five steps to Plain Language

### 5.4 Permissions

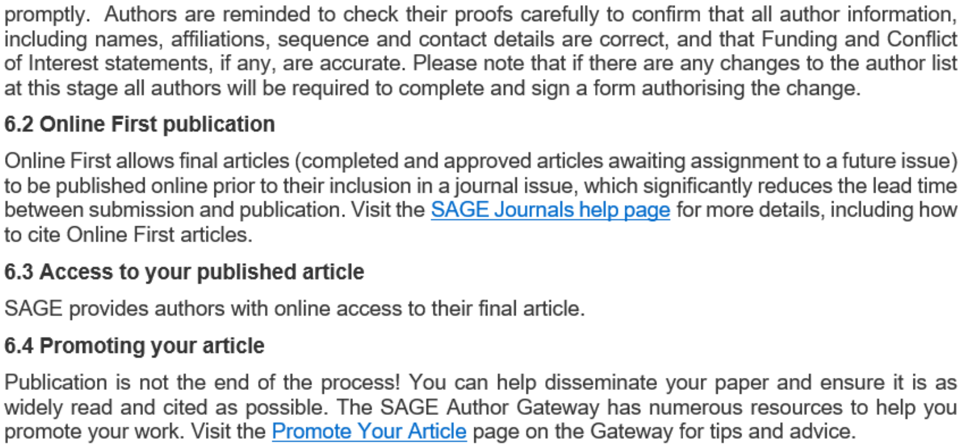
Please also ensure that you have obtained any necessary permission from copyright holders for reproducing any illustrations, tables, figures or lengthy quotations previously published elsewhere. For further information including guidance on fair dealing for criticism and review, please see the Copyright and Permissions page on the SAGE Author Gateway

Back to top

## 6. On acceptance and publication

### 6.1 SAGE Production

Your SAGE Production Editor will keep you informed as to your article's progress throughout the production process. Proofs will be sent by PDF to the corresponding author and should be returned



promptly. Authors are reminded to check their proofs carefully to confirm that all author information, including names, affiliations, sequence and contact details are correct, and that Funding and Conflict of Interest statements, if any, are accurate. Please note that if there are any changes to the author list at this stage all authors will be required to complete and sign a form authorising the change.

### 6.2 Online First publication

Online First allows final articles (completed and approved articles awaiting assignment to a future issue) to be published online prior to their inclusion in a journal issue, which significantly reduces the lead time between submission and publication. Visit the SAGE Journals help page for more details, including how to cite Online First articles.

### 6.3 Access to your published article

SAGE provides authors with online access to their final article.

### 6.4 Promoting your article

Publication is not the end of the process! You can help disseminate your paper and ensure it is as widely read and cited as possible. The SAGE Author Gateway has numerous resources to help you promote your work. Visit the Promote Your Article page on the Gateway for tips and advice.

## Appendix B: Stage 1 Screening Tool

### Stage 1 Screening Tool

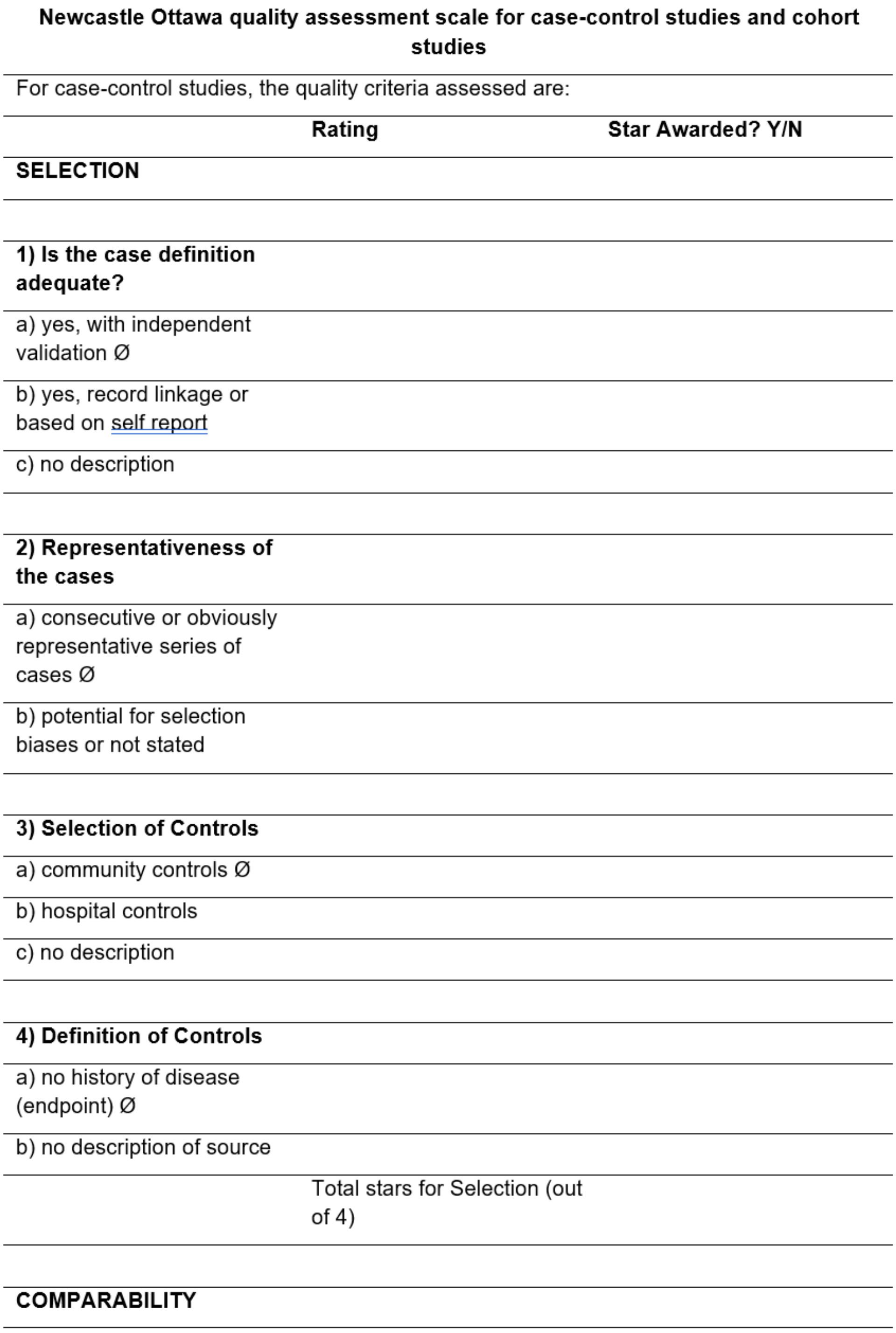
**Review Title:** What are the psychosocial correlates of loneliness for autistic people, based on the literature published between 2000 and 2020?

What does this tell us about the impact of loneliness on the mental health and social functioning of autistic adults and adolescents?

| | | **Inclusion** | **Exclusion** |
|---|---|---|---|
| **Participants** | ***Age*** | Adults 18+<br>Adolescents 10-19 | Children under 10 |
| | ***Gender/Sex*** | All | N/A |
| | ***Diagnoses*** | Diagnoses of:<br>Asperger Syndrome<br>Autism Syndrome<br>Pervasive Developmental Disorder<br>High Functioning Autism<br>Autism Spectrum Disorder | Studies looking at autism characteristics without formal diagnosis (and indicated confirmation of the diagnosis)<br>Known diagnosis of Intellectual/Learning Disability |
| **Study** | ***Design*** | Quantitative<br>Quantitative data to be extracted from mixed methods studies<br>Self-report (for studies that include self- and other- reported data, the self-reported data will be extracted where possible) | Qualitative<br>Reports from others e.g. teachers, parents |
| | ***Participants*** | Studies with 15 or more participants | Studies with less than 15 participants |
| | ***Outcomes*** | Loneliness<br>- with a specific, validated measure of loneliness *or* | N/A |

| | | | |
|---|---|---|---|
| | | - if not a validated measure, the words ‘lonely’ or ‘loneliness’ are included<br>Psychosocial factors | |
| | ***Location*** | Worldwide | N/A |
| **Publication** | ***Language*** | English (including translations) | Not English |
| | ***Publication source/type*** | Empirical papers | Review articles<br>Editorials<br>Dissertations<br>Textbooks<br>Case studies<br>Letters<br>Conference abstracts<br>Commentaries |
| | ***Availability*** | Full-text is available | Full-text not available |
| | ***Dates*** | After January 2000 | Before January 2000 |

## Appendix C: Newcastle Ottowa Scale for Case-control Studies



**Newcastle Ottawa quality assessment scale for case-control studies and cohort studies**

| For case-control studies, the quality criteria assessed are: | | |
|---|---|---|
| | **Rating** | **Star Awarded? Y/N** |
| **SELECTION** | | |
| | | |
| **1) Is the case definition adequate?** | | |
| a) yes, with independent validation Ø | | |
| b) yes, record linkage or based on self report | | |
| c) no description | | |
| | | |
| **2) Representativeness of the cases** | | |
| a) consecutive or obviously representative series of cases Ø | | |
| b) potential for selection biases or not stated | | |
| | | |
| **3) Selection of Controls** | | |
| a) community controls Ø | | |
| b) hospital controls | | |
| c) no description | | |
| | | |
| **4) Definition of Controls** | | |
| a) no history of disease (endpoint) Ø | | |
| b) no description of source | | |
| | Total stars for Selection (out of 4) | |
| | | |
| **COMPARABILITY** | | |

| | |
|---|---|
| **1) Comparability of cases and controls on the basis of the design or analysis** | |
| a) study controls for at least one variable Ø | |
| b) study controls for more than one variable Ø | |
| | Total stars for Comparability (out of 2) |
| | |
| **EXPOSURE** | |
| | |
| **1) Ascertainment of exposure** | |
| a) secure record (eg surgical records) Ø | |
| b) structured interview where blind to case/control status Ø | |
| c) interview not blinded to case/control status | |
| d) written self report or medical record only | |
| e) no description | |
| | |
| **2) Same method of ascertainment for cases and controls** | |
| a) yes Ø | |
| b) no | |
| | |
| **3) Non-Response rate** | |
| a) same rate for both groups Ø | |
| b) non respondents described | |
| c) rate different and no designation | |
| | Total stars for Exposure (out of 3) |

# Appendix D: Newcastle Ottowa Scale for Cross-sectional Studies

**NOS for cross-sectional studies**

| For cross sectional studies, the quality criteria assessed are: | | |
|---|---|---|
| | **Rating** | **Star Awarded? Y/N** |
| **SELECTION** | | |
| | | |
| **1. Representativeness of the sample** | | |
| a) truly representative of the average in the target population Ø | | |
| b) somewhat representative of the average in the target group Ø | | |
| c) selected group of users/convenience sample | | |
| d) no description of the derivation of the included subjects | | |
| | | |
| **2. Sample size** | | |
| a) justified and satisfactory Ø | | |
| b) not justified | | |
| c) no information provide | | |
| | | |
| **3. Non-respondents** | | |
| a) proportion of target sample recruited attains pre-specified target or basic summary of non-respondent characteristics in sampling frame recorded Ø | | |
| b) unsatisfactory recruitment rate, no summary data on non-respondents | | |
| c) no information provided | | |

| | |
|---|---|
| | |
| **4. Ascertainment of the exposure (risk factor)** | |
| a) vaccine records/vaccine registry/clinic registers/hospital records ØØ | |
| b) parental or personal recall and vaccine/hospital records Ø | |
| c) parental/personal recall only | |
| | Total stars for Selection (out of 5) |
| | |
| **COMPARABILITY** | |
| | |
| **1. Comparability of subjects in different outcome groups on the basis of design or analysis. Confounding factors controlled** | |
| a) data/ results adjusted for relevant predictors/risk factors/confounders ØØ | |
| b) data/results not adjusted for all relevant confounders/risk factors/information not provided | |
| | Total stars for Comparability (out of 2) |
| | |
| **OUTCOME** | |
| | |
| **1. Assessment of outcome** | |
| a) independent blind assessment using objective | |

| | |
|---|---|
| validated laboratory method ØØ | |
| b) unblinded assessment using objective validated laboratory methods ØØ | |
| c) used non-standard or non-validated laboratory methods with gold standard Ø | |
| d) no description/non-standard laboratory methods used | |
| | |
| **2. Statistical test** | |
| a) statistical test used to analyse the data clearly described, appropriate and measures of association presented including confidence intervals and probability level (p value) Ø | |
| b) statistical test not appropriate, not described or incomplete | |
| | Total stars for Outcome (out of 3) |

## Appendix E: Template Data Extraction Form

### Data Extraction Form

| |
|---|
| |
| **Record Information** |
| Version obtained (electronic / paper) |
| Study title |
| |
| **Study Characteristics** |
| Author |
| Date of **publication** |
| Journal published in |
| Type e.g. dissertation? |
| When conducted |
| Where conducted |
| Study design |
| Study population |
| Number of participants *including dropouts |
| Method of recruitment |
| Method of analysis |
| Study sponsorship/funder |
| Inclusion criteria |
| Exclusion criteria |
| Autism advisor involvement? |
| Variables studied and how measured |
| |
| **Participant Characteristics** |
| P's age |
| P's sex |
| P's ethnicity |
| Educational level |
| Socioeconomic status |
| Was ASD diagnosis confirmed? How? |

| |
|---|
| Was no LD confirmed? How? |
| Mental health/psychiatric diagnoses |
| Comparison group? Details |
| |
| **Study Results** |
| Bivariate analyses |
| Multivariate analyses |
| |

# Appendix F: Example Quality Assessment form

| | | | |
|---|---|---|---|
| **NEWCASTLE - OTTAWA QUALITY ASSESSMENT SCALE: CASE CONTROL STUDIES** | | | |
| **Study:** Whitehouse, Durkin, Jaquet & Ziatas (2009) | | | |
| | | | |
| | **Tick** | **Star Awarded? Y/N** | **Notes** |
| **SELECTION** | | | |
| | | | |
| **1) Is the case definition adequate?** | | | i.e. did they check the ASD diagnosis |
| a) yes, with independent validation Ø | Diagnosis was confirmed in the study by the Childhood Asperger Syndrome Test (CAST) completed by the parent of each participant - only those with the recommended cut off of 15+ were included | Y | e.g. >1 person/record/time/process to extract information, or reference to primary record source such as x-rays or medical/hospital record) i.e. they re-tested the P's for autism |
| b) yes, record linkage or based on self-report | | | via record linkage (e.g. ICD codes in database) or just self-report with no reference to the primary record i.e. asked them to self-report diagnosis or ? |
| c) no description | | | |
| | | | |
| **2) Representativeness of the cases** | | | Does their sample represent autistic adults/adolescents |
| a) consecutive or obviously representative series of cases Ø | | | Either all eligible cases with outcome of interest over a defined period of time (i.e. every autistic person in the world), all cases in a defined catchment area, all cases in a defined hospital or clinic, group of hospitals, health maintenance organisation, or an appropriate sample of those cases (e.g. random sample) |
| b) potential for selection biases or not stated | No details of sampling method. Assumed to be a convenience sample. Potential for self-selection bias. | N | Not satisfying requirements in part (a), or not stated |
| | | | |
| **3) Selection of Controls** | | | This item assesses whether the control series used in the study is derived from the same population as the cases and essentially would have been cases had the outcome been present |
| a) community controls Ø | All participants were attending mainstream secondary schools | Y | i.e. same community as cases and would be cases if had outcome |
| b) hospital controls | | | Within same community as cases (i.e. not another city) but derived from a hospitalised population |
| c) no description | | | |
| | | | |
| **4) Definition of Controls** | | | |
| a) no history of disease (endpoint) Ø | Controls are not autistic | Y | If cases are first occurrence of outcome, then it must explicitly state that controls have no history of this outcome. If cases have new (not necessarily first) |

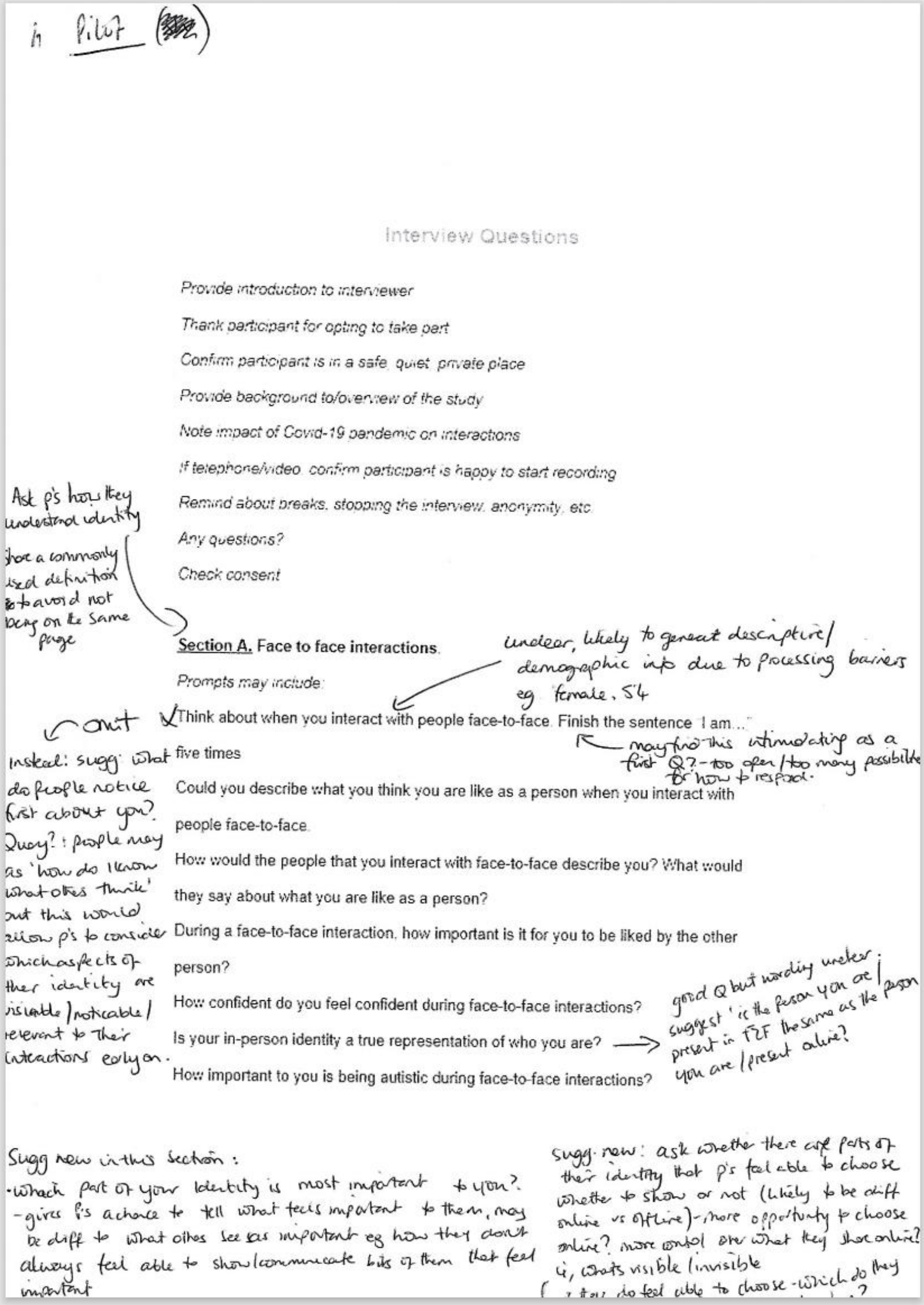
| | | | |
|---|---|---|---|
| | | | occurrence of outcome, then controls with previous occurrences of outcome of interest should not be excluded |
| b) no description of source | | | No mention of history of outcome |
| | Total stars for Selection | 3 out of 4 | |
| | | | |
| **COMPARABILITY** | | | |
| **1) Comparability of cases and controls on the basis of the design or analysis** | | | Either cases and controls must be matched in the design and/or confounders must be adjusted for in the analysis. Statements of no differences between groups or that differences were not statistically significant are not sufficient for establishing comparability. Note: If the odds ratio for the exposure of interest is adjusted for the confounders listed, then the groups will be considered to be comparable on each variable used in the adjustment. |
| a) study controls for at least one variable Ø | The two groups were matched on chronological age, (one star) school year and gender distribution | Yx1 | Including age, sex and comorbidities. |
| b) study controls for more than one variable Ø | The two groups were matched on chronological age, school year (two stars) and gender distribution | Yx1 | Including age, sex and comorbidities. (This criteria could be modified to indicate specific control for a second important factor.) |
| | Total stars for Comparability | 2 out of 2 | |
| | | | |
| **EXPOSURE** | | | |

2926

| | | |
|---|---|---|
| **1) Ascertainment of exposure** | | |
| a) secure record (eg surgical records) Ø | | |
| b) structured interview where blind to case/control status Ø | | |
| c) interview not blinded to case/control status | | |
| d) written self-report or medical record only | Self-report questionnaires | N |
| e) no description | | |
| | | |
| **2) Same method of ascertainment for cases and controls** | | |
| a) yes Ø | Controls completed the same questionnaires | Y |
| b) no | | |
| | | |
| **3) Non-Response rate** | | |
| a) same rate for both groups Ø | | |
| b) non respondents described | | |
| c) rate different and no designation | Not detailed | N |
| | Total stars for Exposure | 1 out of 3 |
| | | |
| | **TOTAL** | **6** |

## Appendix G: Example Interview Schedule

Initial interview schedule draft (before pilot study feedback) with comments from the pilot interviewee:



in Pilot ([redacted])

Interview Questions

*Provide introduction to interviewer*

*Thank participant for opting to take part*

*Confirm participant is in a safe, quiet, private place*

*Provide background to/overview of the study*

*Note impact of Covid-19 pandemic on interactions*

*If telephone/video, confirm participant is happy to start recording*

*Remind about breaks, stopping the interview, anonymity, etc.*

*Any questions?*

*Check consent*

Ask p's how they understand identity

Share a commonly used definition so to avoid not being on the same page

**Section A.** **Face to face interactions.**

*Prompts may include:*

unclear, likely to generat descriptive/demographic info due to processing barriers eg female, 54

omit ✓Think about when you interact with people face-to-face. Finish the sentence "I am…" five times

may find this intimidating as a first Q? - too open/too many possibilite for how to respond.

instead: sugg: what do people notice first about you? Query? : people may as 'how do I know what others think' but this would allow p's to consider which aspects of their identity are visible/noticable/relevent to their interactions early on.

Could you describe what you think you are like as a person when you interact with people face-to-face.

How would the people that you interact with face-to-face describe you? What would they say about what you are like as a person?

During a face-to-face interaction, how important is it for you to be liked by the other person?

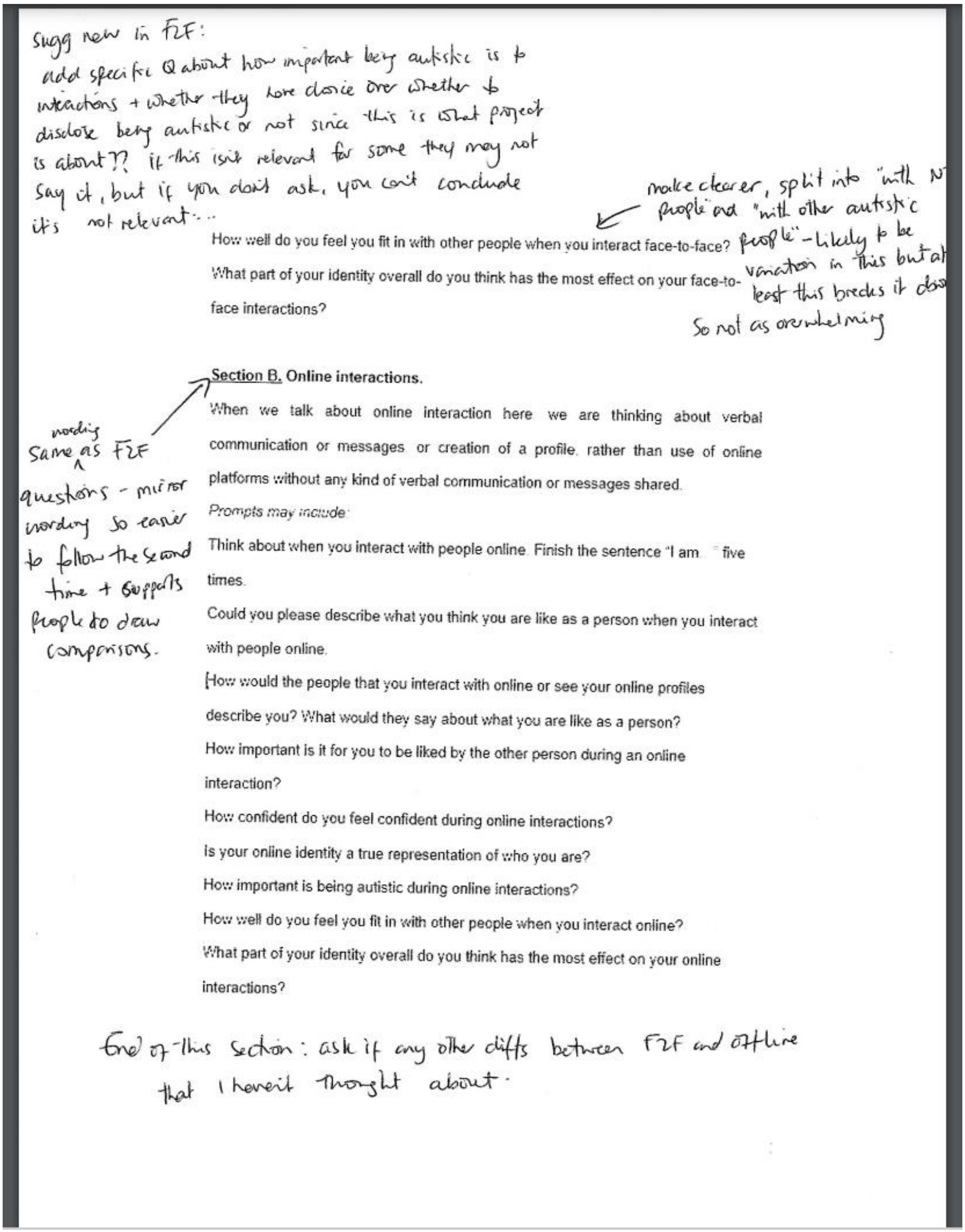
How confident do you feel confident during face-to-face interactions?

Is your in-person identity a true representation of who you are? → good Q but wording unclear: suggest 'is the person you are/present in F2F the same as the person you are/present online?

How important to you is being autistic during face-to-face interactions?

Sugg new in this section:
- which part of your identity is most important to you?
- gives p's a chance to tell what feels important to them, may be diff to what others see as important eg how they don't always feel able to show/communicate bits of them that feel important

sugg. new: ask whether there are parts of their identity that p's feel able to choose whether to show or not (likely to be diff online vs offline) - more opportunity to choose online? more control over what they share online? i, whats visible/invisible
( they do feel able to choose - which do they



Sugg new in F2F:
add specific Q about how important being autistic is to interactions + whether they have choice over whether to disclose being autistic or not since this is what project is about?? if this isn't relevant for some they may not say it, but if you don't ask, you can't conclude it's not relevant...

make clearer, split into "with N people" and "with other autistic people" - likely to be variation in this but at least this breaks it do So not as overwhelming

How well do you feel you fit in with other people when you interact face-to-face?

What part of your identity overall do you think has the most effect on your face-to-face interactions?

**Section B. Online interactions.**

same wording as F2F questions - mirror wording so easier to follow the second time + supports people to draw comparisons.

When we talk about online interaction here we are thinking about verbal communication or messages or creation of a profile, rather than use of online platforms without any kind of verbal communication or messages shared.

*Prompts may include:*

Think about when you interact with people online. Finish the sentence "I am…" five times.

Could you please describe what you think you are like as a person when you interact with people online.

How would the people that you interact with online or see your online profiles describe you? What would they say about what you are like as a person?

How important is it for you to be liked by the other person during an online interaction?

How confident do you feel confident during online interactions?

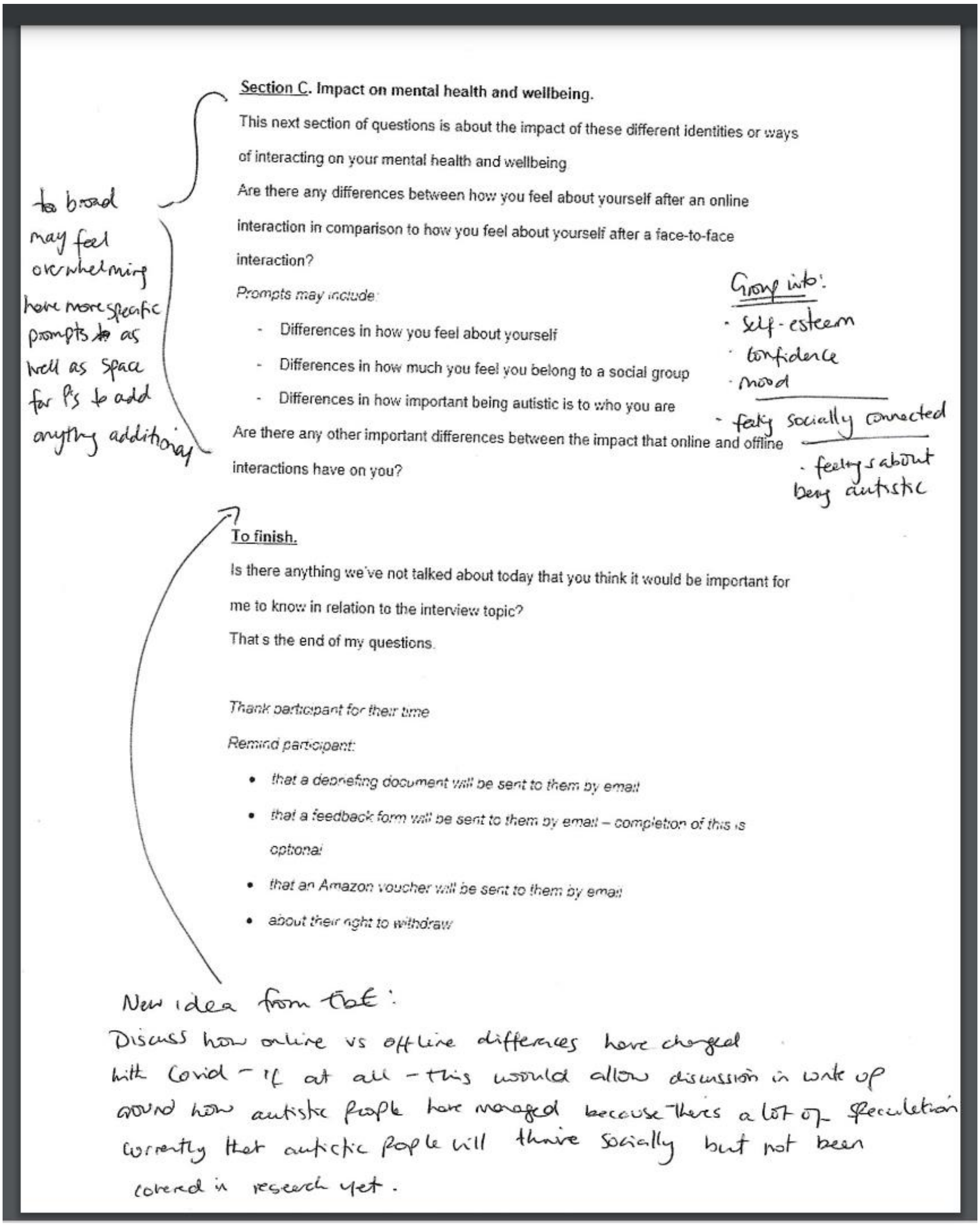
Is your online identity a true representation of who you are?

How important is being autistic during online interactions?

How well do you feel you fit in with other people when you interact online?

What part of your identity overall do you think has the most effect on your online interactions?

End of this section: ask if any other diffs between F2F and online that I haven't thought about.



**Section C. Impact on mental health and wellbeing.**

This next section of questions is about the impact of these different identities or ways of interacting on your mental health and wellbeing

Are there any differences between how you feel about yourself after an online interaction in comparison to how you feel about yourself after a face-to-face interaction?

*Prompts may include:*

- Differences in how you feel about yourself
- Differences in how much you feel you belong to a social group
- Differences in how important being autistic is to who you are

Are there any other important differences between the impact that online and offline interactions have on you?

to broad
may feel
overwhelming
have more specific
prompts ~~to~~ as
well as space
for P's to add
anything additional

Group into:
- self-esteem
- confidence
- mood
- feeling socially connected
- feelings about being autistic

**To finish.**

Is there anything we've not talked about today that you think it would be important for me to know in relation to the interview topic?

That's the end of my questions.

*Thank participant for their time*

*Remind participant:*

- *that a debriefing document will be sent to them by email*
- *that a feedback form will be sent to them by email – completion of this is optional*
- *that an Amazon voucher will be sent to them by email*
- *about their right to withdraw*

New idea from EbE:
Discuss how online vs offline differences have changed with Covid – if at all – this would allow discussion in wake of around how autistic people have managed because there's a lot of speculation currently that autistic people will thrive socially but not been covered in research yet.

Final interview schedule (after pilot study feedback and subsequent discussion with Expert by Experience):

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# Interview Questions

*Provide introduction to interviewer*

*Thank participant for opting to take part*

*Confirm participant is in a safe, quiet, private place*

*Provide background to/overview of the study*

*Note impact of Covid-19 pandemic on interactions*

*If telephone/video, confirm participant is happy to start recording*

*Remind about breaks, stopping the interview, anonymity, etc.*

*Any questions?*

*Check consent*

Section A. **What is your understanding of an 'identity'?** This isn't a test, we just want to find out what identity means to you.

What does the word identity mean to you?

What do you think of when you hear the word identity?

*Provide a definition of 'identity'.* We'll be looking at both of those today.

**Section B. Face to face interactions**.

*Prompts may include:*

In face-to-face interactions, what part of your identity do you think people first notice about you?

Could you describe what you think you are like as a person when you interact with people face-to-face.

v2 04.04.2021

[redacted]

How would the people that you interact with face-to-face describe you? What would they say about what you are like as a person?

Which part of your identity is most important to you during face-to-face interactions?

What part of your identity are you most comfortable sharing with other people during a face-to-face interaction?

What part of your identity are you least comfortable sharing with other people during a face-to-face interaction?

What part of your identity are you most proud of during a face-to-face interaction?

During a face-to-face interaction, how important is it for you to be liked by the other person?

How confident do you feel confident during face-to-face interactions?

What parts of identity do you choose for yourself during a face-to-face interaction?

Are there any parts of your identity are determined for you by other people or by society during a face-to-face interaction?

Is the person you are during face-to-face interactions a true representation of who you are?

How comfortable are you with disclosing your autism diagnosis during face-to-face interactions?

How important to you is being autistic during face-to-face interactions?

Are the people you interact with face-to-face mostly autistic, mostly neurotypical, or a mixture?

How much do you feel you fit in with people who are autistic during face-to-face interactions?

How much do you feel you fit in with people who are not autistic during face-to-face interactions?

What part of your identity overall do you think has the most effect on your face-to-face interactions?

**Section C. Online interactions.**

When we talk about online interaction here, we are thinking about verbal communication or messages, or creation of a profile, rather than use of online platforms without any kind of verbal communication or messages shared.

*Prompts may include:*

What part of your identity do you think people first notice about you during online interactions?

Could you please describe what you think you are like as a person when you interact with people online.

How would the people that you interact with online or see your online profiles describe you? What would they say about what you are like as a person?

Which part of your identity is most important to you during online interactions?

What part of your identity are you most comfortable sharing with other people when you interact online?

What part of your identity are you least comfortable sharing with other people when you interact online?

What part of your identity are you most proud of when you interact online?

How important is it for you to be liked by the other person during an online interaction?

How confident do you feel confident during online interactions?

What parts of your identity do you choose for yourself when you're online?

Are there any parts of your identity that are determined for you by other people or by society when you're online?

Is the person you are during online interactions a true representation of who you are?

How comfortable are you with disclosing your autism diagnosis during online interactions?

How important or relevant to you is being autistic during online interactions?

Are the people you interact with online mostly autistic, mostly neurotypical, or a mixture?

How much do you feel you fit in with people who are autistic during online interactions?

How much do you feel you fit in with people who are not autistic during online interactions?

What part of your identity overall do you think has the most effect on your online interactions?

Overall, do you think there are key differences in how you interact with people in online vs offline interactions?

Are there any other important differences in how you experience interacting online and offline?

Are there any differences in the opportunities available to you in online and offline interactions?

**Section D. Impact on mental health and wellbeing.**

This next section of questions is about the impact of these different identities or ways of interacting on your mental health and wellbeing.

Are there any differences between how you feel about yourself after an online interaction in comparison to how you feel about yourself after a face-to-face interaction?

*Prompts may include:*

**Section D-1.**

- Differences in how you feel about yourself
- Differences in your confidence
- Differences in your mood
- Differences in how comfortable you feel about the interaction

**Section D-2.**

- Differences in how happy you are with your friendships/relationships
- Differences in how supported you feel by other people
- Differences in how much you feel you belong to a social group
- Differences in how well-understood by others you feel

**Section D-3.**

- Differences in how you feel about being autistic
- Differences in how important being autistic is to who you are as a person
- Differences in how relevant being autistic is to your relationships

Are there any other important differences between the impact that online and offline interactions have on you?

**Section E. COVID-19**

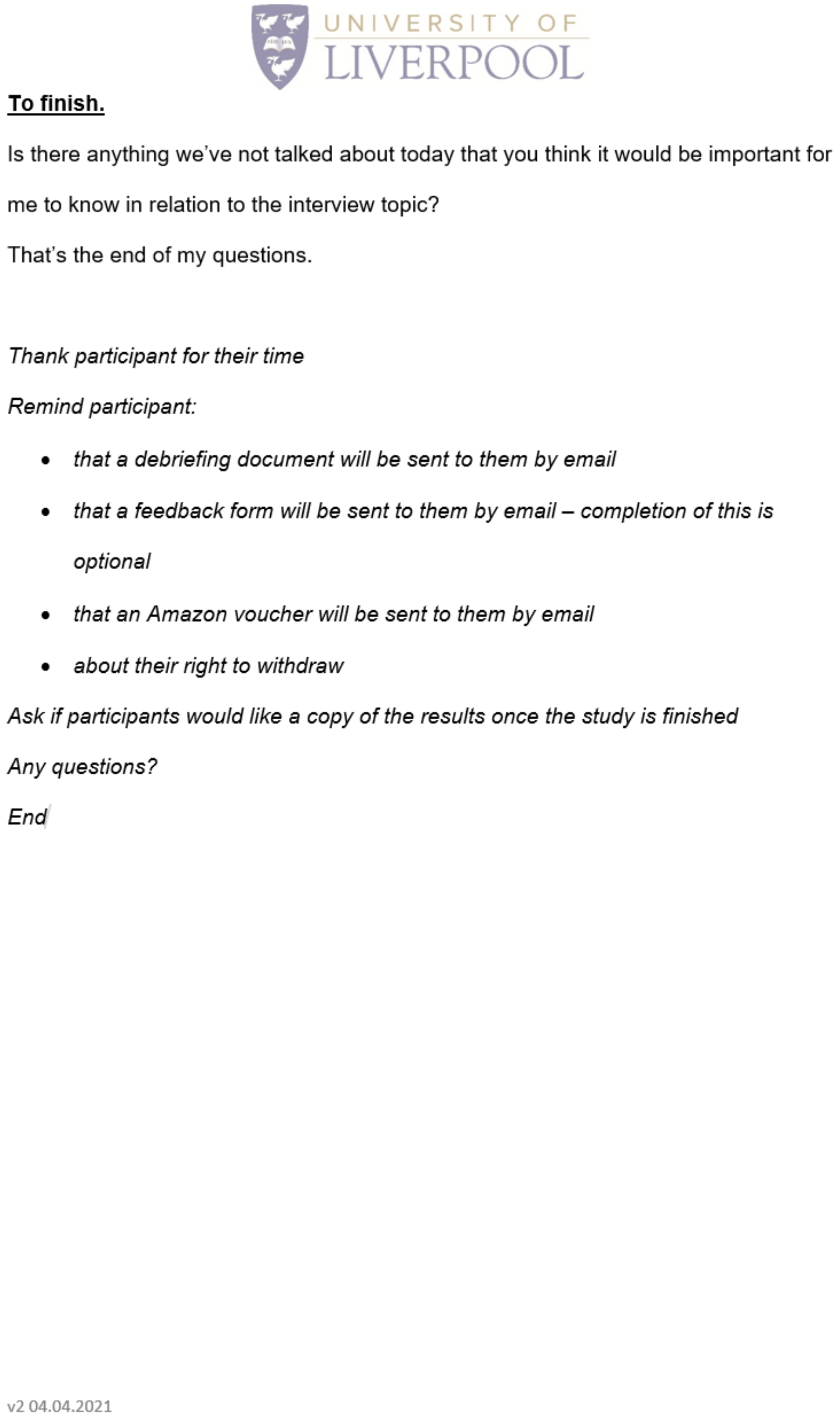
The final section of the interview is about how interacting online and offline has changed since the Covid-19 lockdown measures were introduced.

*Prompts may include:*

Do you feel any different about interacting online since the COVID-19 lockdown measures were introduced?

Are there any differences in how you feel about interacting with people in general since the lockdown measures were introduced?

How do you feel about returning to increased face-to-face interactions in the future, when lockdown measures are lifted?



**To finish.**

Is there anything we've not talked about today that you think it would be important for me to know in relation to the interview topic?

That's the end of my questions.

*Thank participant for their time*

*Remind participant:*

- *that a debriefing document will be sent to them by email*
- *that a feedback form will be sent to them by email – completion of this is optional*
- *that an Amazon voucher will be sent to them by email*
- *about their right to withdraw*

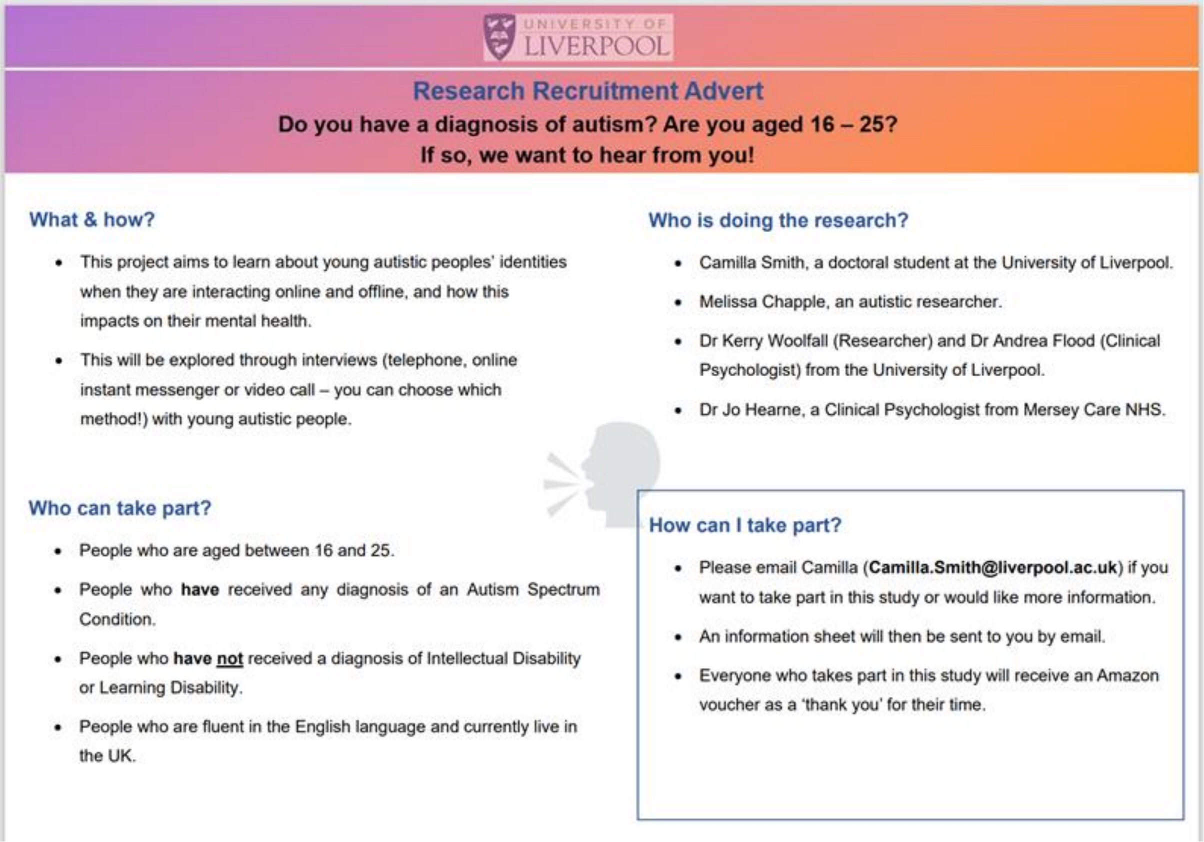
*Ask if participants would like a copy of the results once the study is finished*

*Any questions?*

*End*

v2 04.04.2021

## Appendix H: Recruitment Advert



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### Research Recruitment Advert

**Do you have a diagnosis of autism? Are you aged 16 – 25?**

**If so, we want to hear from you!**

**What & how?**

- This project aims to learn about young autistic peoples' identities when they are interacting online and offline, and how this impacts on their mental health.
- This will be explored through interviews (telephone, online instant messenger or video call – you can choose which method!) with young autistic people.

**Who is doing the research?**

- Camilla Smith, a doctoral student at the University of Liverpool.
- Melissa Chapple, an autistic researcher.
- Dr Kerry Woolfall (Researcher) and Dr Andrea Flood (Clinical Psychologist) from the University of Liverpool.
- Dr Jo Hearne, a Clinical Psychologist from Mersey Care NHS.

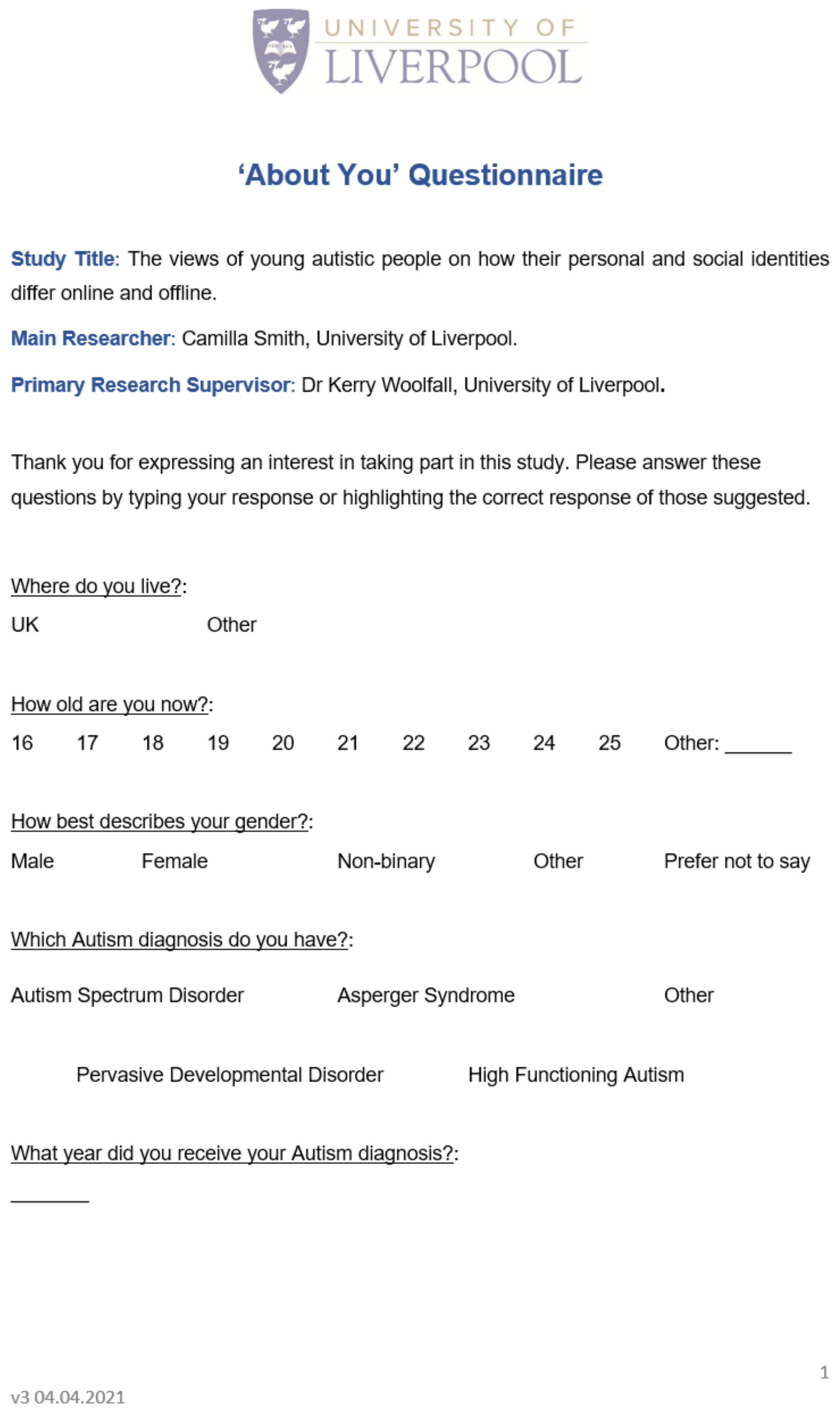
**Who can take part?**

- People who are aged between 16 and 25.
- People who **have** received any diagnosis of an Autism Spectrum Condition.
- People who **have** **not** received a diagnosis of Intellectual Disability or Learning Disability.
- People who are fluent in the English language and currently live in the UK.

**How can I take part?**

- Please email Camilla (**Camilla.Smith@liverpool.ac.uk**) if you want to take part in this study or would like more information.
- An information sheet will then be sent to you by email.
- Everyone who takes part in this study will receive an Amazon voucher as a 'thank you' for their time.

# Appendix I: Eligibility Screening Questionnaire



## ‘About You’ Questionnaire

**Study Title:** The views of young autistic people on how their personal and social identities differ online and offline.

**Main Researcher:** Camilla Smith, University of Liverpool.

**Primary Research Supervisor:** Dr Kerry Woolfall, University of Liverpool.

Thank you for expressing an interest in taking part in this study. Please answer these questions by typing your response or highlighting the correct response of those suggested.

Where do you live?:

UK Other

How old are you now?:

16 17 18 19 20 21 22 23 24 25 Other: ______

How best describes your gender?:

Male Female Non-binary Other Prefer not to say

Which Autism diagnosis do you have?:

Autism Spectrum Disorder Asperger Syndrome Other

Pervasive Developmental Disorder High Functioning Autism

What year did you receive your Autism diagnosis?:

_______

v3 04.04.2021

Do you have a diagnosis of Intellectual Disability or Learning Disability (*this does not include specific learning difficulties like dyslexia, dyscalculia, ADHD etc.*)?:

Yes No

Which social media platforms do you use?:

Facebook Instagram Twitter Snapchat
Skype YouTube Pinterest LinkedIn
Facebook Messenger Reddit Tumblr WeChat TikTok
Other: ________

How many hours per week (approximately) do you spend interacting with others using social media?:

0-10 10-20 20-50 50-100 100-200

Do you play online games that involve interacting with others?:

Yes No

If you answered 'yes' to the above question, how many hours per week (approximately) do you spend gaming online with others?

0-10 10-20 20-50 50-100 100-200

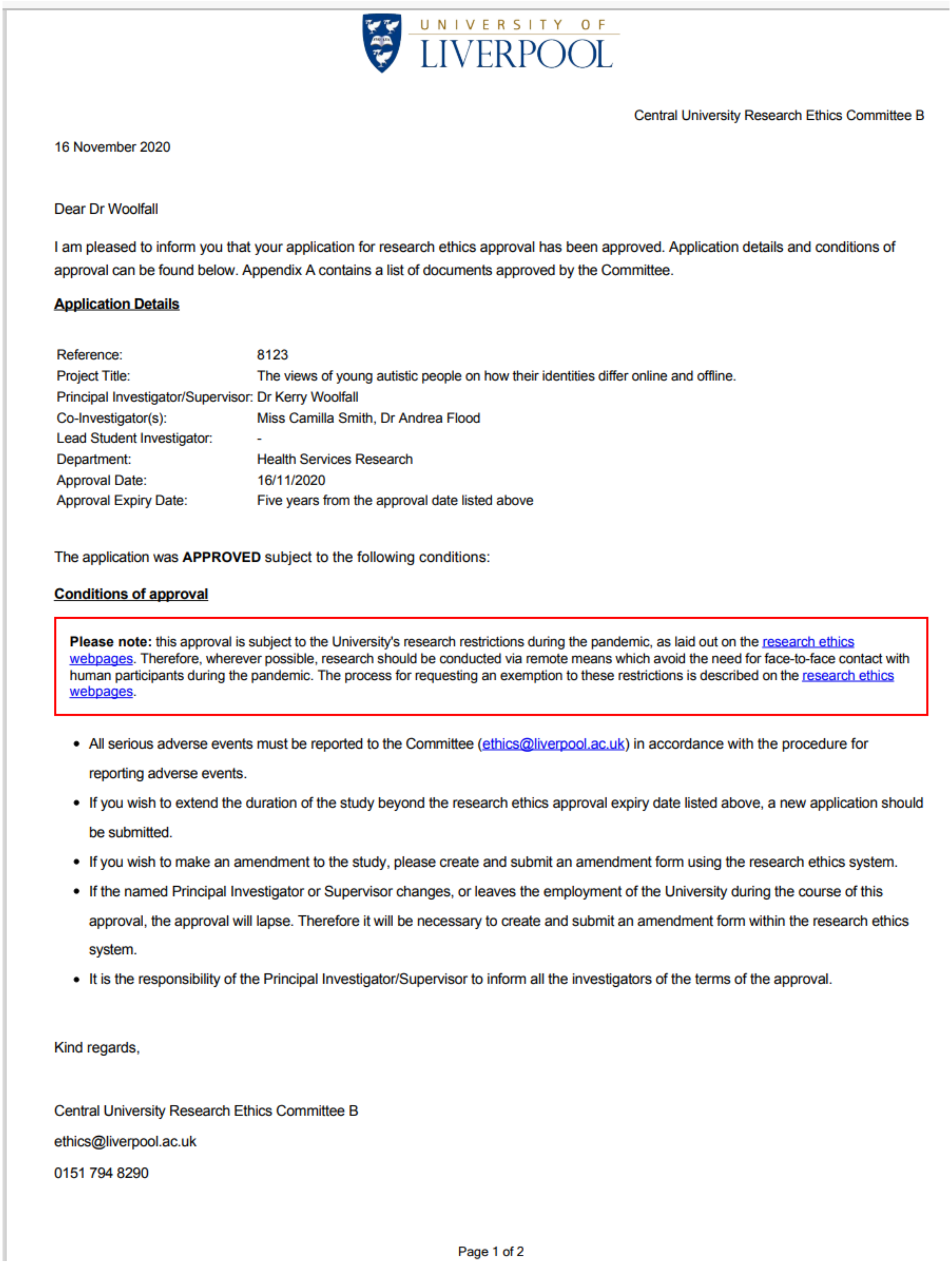
Approximately how many people do you have that you consider to be friends that are *only online* i.e. never met them face-to-face?

______

2955

2956

# Appendix J: Letters of Ethical Approval



Central University Research Ethics Committee B

16 November 2020

Dear Dr Woolfall

I am pleased to inform you that your application for research ethics approval has been approved. Application details and conditions of approval can be found below. Appendix A contains a list of documents approved by the Committee.

**Application Details**

| | |
|---|---|
| Reference: | 8123 |
| Project Title: | The views of young autistic people on how their identities differ online and offline. |
| Principal Investigator/Supervisor: | Dr Kerry Woolfall |
| Co-Investigator(s): | Miss Camilla Smith, Dr Andrea Flood |
| Lead Student Investigator: | - |
| Department: | Health Services Research |
| Approval Date: | 16/11/2020 |
| Approval Expiry Date: | Five years from the approval date listed above |

The application was **APPROVED** subject to the following conditions:

**Conditions of approval**

**Please note:** this approval is subject to the University's research restrictions during the pandemic, as laid out on the research ethics webpages. Therefore, wherever possible, research should be conducted via remote means which avoid the need for face-to-face contact with human participants during the pandemic. The process for requesting an exemption to these restrictions is described on the research ethics webpages.

- All serious adverse events must be reported to the Committee (ethics@liverpool.ac.uk) in accordance with the procedure for reporting adverse events.
- If you wish to extend the duration of the study beyond the research ethics approval expiry date listed above, a new application should be submitted.
- If you wish to make an amendment to the study, please create and submit an amendment form using the research ethics system.
- If the named Principal Investigator or Supervisor changes, or leaves the employment of the University during the course of this approval, the approval will lapse. Therefore it will be necessary to create and submit an amendment form within the research ethics system.
- It is the responsibility of the Principal Investigator/Supervisor to inform all the investigators of the terms of the approval.

Kind regards,

Central University Research Ethics Committee B

ethics@liverpool.ac.uk

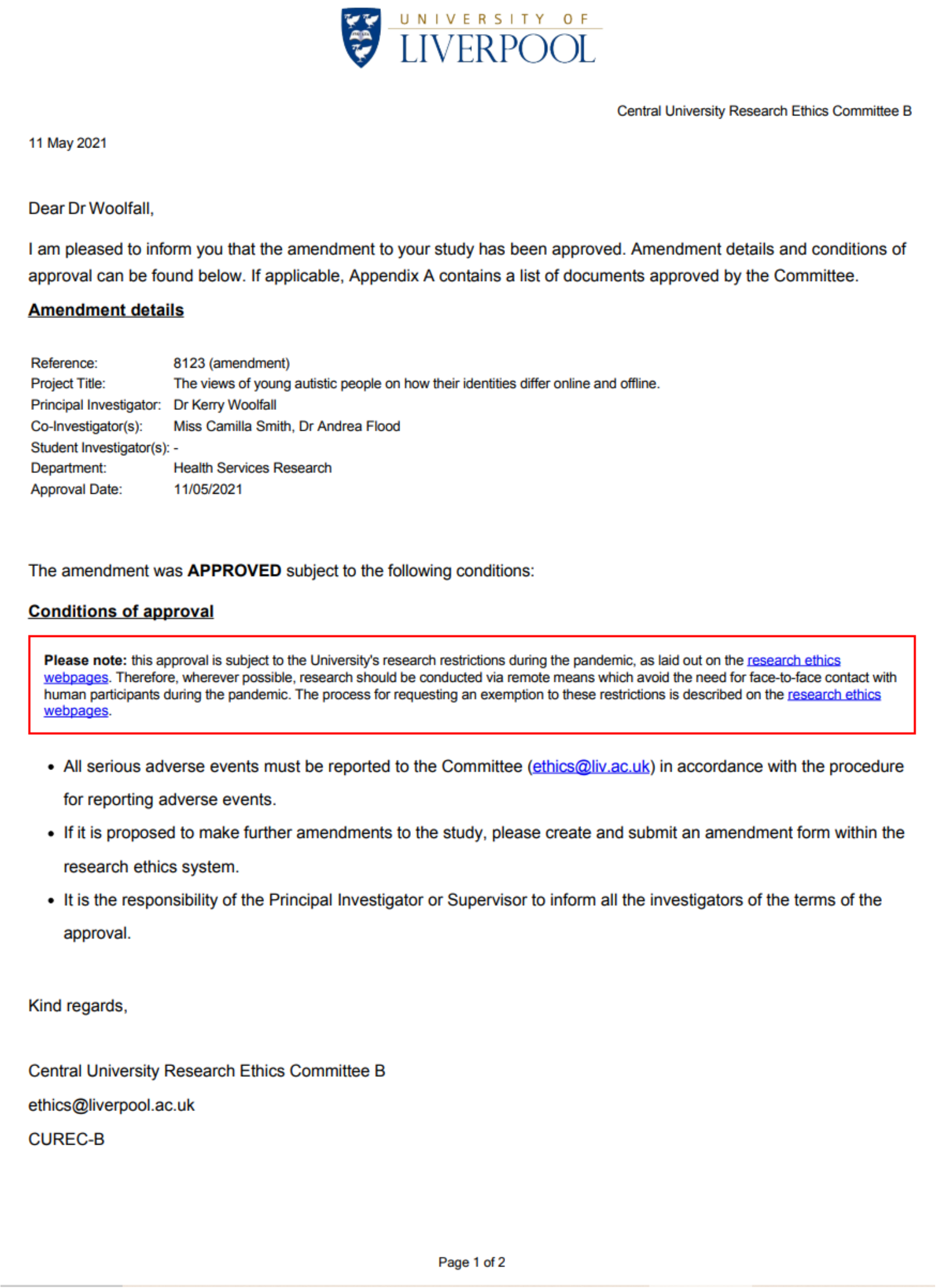
0151 794 8290

**Appendix - Approved Documents**

(Relevant only to amendments involving changes to the study documentation)

The final document set reviewed and approved by the committee is listed below:

| Document Type | File Name | Date | Version |
|---|---|---|---|
| Evidence Of Peer Review | Camilla Smith Proposal RRC Approval letter 24.08.2020 | 24/08/2020 | 1 |
| Interview Schedule | Demographic Info Qs-Eligibility Screener | 22/09/2020 | 1 |
| Interview Schedule | Interview Schedule 23.10 | 23/10/2020 | 1 |
| Advertisement | Recruitment Advert | 30/10/2020 | 2 |
| Debriefing Material | Debriefing Guidance v2 | 30/10/2020 | 2 |
| Research Tools | Distress Protocol v2 | 30/10/2020 | 2 |
| Participant Information Sheet | Participant Information Sheet Full v2 | 06/11/2020 | 2 |
| Participant Information Sheet | Participant Information Sheet Short Version v2 | 06/11/2020 | 2 |
| Participant Consent Form | Consent Form Full v2 | 06/11/2020 | 2 |
| Participant Consent Form | Consent Form Short Version v2 | 06/11/2020 | 2 |
| Debriefing Material | Debriefing Document v1 | 06/11/2020 | 1 |
| Study Proposal/Protocol | Research Proposal v4 06.11.2020 - ETHICS | 06/11/2020 | 4 |
| Research Tools | Applicant Response Document 09.11.2020 | 09/11/2020 | 1 |



UNIVERSITY OF LIVERPOOL

Central University Research Ethics Committee B

11 May 2021

Dear Dr Woolfall,

I am pleased to inform you that the amendment to your study has been approved. Amendment details and conditions of approval can be found below. If applicable, Appendix A contains a list of documents approved by the Committee.

**Amendment details**

| | |
|---|---|
| Reference: | 8123 (amendment) |
| Project Title: | The views of young autistic people on how their identities differ online and offline. |
| Principal Investigator: | Dr Kerry Woolfall |
| Co-Investigator(s): | Miss Camilla Smith, Dr Andrea Flood |
| Student Investigator(s): | - |
| Department: | Health Services Research |
| Approval Date: | 11/05/2021 |

The amendment was **APPROVED** subject to the following conditions:

**Conditions of approval**

**Please note:** this approval is subject to the University's research restrictions during the pandemic, as laid out on the research ethics webpages. Therefore, wherever possible, research should be conducted via remote means which avoid the need for face-to-face contact with human participants during the pandemic. The process for requesting an exemption to these restrictions is described on the research ethics webpages.

- All serious adverse events must be reported to the Committee (ethics@liv.ac.uk) in accordance with the procedure for reporting adverse events.
- If it is proposed to make further amendments to the study, please create and submit an amendment form within the research ethics system.
- It is the responsibility of the Principal Investigator or Supervisor to inform all the investigators of the terms of the approval.

Kind regards,

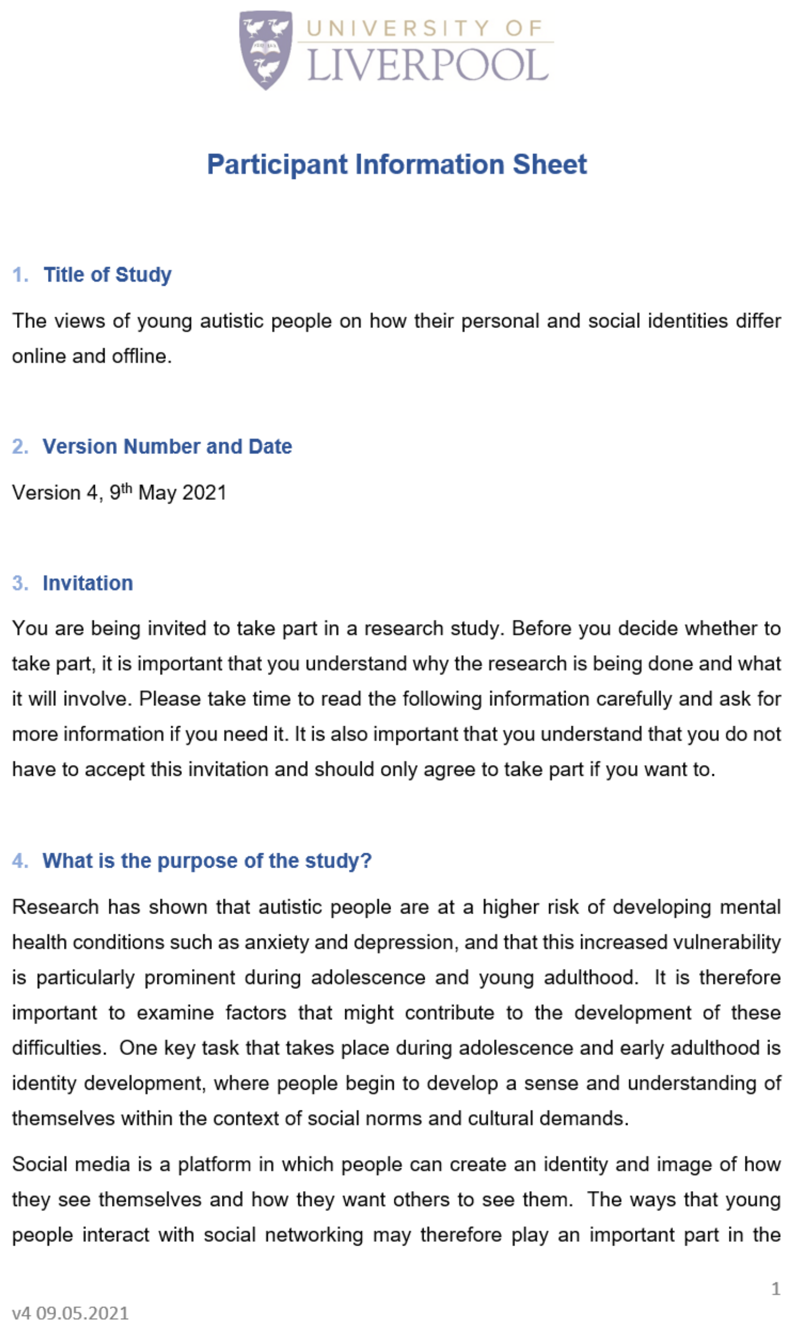
Central University Research Ethics Committee B
ethics@liverpool.ac.uk
CUREC-B

**Appendix - Approved documents**

If applicable, the final document set reviewed and approved by the committee is listed below:

| Document Type | File Name | Date | Version |
|---|---|---|---|
| Default | Consent Form Full v3 | 29/04/2021 | 3 |
| Default | Recruitment Advert v3 | 29/04/2021 | 3 |
| Default | Consent Form Short Version v3 | 29/04/2021 | 3 |
| Default | Participant Information Sheet Short v4 | 09/05/2021 | 4 |
| Default | Participant Information Sheet Full v4 | 09/05/2021 | 4 |

# Appendix K: Participant Information Sheet (Full)



## Participant Information Sheet

### 1. Title of Study

The views of young autistic people on how their personal and social identities differ online and offline.

### 2. Version Number and Date

Version 4, 9th May 2021

### 3. Invitation

You are being invited to take part in a research study. Before you decide whether to take part, it is important that you understand why the research is being done and what it will involve. Please take time to read the following information carefully and ask for more information if you need it. It is also important that you understand that you do not have to accept this invitation and should only agree to take part if you want to.

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

Research has shown that autistic people are at a higher risk of developing mental health conditions such as anxiety and depression, and that this increased vulnerability is particularly prominent during adolescence and young adulthood. It is therefore important to examine factors that might contribute to the development of these difficulties. One key task that takes place during adolescence and early adulthood is identity development, where people begin to develop a sense and understanding of themselves within the context of social norms and cultural demands.

Social media is a platform in which people can create an identity and image of how they see themselves and how they want others to see them. The ways that young people interact with social networking may therefore play an important part in the formation of identity. However, little is known about the impact of social networking on identity given that the online world is a relatively new environment.

The aim of this research study is to understand the views of young autistic people on how their identities differ when they are online (social networking) and offline (face to face), and how this impacts on their mental health.

### 5. Who can take part in the research?

We are looking for:

- People who are aged between 16 and 25.
- People who have received a diagnosis of an Autism Spectrum Condition (including Autism Spectrum Disorder, Asperger Syndrome, High Functioning Autism, and Pervasive Developmental Disorder).
- People who have not received a diagnosis of Intellectual Disability or Learning Disability.
- People who are fluent in the English language.

### 6. Do I have to take part?

No – taking part is completely optional. You can change your mind about being part of the study at any time until the point that your data is anonymised (this will be at least 7 days after your interview), by contacting the study team. You do not need to give a reason if you do decide to withdraw. Deciding not to take part or withdrawing from the study will not have any negative consequences for you. You are welcome to discuss the study with friends and family, before or after taking part, if you so wish.

### 7. What will happen if I take part?

If you tell us that you do want to take part, we will contact you by email or phone (whichever details you have provided) to check that you are eligible to participate in the study.

If you are eligible, we will ask you to complete an Informed Consent Form to show that you understand your rights in relation to the research, and that you are happy to participate. We will also ask whether you would like the interview to take place via telephone, online live-chat or videocall. We will then arrange a time and date for the interview to take place.

Before the interview takes place, we will send you a copy of the questions that you will be asked during the interview. We ask that you find a quiet and private space to complete the interview. We expect the interviews will last around 1 hour.

During the interview, you will be asked some questions about your identity. There will be questions that ask you to think about when you are interacting with people online (using social networking sites), and when you are interacting with people offline (face to face). You will also be asked about the impact of these online and offline identities on your mental health and wellbeing. Only answer the questions you want to answer – if there are some questions you do not want to answer, that's okay, the rest of the information you provide can still be included in the study. We can take a 15-minute break half way through the interview if you would like to. If your interview is by telephone or videocall, it will be recorded and transcribed (we will require your consent for this), so we ask that you complete the interview in a quiet area.

### 8. How will my data be used?

The University processes personal data as part of its research and teaching activities in accordance with the lawful basis of 'public task', and in accordance with the University's purpose of "advancing education, learning and research for the public benefit.

Under UK data protection legislation, the University acts as the Data Controller for personal data collected as part of the University's research. The Primary Research Supervisor acts as the Data Processor for this study, and any queries relating to the handling of your personal data can be sent to Dr Kerry Woolfall: Woolfall@liverpool.ac.uk.

Further information on how your data will be used can be found in the table below.

| | |
|---|---|
| How will my data be collected? | If you agree to take part, you will be invited to take part in an interview. You will be asked to choose whether this is via telephone, online live-chat or videocall. If your interview is by telephone or videocall, it will be audio recorded, with your permission. |
| What measures are in place to protect the security and confidentiality of my data? | Once the interview is completed, your interview data will be transcribed (if completed by telephone or videocall) or extracted (if completed by online live-chat). It is at this point that your data will be anonymised, that is, any information that identifies you will be removed. Your anonymised transcript will be stored in a secure folder on a password-protected computer. Your consent form (which will have your name on it) will be stored separately. |
| How will my data be stored? | Your anonymised transcript will be stored in a secure folder on a password-protected computer. Your consent form (which will have your name on it) will be stored separately. |
| How long will my data be stored for? | If your interview is done by telephone or videocall, the audio file will be deleted as soon as it has been transcribed. Interview transcripts and consent forms will be stored |

| | |
|---|---|
| | (separately) for 10 years in line with Data Protection Law. |
| Will my data be anonymised? | Your data will be anonymised at the point that your data is transcribed (if by telephone or videocall) or extracted from the live-chat (if by online live-chat). |
| How will my data be used? | Your anonymised data will be used within a Doctorate in Clinical Psychology thesis and will be used to work towards publication within journals, and a summary of the research findings may be presented at conferences. The outcomes of the research will be made available to you once the research is finished. |
| Who will have access to my data? | Only the research team will have access to your data. |
| Will my data be archived for use in other research projects in the future? | There are no plans to re-use your data in future research projects |
| How will my data be destroyed? | If your interview is completed by telephone or videocall, the audio file will be deleted once the data has been transcribed. Your Interview transcript and Consent Form will be deleted after 10 years, in line with Data Protection Law. |

## 9. Expenses and / or payments

If you choose to take part, an Amazon voucher will be sent to you by email or by post (whichever you choose) to thank you for your time.

## 10. Are there any risks in taking part?

There are no significant risks associated with taking part in this study. However, if you do become distressed in any way, the interview can be stopped at any time. We would encourage you to discuss this with either the main researcher/interviewer (Camilla Smith) or the research supervisor. If you would like further support, you will be provided with a telephone number to speak with The Samaritans which is a free, confidential listening and counselling service available to people of all ages.

## 11. Are there any benefits of taking part?

By sharing your experiences with us, you will help us to improve our understanding of identity development and identity challenges for autistic people. We hope this will help us to learn ways of supporting autistic people who face identity challenges and will direct future research in this area.

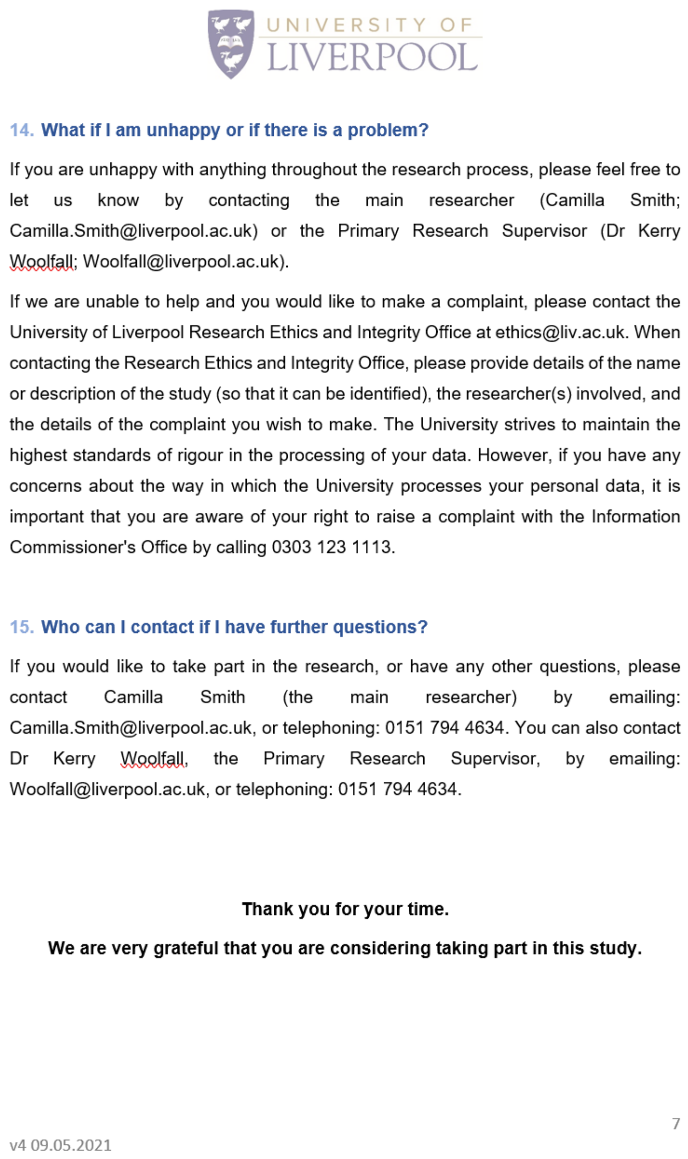
## 12. What will happen to the results of the study?

The results of the study will be written up to form part of a Doctorate in Clinical Psychology thesis, and will be sent to a scientific journal for publication. You will not be identifiable from any part of the write up of the study.

The outcomes of the research will be made available to you once the research is finished. We will ask how best to contact you if you would like to receive a copy of the research findings, or we can discuss them with you by telephone.

## 13. What will happen if I want to stop taking part?

You can change your mind about being part of the study until the point that your data is anonymised. This will be at least 7 days after your interview. If you do want to withdraw from the study, just email one of the research team. You do not need to give a reason if you do decide to withdraw. Deciding not to take part or withdrawing from the study will not have any negative consequences for you.



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### 14. What if I am unhappy or if there is a problem?

If you are unhappy with anything throughout the research process, please feel free to let us know by contacting the main researcher (Camilla Smith; Camilla.Smith@liverpool.ac.uk) or the Primary Research Supervisor (Dr Kerry Woolfall; Woolfall@liverpool.ac.uk).

If we are unable to help and you would like to make a complaint, please contact the University of Liverpool Research Ethics and Integrity Office at ethics@liv.ac.uk. When contacting the Research Ethics and Integrity Office, please provide details of the name or description of the study (so that it can be identified), the researcher(s) involved, and the details of the complaint you wish to make. The University strives to maintain the highest standards of rigour in the processing of your data. However, if you have any concerns about the way in which the University processes your personal data, it is important that you are aware of your right to raise a complaint with the Information Commissioner's Office by calling 0303 123 1113.

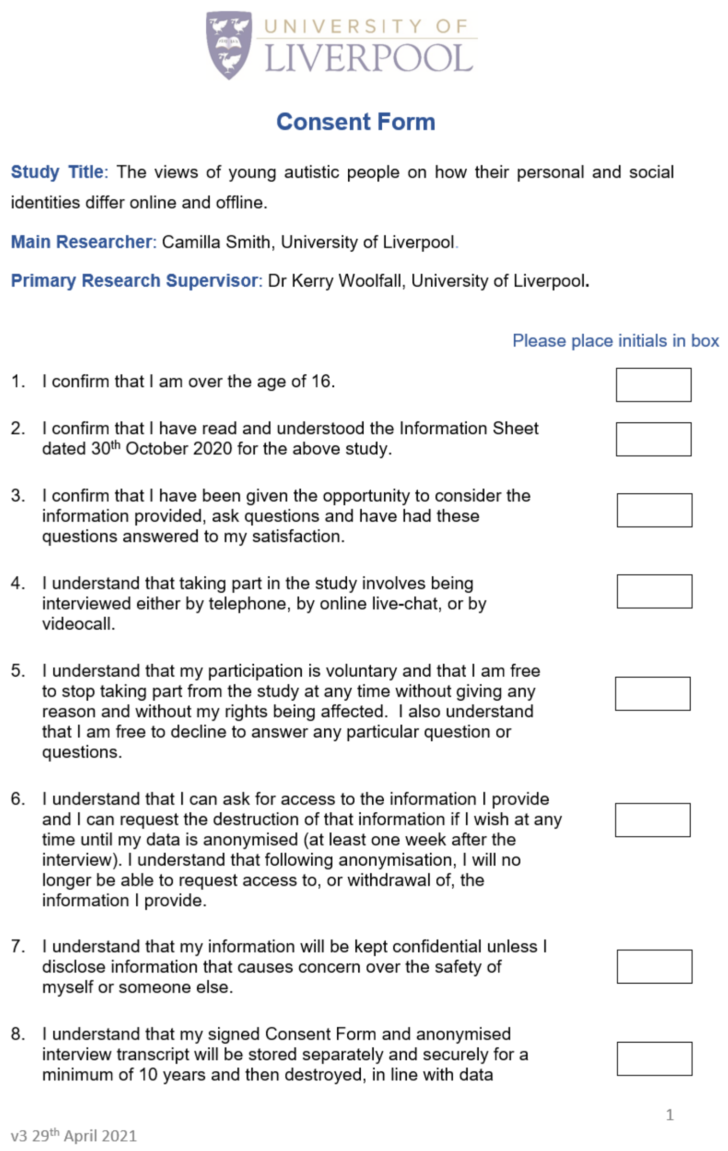
### 15. Who can I contact if I have further questions?

If you would like to take part in the research, or have any other questions, please contact Camilla Smith (the main researcher) by emailing: Camilla.Smith@liverpool.ac.uk, or telephoning: 0151 794 4634. You can also contact Dr Kerry Woolfall, the Primary Research Supervisor, by emailing: Woolfall@liverpool.ac.uk, or telephoning: 0151 794 4634.

**Thank you for your time.**

**We are very grateful that you are considering taking part in this study.**

# Appendix L: Consent Form (Full)



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## Consent Form

**Study Title**: The views of young autistic people on how their personal and social identities differ online and offline.

**Main Researcher**: Camilla Smith, University of Liverpool.

**Primary Research Supervisor**: Dr Kerry Woolfall, University of Liverpool.

Please place initials in box

1. I confirm that I am over the age of 16. ☐
2. I confirm that I have read and understood the Information Sheet dated 30th October 2020 for the above study. ☐
3. I confirm that I have been given the opportunity to consider the information provided, ask questions and have had these questions answered to my satisfaction. ☐
4. I understand that taking part in the study involves being interviewed either by telephone, by online live-chat, or by videocall. ☐
5. I understand that my participation is voluntary and that I am free to stop taking part from the study at any time without giving any reason and without my rights being affected. I also understand that I am free to decline to answer any particular question or questions. ☐
6. I understand that I can ask for access to the information I provide and I can request the destruction of that information if I wish at any time until my data is anonymised (at least one week after the interview). I understand that following anonymisation, I will no longer be able to request access to, or withdrawal of, the information I provide. ☐
7. I understand that my information will be kept confidential unless I disclose information that causes concern over the safety of myself or someone else. ☐
8. I understand that my signed Consent Form and anonymised interview transcript will be stored separately and securely for a minimum of 10 years and then destroyed, in line with data ☐

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v3 29th April 2021

protection requirements at the University of Liverpool. I understand that only the research team will have access to my data.

9. I agree to have debrief information sent to me by email after the interview is completed. ☐

10. I agree to take part in this study. ☐

11. I agree to have my interview audio-recorded (if I choose a telephone or videocall interview). ☐

**Name of person giving consent:**

**Date:**

**Signature:**

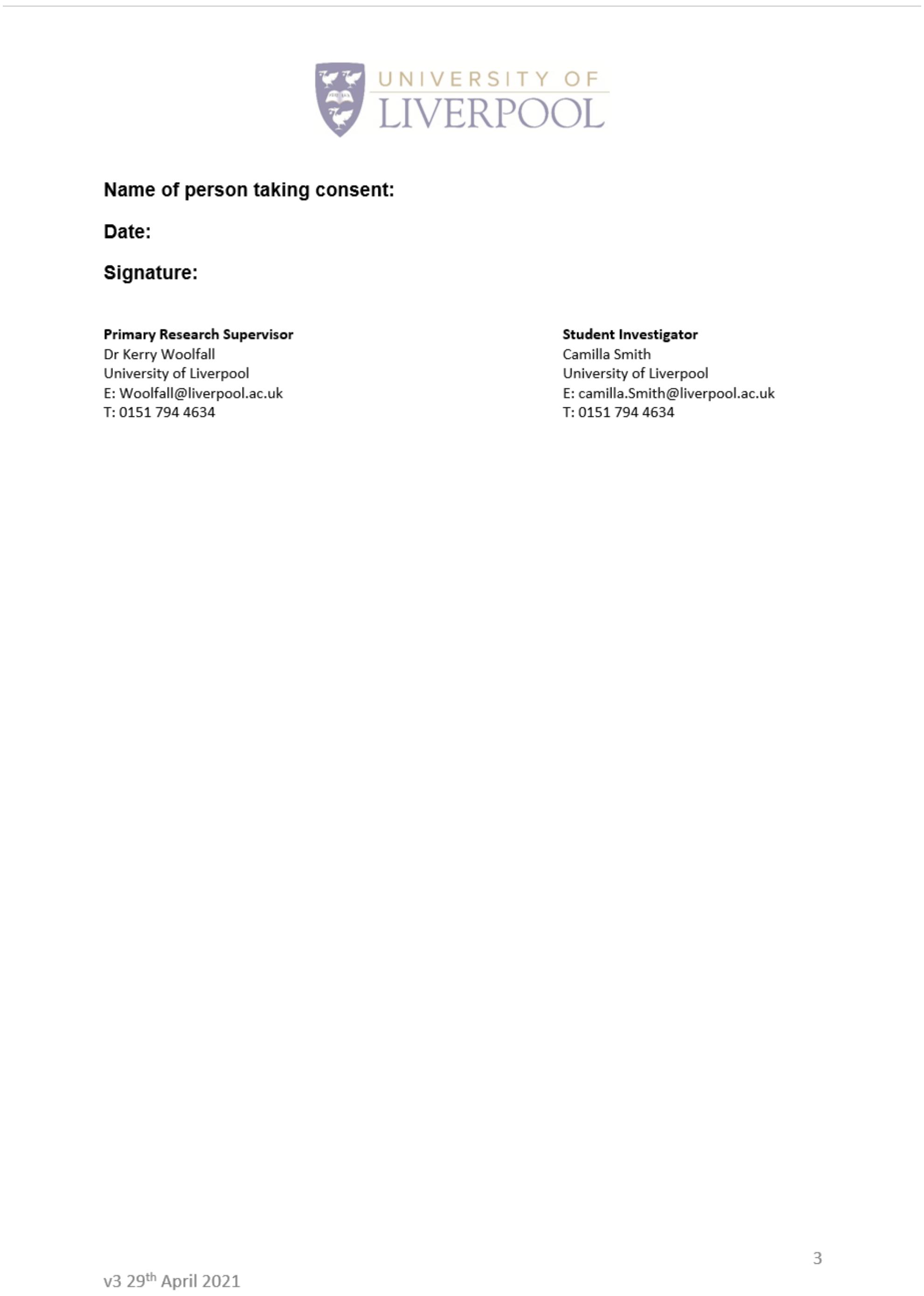
Please choose **one** of the following:

If you would like your interview to be done by **telephone**, please provide the **telephone number** you would like us to use: ___________________________

If you would like your interview to be done by **online instant messenger**, please provide the **email address/Skype ID** you would like us to use: ____________________________

If you would like your interview to be done by **online video call**, please provide the **email address/Skype ID** you would like us to use: ____________________________

When you have completed this form, please email it back to: **Camilla.Smith@liverpool.ac.uk**.



**Name of person taking consent:**

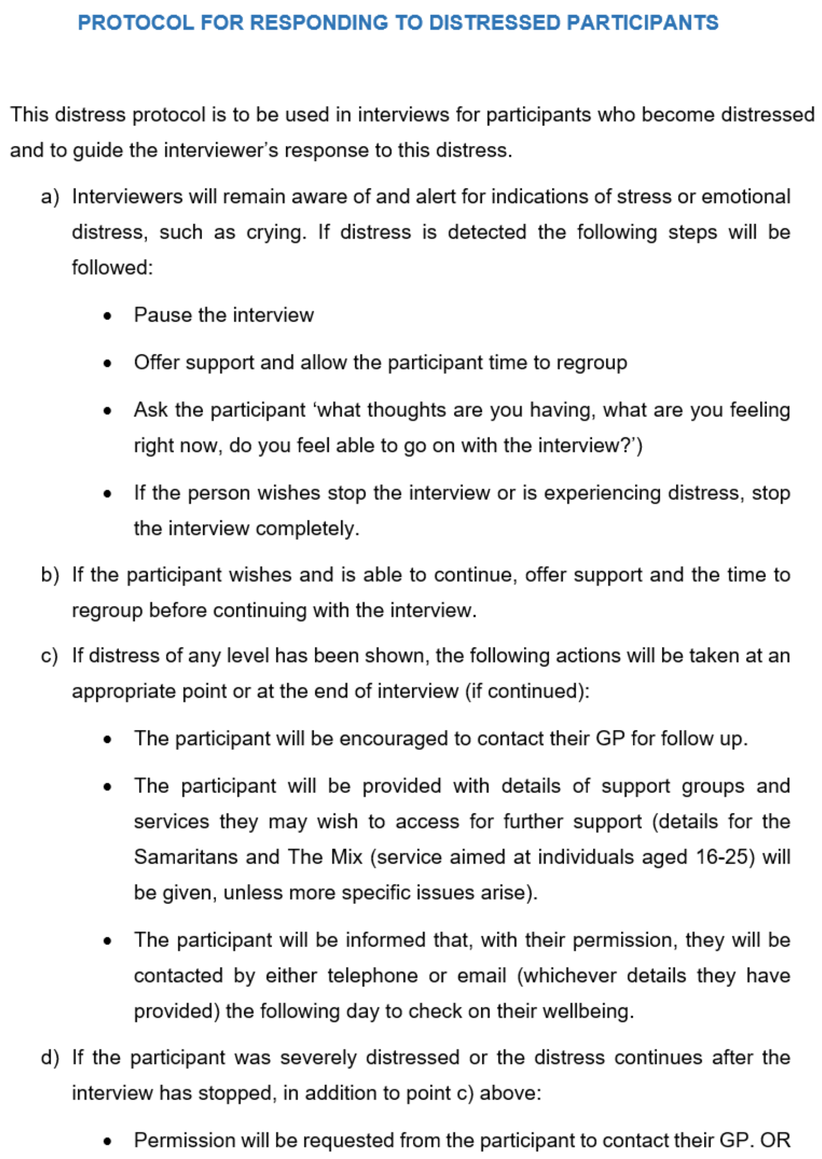
**Date:**

**Signature:**

**Primary Research Supervisor**
Dr Kerry Woolfall
University of Liverpool
E: Woolfall@liverpool.ac.uk
T: 0151 794 4634

**Student Investigator**
Camilla Smith
University of Liverpool
E: camilla.Smith@liverpool.ac.uk
T: 0151 794 4634

# Appendix M: Distress Protocol



## PROTOCOL FOR RESPONDING TO DISTRESSED PARTICIPANTS

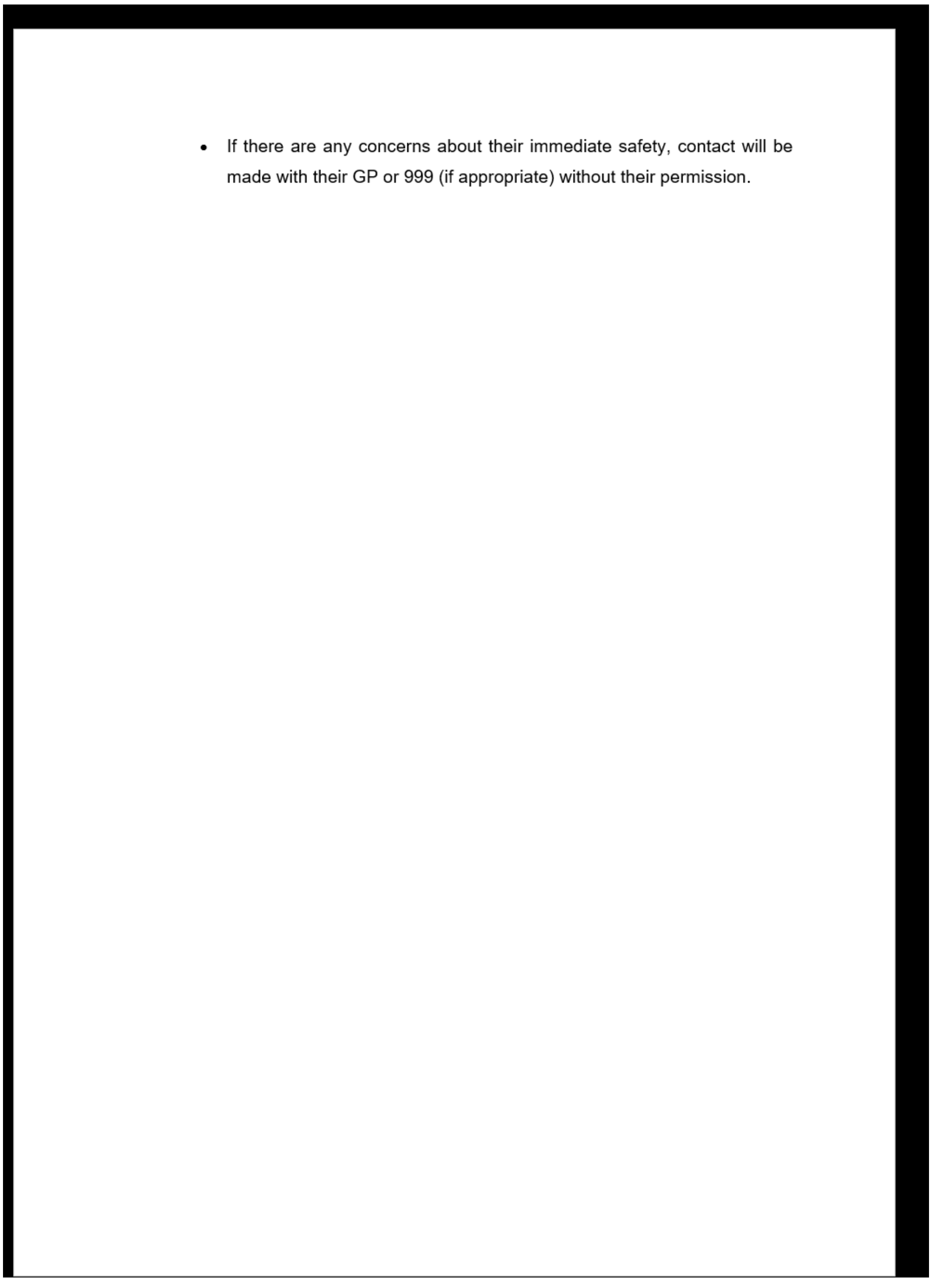
This distress protocol is to be used in interviews for participants who become distressed and to guide the interviewer's response to this distress.

a) Interviewers will remain aware of and alert for indications of stress or emotional distress, such as crying. If distress is detected the following steps will be followed:
    - Pause the interview
    - Offer support and allow the participant time to regroup
    - Ask the participant 'what thoughts are you having, what are you feeling right now, do you feel able to go on with the interview?')
    - If the person wishes stop the interview or is experiencing distress, stop the interview completely.

b) If the participant wishes and is able to continue, offer support and the time to regroup before continuing with the interview.

c) If distress of any level has been shown, the following actions will be taken at an appropriate point or at the end of interview (if continued):
    - The participant will be encouraged to contact their GP for follow up.
    - The participant will be provided with details of support groups and services they may wish to access for further support (details for the Samaritans and The Mix (service aimed at individuals aged 16-25) will be given, unless more specific issues arise).
    - The participant will be informed that, with their permission, they will be contacted by either telephone or email (whichever details they have provided) the following day to check on their wellbeing.

d) If the participant was severely distressed or the distress continues after the interview has stopped, in addition to point c) above:
    - Permission will be requested from the participant to contact their GP. OR



- If there are any concerns about their immediate safety, contact will be made with their GP or 999 (if appropriate) without their permission.

# Appendix N: Participant Information Sheet (Short)

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## Information Sheet – Short Version

### Title of Study

The views of young autistic people on how their personal and social identities differ online and offline.

### What is this study about?

You have been invited to take part in a research study about autism. In this study, we want to find out how autistic people's identities differ when they are interacting online (using social networking sites) and offline (face-to-face). We also want to find out how this impacts on autistic people's mental health and wellbeing.

### Why have I been invited to take part?

We are inviting people who:

- are aged between 16 and 25.
- **have** received a diagnosis of an Autism Spectrum Condition (including Autism Spectrum Disorder, Asperger Syndrome, High Functioning Autism, and Pervasive Developmental Disorder).
- **have not** received a diagnosis of Intellectual Disability or Learning Disability.
- are fluent in the English language.

## How will it help me?

The study will not help you personally, but we hope that you will enjoy taking part. We also hope that the results will improve our understanding of identity development for autistic people and help us to support young autistic adults who face identity challenges. If you choose to take part, an Amazon voucher will be sent to you by email or by post (whichever you choose) to thank you for your time.

## What information will I be asked to give?

You will be asked to complete a consent form before you take part in the interview. This form will ask if you agree to take part in the research project after reading this information sheet and the standardised information sheet provided. It will also ask you to give either your email address or your telephone number and postal address, so that we can communicate with you about the study.

If you agree to take part using the consent form, you will be asked to answer some questions about yourself. The questions will cover things like:

- Your age
- Your gender
- Information about how much you use social networking sites
- Information about your important relationships

This information will be kept separate from your name to protect your identity.

After you have completed the forms, you will be invited to take part in an interview.

You can choose whether the interview takes place by telephone, by online live-chat or by videocall. The interview will be one-to-one with yourself and the researcher. We will ask you about different parts of your identity. Interviews are informal, in that you are not being assessed, we simply want to find out about your views and experiences.

## Do I have to take part?

No – whether or not to take part in this study is completely up to you. It is ok if you do not want to take part. If you decide to take part and later decide you don't want to take part, you can change your mind and leave the study for up to 7 days after your interview (this is because, after 7 days we will remove any information that identifies you so that your information stays private). You do not explain why you chose to leave. Deciding not to take part will not have any negative consequences for you. We ask that you complete the interview alone in a quiet, private room, but you can speak to your friends and family about the study before or after the interview if you would like to.

## What will I have to do?

If you want to take part in this study, please complete the Consent Form and return it by email to the main researcher:

Camilla.Smith@liverpool.ac.uk.

You will then be contacted by email or by telephone (using the details you have provided on the Consent Form) to arrange a date and time for the interview that is convenient for you. We will send you the interview questions before the date of the interview. You can choose whether you do the interview by telephone or by online live-chat. You can ask any questions about the research by emailing the main researcher.

On the day of the interview, you will be asked again to confirm that you want to take part in the study. If your interview is by telephone or videocall, with your permission, the interview will be recorded. You will be offered a 10-minute break half-way through the interview.

## Will you tell anyone if I take part?

Researchers involved with this study will know you have taken part. If the ethics department want to review the study they might also see your information, but would not tell anybody else that you have taken part. We will not pass on information about you or use it in other research projects without your permission. However, if you tell us something that makes us worried about your safety or the safety of someone else then we will need to pass this information on. Your information from the interview will be stored separate from any information that could identify who you are. The consent forms you fill out will be stored in locked cabinets and kept separate from any identifying information.

## How will I find out the results of the study?

When the study has finished and the researchers have analysed the results, they will then write up an academic report on the findings which will be sent to a scientific journal for publication. We will also summarise the research in other, autism-friendly ways. You can ask the researcher to send you a copy of the final academic report, or an autism-friendly summary of the report.

## Who is organising this study?

This study is being run by researchers at the University of Liverpool:

- The lead researcher is Camilla Smith, a Doctoral Student at the University of Liverpool.
- Melissa Chapple, an Expert by Experience, is advising on the research project.
- The research is being supervised by Dr Kerry Woolfall and Dr Andrea Flood (the University of Liverpool) and Dr Jo Hearne (Mersey Care NHS).

Before any research goes ahead it has to be checked by a Research Ethics Committee. They make sure that the research is fair. Your project has been checked by the Research Ethics Committee at the University of Liverpool.

## What if I am not happy about something?

If you are unhappy with anything throughout the research process, please let us know by contacting one of the research team. You can find their contact details at the bottom of this page.

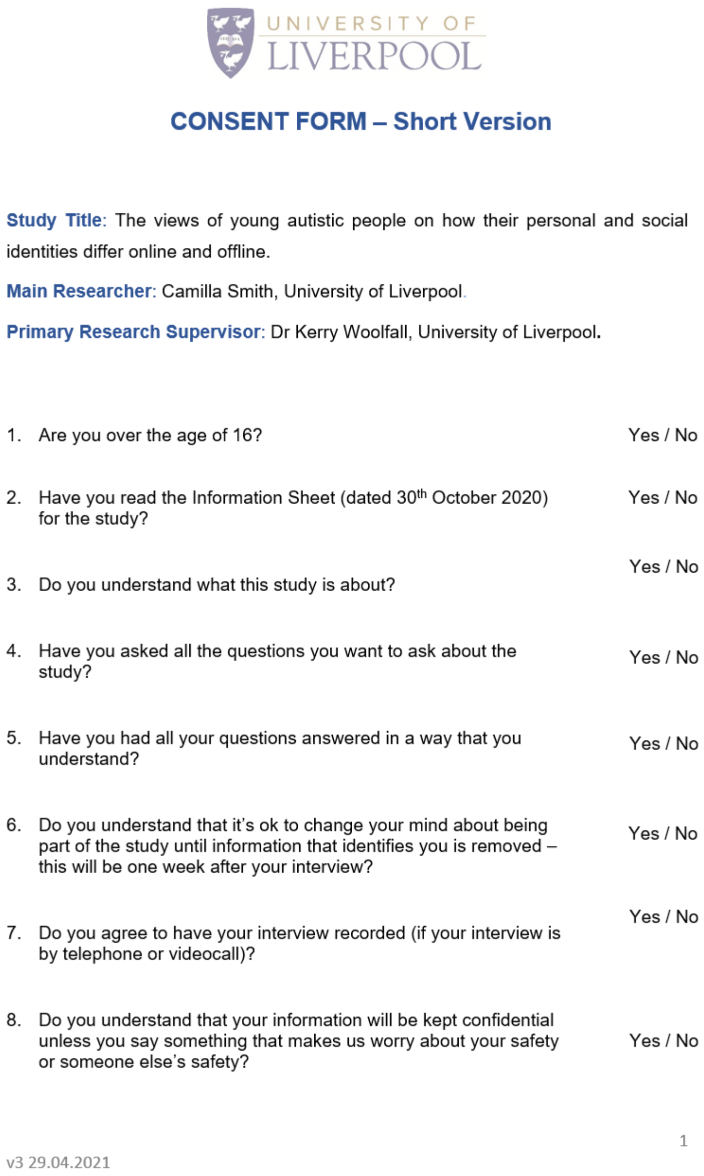
If we are unable to help and you would like to make a complaint, please contact the University of Liverpool Research Ethics and Integrity Office at ethics@liv.ac.uk. When contacting the Research Ethics and Integrity Office, please provide details of the name or description of the study (so that it can be identified), the researcher(s) involved, and the details of the complaint you wish to make.

## Can I talk to the researcher before taking part?

Yes, you can contact the following people with any questions you have:

- The lead researcher, Camilla Smith
    - By email: Camilla.Smith@liverpool.ac.uk
    - By telephone: 0151 794 4634
- The primary research supervisor, Dr Kerry Woolfall
    - By email: Woolfall@liverpool.ac.uk
    - By telephone: 0151 794 4634

# Appendix O: Consent Form (Short)



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## CONSENT FORM – Short Version

**Study Title**: The views of young autistic people on how their personal and social identities differ online and offline.

**Main Researcher**: Camilla Smith, University of Liverpool.

**Primary Research Supervisor**: Dr Kerry Woolfall, University of Liverpool.

| | |
|---|---|
| 1. Are you over the age of 16? | Yes / No |
| 2. Have you read the Information Sheet (dated 30th October 2020) for the study? | Yes / No |
| 3. Do you understand what this study is about? | Yes / No |
| 4. Have you asked all the questions you want to ask about the study? | Yes / No |
| 5. Have you had all your questions answered in a way that you understand? | Yes / No |
| 6. Do you understand that it's ok to change your mind about being part of the study until information that identifies you is removed – this will be one week after your interview? | Yes / No |
| 7. Do you agree to have your interview recorded (if your interview is by telephone or videocall)? | Yes / No |
| 8. Do you understand that your information will be kept confidential unless you say something that makes us worry about your safety or someone else's safety? | Yes / No |

v3 29.04.2021

9. Do you agree to have some information sent to you by email or by post after the interview is finished? Yes / No

10. Would you like to take part in this study? Yes / No

If any answers are “no” or you don’t want to take part, don’t sign your name!

If you **do** want to take part, please sign your name here: ___________

Please type the date here: __________

Please choose one of the following:

If you would like your interview to be done by **telephone**, please provide the **telephone number** you would like us to use: ___________________________

If you would like your interview to be done by **online live-chat** or **videocall**, please provide the **email address** you would like us to use:

____________________________

When you have completed this form, please email it back to: **Camilla.Smith@liverpool.ac.uk**.

The researcher needs to sign this form too.
Researcher’s name: ____________
The date: __________

**Primary Research Supervisor**
Dr Kerry Woolfall
University of Liverpool
E: Woolfall@liverpool.ac.uk
T: 0151 794 4634

**Student Researcher**
Camilla Smith
University of Liverpool
E: Camilla.Smith@liverpool.ac.uk
T: 0151 794 4634

# Appendix P: Debriefing Document

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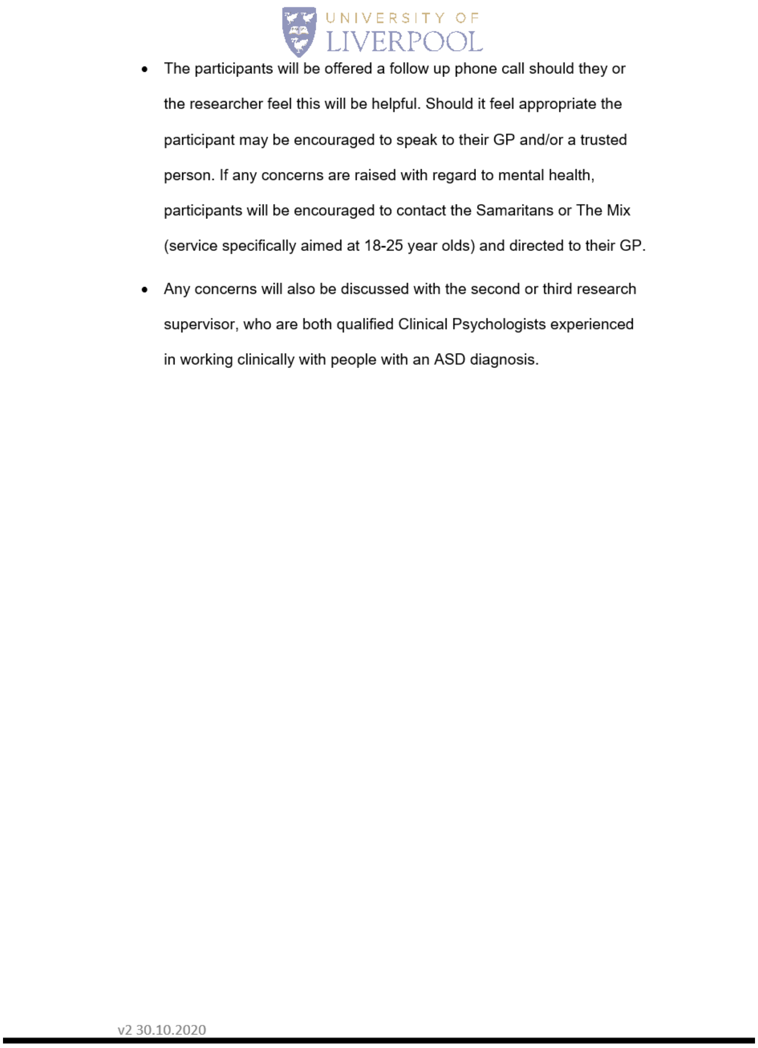
**Debriefing Document**

**(to be followed at the end of each interview)**

**The views of young autistic people on how their identities differ online and offline.**

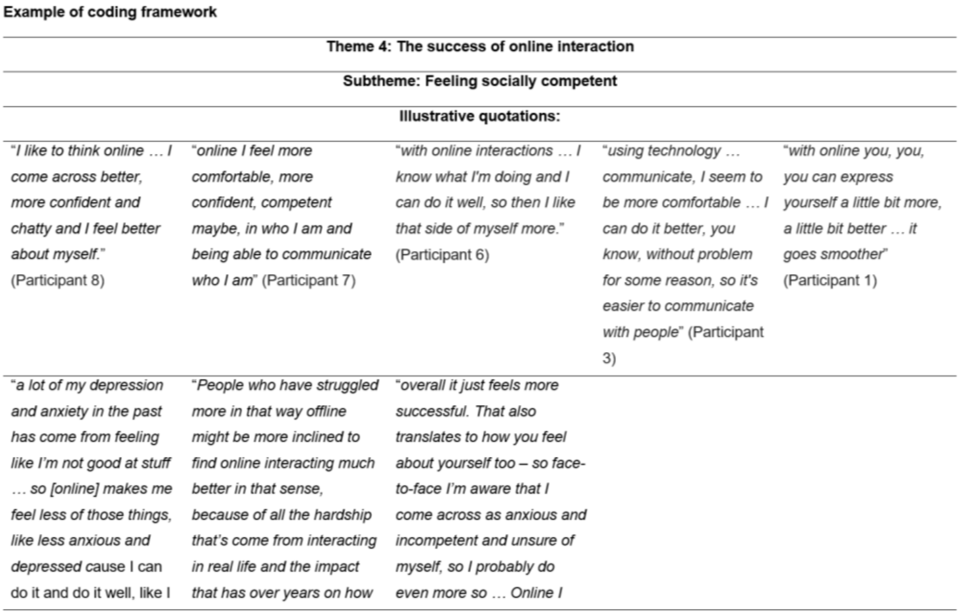
- The participants will have an opportunity to go through the PIS again and to ask any further questions they may have now they have completed the interview.
- The participants will be asked how they have found the interview process.
- They will be asked if there is anything they found helpful or unhelpful during the process.
- They will be asked if they would have liked anything to be done differently.
- *If no concerns are raised the interview will end here and participants will be given a copy of the Debriefing Document. If concerns are raised then the following points will be considered and discussed.*
- Should any distress or discomfort be observed or reported the distress policy will be followed.

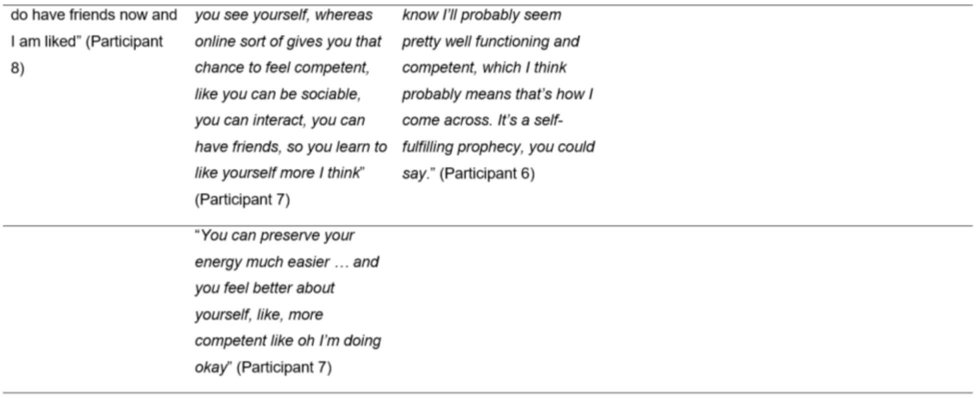
v2 30.10.2020



- The participants will be offered a follow up phone call should they or the researcher feel this will be helpful. Should it feel appropriate the participant may be encouraged to speak to their GP and/or a trusted person. If any concerns are raised with regard to mental health, participants will be encouraged to contact the Samaritans or The Mix (service specifically aimed at 18-25 year olds) and directed to their GP.
- Any concerns will also be discussed with the second or third research supervisor, who are both qualified Clinical Psychologists experienced in working clinically with people with an ASD diagnosis.

# Appendix Q: Example Coding Structure





**Example of coding framework**

**Theme 4: The success of online interaction**

**Subtheme: Feeling socially competent**

**Illustrative quotations:**

| | | | | |
|---|---|---|---|---|
| *"I like to think online … I come across better, more confident and chatty and I feel better about myself."* (Participant 8) | *"online I feel more comfortable, more confident, competent maybe, in who I am and being able to communicate who I am"* (Participant 7) | *"with online interactions … I know what I'm doing and I can do it well, so then I like that side of myself more."* (Participant 6) | *"using technology … communicate, I seem to be more comfortable … I can do it better, you know, without problem for some reason, so it's easier to communicate with people"* (Participant 3) | *"with online you, you, you can express yourself a little bit more, a little bit better … it goes smoother"* (Participant 1) |
| *"a lot of my depression and anxiety in the past has come from feeling like I'm not good at stuff … so [online] makes me feel less of those things, like less anxious and depressed* cause I can do it and do it well, like I do have friends now and I am liked" (Participant 8) | *"People who have struggled more in that way offline might be more inclined to find online interacting much better in that sense, because of all the hardship that's come from interacting in real life and the impact that has over years on how you see yourself, whereas online sort of gives you that chance to feel competent, like you can be sociable, you can interact, you can have friends, so you learn to like yourself more I think"* (Participant 7) | *"overall it just feels more successful. That also translates to how you feel about yourself too – so face-to-face I'm aware that I come across as anxious and incompetent and unsure of myself, so I probably do even more so … Online I know I'll probably seem pretty well functioning and competent, which I think probably means that's how I come across. It's a self-fulfilling prophecy, you could say."* (Participant 6) | | |
| | *"You can preserve your energy much easier … and you feel better about yourself, like, more competent like oh I'm doing okay"* (Participant 7) | | | |