‘Who am I?’ Do conceptions of personal identity and acculturation relate to psychological wellbeing and positive self-concept in autistic adolescents?

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# Executive Summary

The current project investigates how autistic[[1]](#footnote-1) adolescents view themselves and their relationships with peers, and how these concepts relate to psychological wellbeing. Part One is a systematic review of the qualitative literature relating to autistic adolescents’ experiences of peer relationships. Part Two is an empirical, exploratory study examining the relationship between autistic adolescents’ sense of personal identity, acculturation and psychological wellbeing. Part Three integrates findings form Parts One and Two, and discusses their impact and dissemination.

**Part One: The Experiences of Peer Relationships Amongst Autistic Adolescents: A Systematic Review of the Qualitative Evidence**

During the adolescent period, autistic adolescents start to develop heightened awareness of social isolation and victimisation, which increases the likelihood of them experiencing mental health difficulties. A comprehensive understanding of how autistic adolescents view their relationships with peers, and how they perceive peer victimisation, seemed important context to have when investigating how these young people view themselves and being autistic.

Qualitative research allows the opportunity to investigate meaning of phenomenon, such as friendship, with the purpose of understanding experiences within the context of everyday life. There was a distinct gap in the literature, where a comprehensive accumulation of autistic adolescents’ qualitative accounts of peer relationships was missing. The current review aimed to fill this gap and thus further develop understanding of autistic adolescents’ social experiences.

A meta-aggregative approach was followed, developed by the Joanna Briggs Institute (JBI), to synthesize findings across included studies. This approach seeks to produce directive statements to guide practitioners and policy makers. Qualitative journal articles published between 1997-2017, that sampled autistic adolescents aged 10-19 were included in the review. Articles were selected by searching two databases (PsychInfo and Scopus), by reviewing citations and by searching Google Scholar. 10 papers were considered eligible, after two independent reviewers searched and screened potentially relevant studies, excluding 242 that did not meet the inclusion criteria. The selected papers were assessed for methodological validity and quality. Qualitative data was extracted from included papers, including citation details, population, phenomena of interest, methodology and findings. Research findings were synthesized using JBI’s meta-aggregative approach, which involved generating a set of statements that represented the collection of findings, through assembling and categorizing them based on similarity in meaning.

Included studies varied in terms of geographical location, setting and focus, however most of the studies were conducted in the UK and took place in a school setting. Additional informants were interviewed in four out of ten studies. 179 individuals were involved in the included studies. All studies scored reasonably well using the quality assessment tool, with at least seven out of ten of the quality criterion items being met.

The review revealed findings under four main themes: understanding friendship, having and wanting friends, the challenges of peer relationships, and overcoming challenges. Autistic adolescents understood the concept of friendship, though this understanding was often limited in content and somewhat different to how others might describe friendship. Descriptions of friendships could appear scripted or learnt. Many of the young people interviewed said that they struggled with understanding and following covert social rules. Autistic adolescents could identify qualities that they would find important in a friend, though there tended to be more emphasis on shared interests and activities than on intimate qualities of friendship. Most autistic adolescents wanted and had friends, but there were also reported feelings of loneliness, when making friends was difficult to achieve.

Autistic adolescents were often aware that they had a reputation and understood the concept of others viewing them differently to how they viewed themselves. Some were more concerned about reputation than others, making efforts to ‘fit in’. Autistic adolescents faced multiple challenges in negotiating peer relationships, for example finding it difficult to approach others and misunderstanding social conventions. Group interactions were identified as particularly challenging. Peer rejection and victimisation was found to be common towards autistic adolescents, resulting in negative emotions, such as sadness and anxiety. Many young people blamed themselves or their autism for their negative treatment. Some accepted and others rejected autism as part of their identity in social settings, but most autistic adolescents recognised that characteristics of autism made their social interactions more difficult.

Many of those interviewed showed resourcefulness and resilience in their efforts to overcome challenges in peer relationships. Some were able to mask their difficulties by studying and imitating others. Some experiences of ‘camouflaging’ had negative repercussions, such as exhaustion and threats to self-perception. Responses to peer victimisation varied, with some turning to support from parents and teachers, and others adapting their behaviour to try and prevent further bullying from occurring.

Links are made between the reviewed findings and previous quantitative research, which show reasonable agreement and consistency. Combining studies from different settings, theoretical backgrounds and with different quality ratings has its challenges, which should be considered when reviewing findings and conclusions. Findings have implications for policy, practice and research. Autistic adolescents may benefit from additional support in school to help them understand social rules and negotiate friendships. School staff and parents might also perceive autistic adolescents to be coping better than they are, due to a tendency for them to mask their difficulties. Efforts should therefore be made to increase understanding and acceptance of autism and encourage these young people to show their true selves, to minimize the risk of them developing mental health problems. Further research is needed to test recommendations and practical strategies that might facilitate meaningful social inclusion for autistic adolescents.

**Part Two: Empirical study. ‘Who am I?’ Do Conceptions of Personal Identity and Acculturation Relate to Psychological Wellbeing and Positive Self-concept in Autistic Adolescents?**

Alongside peer relationships becoming more complex and challenging for autistic adolescents, other factors should be considered when attempting to understand their increased risk for developing mental health difficulties. Part Two details an exploratory empirical study investigating the idea that identity development, which is a key task of adolescence, may be related to psychological wellbeing for autistic adolescents. Identity can be defined as the way a person understands and views him or herself and is often viewed by others. This process can be particularly difficult to navigate when an individual has a disability or condition, such as autism, perhaps due to a growing awareness of being different or being stigmatized, which could impact the development of self-concept.

During adolescence, many autistic individuals start to question their identity and where they fit in. Social relationships are known to play a key role in the process of developing self-concepts in autistic adolescents, particularly as these young people often experience peer victimisation which could lead a person to internalize a negative view of the self. The role of social identity and group membership is considered, using research findings from ethnic and minority group identity literature.

Acculturation, which is the process of adopting the cultural traits or social patterns of another group, is described as a task that autistic adolescents face, in terms of exploring and committing to a preferred cultural identity. Autistic adolescents can align to non-autistic culture (separated), autistic culture (assimilated), both (bicultural) or neither (marginalized) cultures. A sense of shared social identity has been shown to be protective against negative consequences of marginalization in some minority groups, raising the possibility that aligning to a cultural group may relate to better psychological wellbeing in autistic adolescents.

The empirical study is an exploratory, cross-sectional, single group, correlational study, with strength of identity (as measured by the Twenty Statements Task; TST) and alignment to autistic culture (as measured by the Autism Identity Scale; AIS) as the predictor variables, and psychological wellbeing (as measured by the Strengths and Difficulties Questionnaire; SDQ) and positive or negative self-concept (as measured by the proportion of positive and negative statements produced in the TST) as the dependent variables. Hypotheses were as follows: (H1) there will be a positive relationship between strength of personal identity and psychological wellbeing in autistic adolescents; (H2) those who align to only autistic or non-autistic culture will have better psychological wellbeing outcomes than those who align to both or neither cultures (H2); and those who align to only autistic or non-autistic culture will have more positive self-concepts than those who align to both or neither cultures (H3).

Twenty-nine participants were recruited through mainstream schools in London and through a specialist service for autistic individuals and their parents. All participants had a formal diagnosis of an Autism Spectrum Condition (ASC). Each participant met with the researcher on one occasion, for 40 minutes, to complete the measures.

Results indicated that H1 was not supported; a hierarchical multiple regression analysis, controlling for the effects of age, gender and verbal IQ, revealed no relationship between strength of personal identity and psychological wellbeing. H2 was also not supported due to insufficient power to use inferential statistics. However, descriptive statistics indicated that those in the marginalized group had the highest SDQ total difficulties scores and the lowest scores were found in the assimilated group. H3was not supported due to insufficient power to use inferential statistics. However, descriptive statistics indicated that those in the marginalized group generated a lower proportion of positive and a higher proportion of negative statements about themselves than those in the assimilated group.

The current sample had poorer levels of psychological wellbeing compared to general population means, which is consistent with previous research. In general, participants felt more aligned to non-autistic than autistic culture and approximately half of the current sample mentioned autism in their identity descriptions. Findings indicated that aligning oneself more to non-autistic culture, rather than to neither culture, may have benefits for positive self-concept. Those in the assimilated group may have explored and committed to a preferred identity, which has been previously demonstrated to have positive effects on self-esteem and psychological wellbeing.

Empirical study findings are discussed in terms of their relation to previous research, with links being made to findings from ethnic minority group literature and previous autism literature. Findings should be interpreted with awareness of certain limitations, particularly pertaining to the sample. The sample size is small, despite efforts to increase numbers, which limits the power of the findings and increases the chance of making a Type Two error. Further limitations are discussed in relation to the challenges of measuring identity and of applying the acculturation model to the autistic population.

Implications for research and practice are presented, for example to encourage the development of programmes that support autistic adolescents to explore their autistic and non-autistic identities, to help them to commit to a preferred identity. Future research should examine the factors that contribute to acculturation, to further understand how to facilitate this process.

**Part Three: Integration, Impact and Dissemination Summary**

The current project aimed to investigate psychological wellbeing in autistic adolescents, with focus on identity development. Working out a sense personal identity (‘Who am I?’) and social identity (‘Where do I fit in’) often incorporates how one is viewed by others, hence it was considered important to firstly explore autistic adolescents’ experiences of peer relationships via systematic review.

The potential for impact at multiple systemic levels is presented, including for autistic individuals, their mainstream peers, their families, schools and society at large. Primarily, the project addresses the importance of encouraging identity exploration to help autistic adolescents commit to a preferred identity. Identity exploration might involve acquiring information about autistic and non-autistic culture, repeated exposure to both groups, and celebration of an individual’s unique qualities.

Project findings will be disseminated using a theoretically-informed approach, to access a variety of individuals, groups and services, with emphasis on delivering key messages from the project in a way that involves those included in research, and those to whom findings are most relevant. The principal message to be communicated will be that more should be done, both in research and practice, to heighten awareness of the ideas of autistic acculturation, and to help autistic adolescents to consider their personal identity and what autism means to them. Channels of communication will include social media, research handouts, submission to peer-reviewed journals and presentation of findings at relevant conferences.

## Part One.

# The Experiences of Peer Relationships Amongst Autistic Adolescents: A Systematic Review of the Qualitative Evidence

## Abstract

Peer relationships can be especially difficult for autistic adolescents, given their marked social communication difficulties. The purpose of this systematic review is to synthesize reported qualitative findings on how autistic adolescents experience peer relationships, including the rewards and challenges, from their perspective. PRISMA guidelines and the Joanna Briggs Institute meta-aggregative approach to qualitative synthesis informed the review process. Articles included were published in the last 10 years, specific to autistic adolescents between the ages of 10 to 19. Of the 75 articles meeting eligibility for full-text review, found by searching the databases PsychInfo and Scopus, 10 matched the final inclusion criteria. The review includes the perspectives of others (e.g. parents, support workers), from included papers where these were reported in addition to the adolescent viewpoint. Findings relating to four main themes emerged from the qualitative synthesis: understanding friendship, having and wanting friends, challenges of peer relationships and overcoming challenges. Fourteen sub-topics are described in detail, for example that autistic adolescents do have and want friends, though this is often not easily achieved, leading to feelings of loneliness. Findings also revealed experiences of peer rejection and victimisation, and specific factors that might make building positive peer relationships difficult, such as group settings. Autistic adolescents face a number of difficulties with understanding social rules and conventions, which seems to make peer relationships difficult. However, due to many autistic adolescents’ desire for friendship, some have developed ways of overcoming these challenges. The current review highlights that additional support is needed to support the development of autistic adolescents’ social skills and awareness; further research is needed to establish how this could be done most effectively.

## 

## Introduction

### Autism and Adolescence

Autism is a pervasive neurodevelopmental disorder, characterised by difficulties with social communication and interaction, as well as restrictive and repetitive patterns of behaviour, activities or interests (DSM-5; American Psychiatric Association, 2013). The estimated prevalence rates for autism spectrum conditions (ASCs) is 0.6% of the general population (Charman, 2002).

Adolescence can be especially difficult for individuals on the autism spectrum, as social expectations increase and peer relations become more complex (Adreon & Stella, 2001). McGovern and Sigman (2005) found that the desire for social relations increases markedly in many autistic individuals by adolescence, which can be difficult to manage due to social difficulties experienced throughout the lifespan. For example, adolescence often requires the learning of more complex social rules, such as understanding humour and slang, taking the perspectives of others to understand emotions and situations, and interpreting subtle social cues within the context of the social environment (Frostad & Pijl, 2007). These are areas that many autistic individuals might find particularly difficult (Chamberlain, Kasari & Rotheram-Fuller, 2007). Furthermore, autistic youth may develop heightened awareness of social isolation and victimisation during this age period (Kuusikko et al., 2008).

### Friendship

Friendships among young people (irrespective of autism) provide an important context for social, emotional and cognitive development (Waldrip, Malcomn & Jensen-Campbell, 2008). Helm (2005) defines friendship as a personal relationship, requiring some degree of intimacy, that involves concern on the part of each friend for the welfare of the other. Friendships can provide young people with the opportunity to practice interpersonal skills, to use a variety of emotional expressions, to exchange ideas, to share, and to cooperate, therefore they may be considered a core part of adolescent development (Berndt, 1992). It is also known that aspects of friendship change with age and intimate peer relationships tend to become increasingly valuable with age for adolescents (Jankowski, Moore, Merchant, Kahn & Pfeifer, 2014).

Social interactions, and particularly building and maintaining friendships, can be particularly difficult for autistic people because they find interpreting subtle social cues challenging, particularly non-verbal body language (Koning & Magill-Evans, 2001). They may also have difficulty with automatically considering someone else’s perspective, motives, thoughts and feelings (Ruffman, Garnham, & Rideout, 2001; Senju, Southgate, White, & Frith, 2009), although learning explicitly about mental states is possible (Bowler, 1992; Happé, 1995; Scheeren, de Rosnay, Koot, & Begeer, 2013). Cognitively able autistic adolescents report increased concerns about their friendships and an increasing awareness that they are different to other people (Carrington, Templeton & Papinczak, 2003b). However, they also report that they would like to fit in and have friends (Daniel & Billingsley, 2010).   
Bullying and Peer Victimisation  
 Autistic children and adolescents are common targets of bullying during their school-aged years (Cappadocia et al. 2012; Schroeder, Cappadocia, Bebko, Pepler & Weiss, 2014; Van Roekel, Scholte & Didden, 2010), with this group being up to four times more likely to experience bullying than students without disabilities (Sterzing, Shattuck, Narendorf, Wagner & Cooper, 2012). Risk factors that might put autistic individuals at higher risk of being victimized by peers include having limited social skills (Kloosterman, Kelly, Craig, Parker & Javier, 2013; Schroeder et al., 2014), fewer or lower quality peer relationships (Rowley et al., 2012; Wainscot, Naylor, Sutcliffe, Tantam & Williams, 2008), communication difficulties (Nabuzoka, 2003) and difficulty regulating emotions (Schroeder et al., 2014). Additionally, research using a sample of typical adolescents shows individuals with poor social skills and few friends are marginalized and unprotected within the social group and are therefore vulnerable to the abuse of power by peers (Delfabbro et al., 2006); this could also help to explain continued victimisation amongst autistic youth. Finally, it is worth considering that experiences of victimisation may exacerbate social difficulties among autistic adolescents, making it even more difficult to form and maintain friendships (Van Roekel et al., 2010).   
 Research has shown that autistic individuals are at higher risk of developing psychiatric difficulties, particularly anxiety and depression symptoms (e.g. Tantam, 2000; Ghaziuddin, Ghaziuddin, & Greden, 2002), and this increased vulnerability is particularly prominent during adolescence (e.g. Vickerstaff, Heriot, Wong, Lopes & Dossetor, 2007; Lecavalier, 2006). Strang et al. (2012) conducted a large-scale study looking at autistic children and adolescents and found that 40% of their sample had borderline or clinical levels of depression and/or anxiety symptoms. Van Roekel et al. (2010) found that frequent victimisation was related to many mental health problems among young autistic people. Autistic youths who experienced high levels of victimisation (once or more per week) were rated by their parents as having higher levels of anxiety, hyperactivity, self-injurious and stereotypic behaviours, and over sensitivity than those who experienced no victimisation or experienced low levels of victimisation (i.e. less than once per week).   
 As described, existing literature would suggest that autistic adolescents may have some difficulty negotiating friendships, which could exacerbate their risk towards being victims of bullying. It is therefore important to hear the perspective of these young people and aim to better understand their experiences, in order to provide the appropriate support. Much of the research that has investigated the nature of friendships in autistic adolescents (e.g. Orsmond, Krauss & Seltzer, 2004; Bauminger & Schulman, 2003), and risk and protective factors for peer victimisation (e.g. Van Roekel et al., 2010), has used methodologies (e.g. self-report, closed-ended questionnaires) that have left important gaps in our knowledge about their specific experiences, such as how individuals were affected by these experiences. Qualitative research affords “people who are often studied but seldom heard” (Taylor, Ferguson & Ferguson 1992, p. 14), such as autistic adolescents, an opportunity to inform the investigations surrounding them. This methodology allows researchers to investigate questions that ask for meaning of phenomena, such as friendship, with the purpose of understanding the human experience within the context of everyday life (Seamon, 2000). Studies utilising this methodology therefore formed the focus of this review.   
The Current Review  
 Systematic synthesis of relevant qualitative studies of friendship and victimisation experiences of autistic youths can provide a more complete understanding than that derived from individual studies alone. It can assist in the interpretation of single studies; help explain variation or conflicts in single study findings; enable the development of new theories; and help inform the design of new interventions. It may also help to identify gaps in the existing literature and therefore highlight areas for future research.   
 In this review, we consider the perspectives of autistic young people and, in some cases, their parents and teachers, regarding experiences of peer relationships, including experiences of friendships and peer victimisation. By accumulating relevant studies to form a more comprehensive picture of the topic area, the findings of this review will help to answer the question, ‘How do autistic adolescents perceive peer relationships, including the rewards and challenges?’ The qualitative synthesis will have implications for a range of stakeholders, including non-government organisations, national policy makers and, importantly, young autistic people, their schools and their families.

## 

## Method

A meta-aggregative approach was followed, developed by the Joanna Briggs Institute (JBI; Pearson, 2004), to synthesize findings across included studies. This approach models the Cochrane Collaboration process to review and analyse randomized clinical trials, yet remains sensitive to the nature of qualitative approaches to research. Specifically, the JBI Qualitative Assessment and Review Instrument (JBI QARI; Joanna Briggs Institute, 2014) was used to assist in the process of qualitative review, which was developed specifically for meta-aggregation. This approach is sensitive to the practicality and usability of the primary author’s findings and does not seek to re-interpret those findings. The JBI approach produces directive statements, capturing key messages from the cumulative findings, which can be used to guide practitioners and policy makers.

### Inclusion Criteria

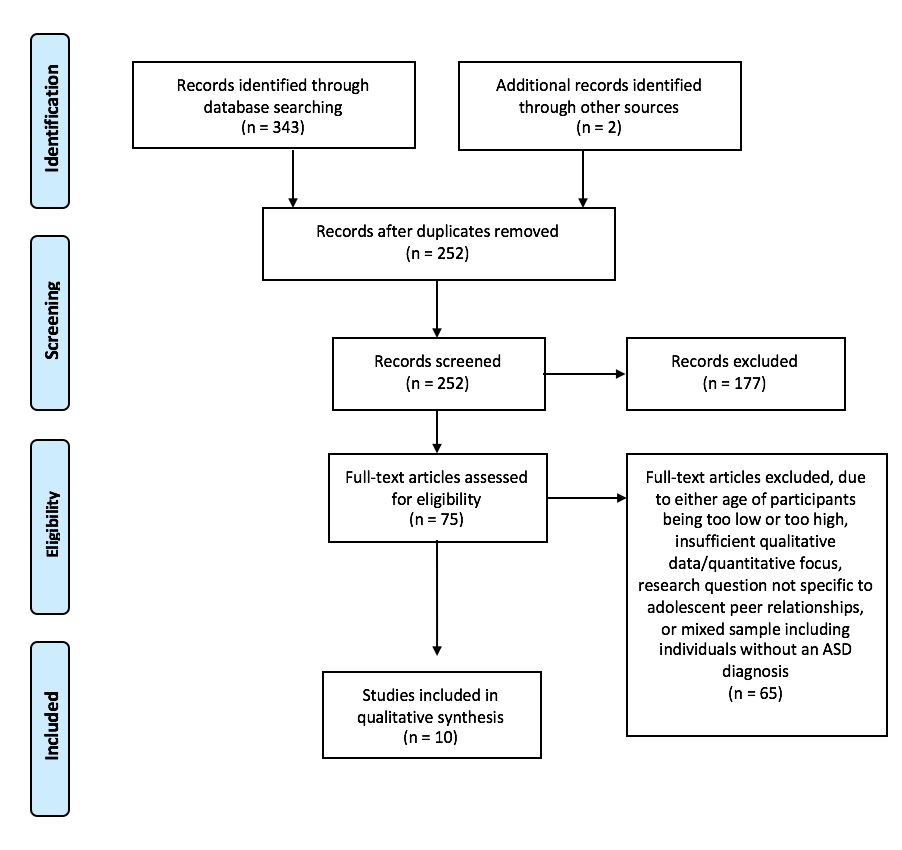
Studies that examined the experiences of peer relationships in autistic adolescents were included, with specific reference to experiences of friendships and/or of peer victimisation. Studies were included from any discipline or theoretical tradition that used primarily qualitative methods; research using qualitative and quantitative methods (mixed methods) were included, where qualitative findings were reported. Both published and unpublished studies reported in English were considered; papers published in other languages were not considered due to resource limitations.

Studies published between the years of 1997-2017 were included. Papers older than twenty years may no longer be relevant to today’s youth population. To assess adolescent perspectives, the inclusive age range for participants was 10-19 years old, in line with the recent perspective that age this range corresponds more closely to adolescent growth and development (Sawyer, Azzopardi, Wickremarathne & Patton, 2018). Participants in the included studies had to have a formal diagnosis of an Autism Spectrum Condition (ASC).

For consistency and quality assurance purposes, only published articles were included in the synthesis, therefore excluding dissertations. Studies where the topic of interest was romantic relationships were also excluded, as this was thought to be a related, but separate, topic.

### Search Strategy and Study Selection

Figure 1 maps out the process by which articles were selected for the current review. Two databases were searched, PsychInfo and Scopus, using the keywords: (Abstracts) “(Autis\* OR Asperger\* OR ASD OR ASC) AND (Asolescen\* OR Youth\* OR Teen\* OR “young people”) AND (Friend\* OR belonging OR bully\* OR “social isolation” OR Lonel\* OR Victimi\* OR Relationship\* OR Peer\*)”, from 1997, where available, until 2017. This process was complemented by reviewing citations, searching Google Scholar, checking existing systematic reviews in the topic area of interest, and expert referrals. Additional articles were included as they became available. The search, assessment, and retrieval process outlined by Barroso et al. (2003) was used. Initial searches identified 345 citations, across both databases and other search methods. After scanning for duplication, 252 studies were identified for screening. The titles and abstracts of potentially relevant studies were screened to ensure they examined autistic adolescent experiences of peer relationships, excluding 177 papers and retrieving potentially eligible papers (n=75). After scanning these full texts, 63 studies were not considered eligible and 12 were considered potentially eligible, based on our inclusion criteria. A second reviewer independently repeated the search and screening process, and disagreements (n=4 papers) were discussed. Following discussion, two more papers were excluded because they did not include sufficient qualitative data, or because the focus did not appear to be specific enough to adolescent peer relationships. The final synthesis therefore included 10 papers.

  
*Figure 1*. Prisma diagram. This figure illustrates the search process and study selection

### Quality Assessment

Qualitative papers selected for retrieval were assessed by two independent reviewers for methodological validity, prior to inclusion in the review, using a standardized critical appraisal instrument from the JBI-QARI (Appendix 1). Any disagreements that arose between reviewers were resolved through discussion, or with a third reviewer where necessary.

Evaluating study quality allowed the researchers to describe the range of quality across the included studies. No studies were excluded on the basis of quality. This approach was taken as there is still no consensus among qualitative researchers on the role of quality criteria and how they should be applied (Dixon-Woods, Shaw, Agarwal & Smith, 2004), particularly for assessing study quality for systematic reviews. Additionally, users of the qualitative synthesis methods have found that poorer-quality studies tend to contribute less to synthesis (Noblit & Hare, 1988), so the synthesis therefore becomes “weighted” towards findings of the better-quality studies.

### Data Extraction

Qualitative data was extracted from papers included in the review using the standardised data extraction tool from the JBI-QARI. Data extraction in a meta-aggregation is a multi-phase process, with general details of the papers, including the citation details, the population, phenomena of interest, and context, as well as methodology, methods, settings and cultural information retrieved from papers, before moving to extraction of findings. Each finding was taken as a verbatim extract of the author’s analytic interpretation of their results or data, accompanied by either a participant voice, fieldwork observations or other data.

Findings were identified for extraction by repeated reading of the text, and selection of the themes from the results section of the paper. A level of credibility was allocated to each extracted finding, based on the reviewers’ perceptions of the degree that it was supported by specific illustrations in the text. Findings were individually rated as either ‘Unequivocal’ (findings accompanied by an illustration that is beyond reasonable doubt and therefore not open to challenge), ‘Credible’ (findings accompanied by an illustration lacking clear association with it and therefore open to challenge) and ‘Unsupported’ (findings not supported by data). Findings rated as unsupported were not included in this review.

Data was extracted by two independent reviewers and disagreements were negotiated. It was agreed in advance by reviewers that if a study included multiple areas of focus, only findings relating to peer relationships would be extracted from the paper. For example, Humphrey and Lewis (2008) described autistic adolescents’ school experiences, including experiences of peer relationships and experiences of working with teachers and other staff, however only the findings relating to the current review topic were extracted, categorised and synthesized.

### Data Synthesis

Qualitative research findings were, where possible, pooled using JBI’s meta-aggregative approach. This process involved generating a set of statements that represented the collection of findings, through assembling and categorizing them on the basis of similarity in meaning. Categories can be defined as brief descriptions of a key concept arising from the aggregation of two or more similar findings (JBI, 2014). These were then considered together to form synthesised findings, containing at least two categories, which are overarching descriptions of a group of categorized findings. Synthesized findings are expressed as ‘indicatory’ statements that can be used to generate recommendations for policy and practice. Category descriptions and synthesised findings were developed by two independent reviewers and assessed for similarity by a third reviewer.

## 

## Results

### Study Characteristics

Ten studies published between 2003 and 2016 were included in this review. The studies were conducted in the UK (5), Australia (2) and the USA (3) (Table 1). The study settings varied, but most were conducted in a school setting. Many of the studies were concerned with autistic adolescents’ experiences of friendship (5), though some focused more generally on the social experiences of autistic adolescents (2), or more specifically on peer victimisation (1), reputation concerns (1) or school experiences (1); however, all included studies addressed the topic of peer relationships. Study design and analytical approach varied between studies (see Table 1), though all studies used semi-structured interviews and most used thematic analysis (TA; 4) or interpretative phenomenological analysis (IPA; 3) to analyse interview responses.

Table 1

*Characteristics of Primary Included Studies*

|  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- |
| Reference | Country | Design | | Setting | Participant Characteristics | Analytical approach |
| **Cage, Bird and Pellicano (2016)** | UK | | Semi-structured interviews | Specialist autism provisions in mainstream secondary schools | 12 autistic adolescents (aged 11-15; 11 males, 1 female; IQ>70;) and 5 members of school staff. | TA |
| **Daniel and Billingsley (2010)** | US | | Semi-structured interviews, field notes and document reviews | Participant’s homes or alternative location | 7 boys (aged 10-14; good verbal communication; IQ>70) and 17 parents and teachers of the boys | IPA |
| **Fisher and Taylor (2015)** | USA | | Semi-structured interviews (Using Autism Diagnostic Observation Schedule (*ADOS)* questions, module 4) | Research site | 30 students (aged 17-19; 26 males, 4 females; mean IQ = 93.5) | TA |
| **O’Hagan and Hebron (2016)** | UK | | Case study, semi-structured interviews | Rural mainstream school with a specialist ASC resource provision | 3 male students (aged 13-15), a parent of each boy and 3 key workers (one support worker, one teaching assistant and the head of resource provision) | A hybrid approach of incorporating both inductive and deductive TA was adopted (Braun & Clarke 2006) |
| **Sedgewick, Hill, Yates, Pickering and Pellicano (2016)** | UK | | Mixed methods: Friendship Qualities Scale, Social Responsiveness Scale, semi-structured interviews | Special needs schools in the south of England | 46 students (aged 12-16; 13 autistic girls, 13 girls without autism, 10 autistic boys and 10 boys without autism; all Ps had a Statement of Needs due to a mixture of primary needs, including moderate intellectual disability (n=16) and specific language impairment (n=11) | TA, guided by Braun and Clarke (2006). |
| **Tierney, Burns and Kilbey (2016)** | UK | | Semi-structured interviews | Mutually agreed, private location | 10 girls (aged 13-16) | IPA |
| **Vine Foggo and Webster (2016)** | Australia | | Semi-structured interviews | All via phone or written reflections | 7 girls (aged 13-17; mainstream school educated; clinical diagnosis of an ASC) | Inductive TA |
| **Howard, Cohn and Orsmond (2006)** | USA | | Case study; semi-structured interviews, photographs taken by the young person, quality of life measures | Private university | One boy (aged 12; home schooled; IQ>70) and his mother | Grounded theory |
| **Humphrey and Lewis (2008)** | UK | | Semi-structured interviews, pupil diaries and pupil drawings | Mainstream secondary school in the north-west of England | 20 students (aged 11-17) | IPA |
| **Carrington, Templeton and Papinczak (2003)** | Australia | | Semi-structured interviews | School providing support services to students with different learning needs | 5 students (aged 14-17) | The method of constant comparison advocated in seminal work by Glaser and Strauss (1967) |

### 

### Participant Characteristics

Two of the studies used a female-only sample and three studies investigated only males; the remaining five studies used a sample of males and females (Table 1). Four of the studies interviewed informants, such as a parent or teacher, in addition to the young person interviews. Sample sizes ranged from one to 46 (median=13.5). 179 individuals were involved in the included studies.

All of the adolescent participants in the studies had a formal diagnosis of an ASC (including Asperger’s syndrome, autism spectrum disorder (ASD) and high-functioning autism). Their educational settings varied; five studies recruited from mainstream schools, one study recruited from a specialist provision school, a case study participant was home schooled, and for the remaining three studies the participants’ educational setting is unknown. Some studies reported their participants had IQ scores in the typical range (n=4) and the remaining studies did not comment on this.

### Methodological Quality

All studies justified their use of a qualitative approach or specified the underlying theoretical framework, though few studies reported on their role as a researcher (n=5). All studies described the method of analysis, and there was congruity between the research methodology and interpretation of results, and between the analysis of the data and conclusions drawn. All studies scored reasonably well using the quality assessment instrument (Table 2), with at least 7 out of ten of the quality criterion items being met. It was sometimes unclear (n=3) if the research was ethical according to current criteria, though this was considered to reflect the quality assessment tool’s ability to measure only the quality of reporting.

Table 2

*Methodological Quality of Included Studies (n=10) JBI QARI Critical Appraisal Checklist for Interpretive & Critical Research.*

|  |  |  |  |
| --- | --- | --- | --- |
| Quality Criterion | Agreed Assessment for Each Study | |  |
| **Met Criterion** | **Did Not Meet Criterion** | **Unclear** |
| **Is there congruity between the stated philosophical perspective and the research methodology?** | 9 | 0 | 1 |
| **Is there congruity between the research methodology and the research question or objectives?** | 10 | 0 | 0 |
| **Is there congruity between the research methodology and the methods used to collect data?** | 10 | 0 | 0 |
| **Is there congruity between the research methodology and the representation and analysis of data?** | 10 | 0 | 0 |
| **Is there congruity between the research methodology and the interpretation of results?** | 10 | 0 | 0 |
| **Is there a statement locating the researcher culturally or theoretically?** | 5 | 4 | 1 |
| **Is the influence of the researcher on the research, and vice-versa, addressed?** | 5 | 5 | 0 |
| **Are participants, and their voices, adequately represented?** | 10 | 0 | 0 |
| **Is the research ethical according to current criteria or, for recent studies, is there evidence of ethical approval by an appropriate body?** | 7 | 0 | 3 |
| **Do conclusions drawn in the research report follow from the analysis, or interpretation, of the data?** | 10 | 0 | 0 |

### Findings of the Review

A QARI-view graph (Appendix 2) was developed, containing: a complete synthesis of the findings; the aggregation of findings in to categories; and the development of synthesized findings and their descriptions. Levels of credibility were attributed to each finding and were parenthesized in brackets. A third reviewer deemed there to be good agreement between the reviewers about their independently-developed graphs, which were aggregated via collaborative discussion to form an agreed template.

The full content of the graph will be detailed in plain text below. The review revealed synthesized findings under four main themes, illustrated in Figure 2: understanding friendship, having and wanting friends, the challenges of peer relationships, and overcoming challenges. Each primary theme, containing sub-topics, is illustrated in Boxes 1-4 using direct quotes.

**Understanding Friendship**

**Having and Wanting Friends**

Describing friendship

Important qualities of friendship

Differences in understanding of friendship

Desire for friendships

Having friends

Reputation concerns

**Challenges of Peer Relationships**

**Overcoming Challenges**

Group interaction

Peer rejection and victimization

Support from others

Responding to bullies

Age

Adapting behaviour

Identity

Making Friends

*Figure 2.* Themes and sub-topics that emerged from the reviewed papers.

### Understanding Friendship

**Box 1: Understanding Friendship**

**Describing Friendship**

*[about an acquaintance]* “You sort of know them, you talk to them sometimes, but you don’t really do stuff. You just see them at school and that.” (young person (YP); Carrington et al., 2013)

“If they just decided, “I’m gonna list a giant book of teenage girl etiquette so that…every single teenage girl has to live to these standards”… if only that happened…I’d be able to interact with them in the right way.” (YP; Tierney et al., 2016)

“I understand that I have friends but it’s quite hard to understand the concept of it.” (YP; Cage et al., 2016)

**Differences to others’ understanding**

“He’s got a couple of friends on there [Xbox live] from primary school who he’s actually getting along a lot better with now they’re not face to face. It’s not what I would call a proper friendship but I think in his mind they’re friends.” (YP’s mother; O’Hagan & Hebron, 2016)

‘I don’t think he truly knows what the word friendship is. Like, I have a friend from childhood and that’s what I would call proper friendship’ (YP’s father; O’Hagan & Heborn, 2016)

**Important qualities of friendship**

“[A friend is] someone that looks out for you, and you have to look out the same.” (YP; Howard et al., 2006)

“A friend is someone trustworthy, nice and will understand you.” (YP; Foggo & Webster, 2016)

“They have their friendships, so the two boys in our class who like London transport and buses, there is some form of friendship you can see there. It is not the typical form of playing together but they have a shared interest.” (Learning Support Assistant (LSA)); Cage et al., 2016)

Describing friendship.Autistic adolescents could understand and describe friendship, drawing from their own experiences, though they had some difficulty with the concept and using language to describe it (Carrington et al., 2003; Sedgewick et al., 2016). Carrington et al.’s (2003) participants had difficulty talking about friendships in-depth and recognising friendship language. They could understand acquaintances in unemotional terms, which was easier than describing a friend. Some found describing people who would not be a friend easier than describing who would be, and ways of describing friendships were somewhat rigid. Descriptions of ‘what is a friend’ varied between participants, and generally it was a concept that autistic adolescents found difficult to articulate. Sedgewick et al. (2016) found that autistic adolescents often provided ‘scripted’ responses to questions, as if they were echoing something they had heard before, for example using adult phrases when describing friends (e.g. “happy old chaps”). Autistic girls used scripting more in relation to emotional expectations and included phrases such as, “say “Don’t cry” and stuff”.

Differences to others’ understanding.Autistic adolescents often understood and experienced friendships differently to their typically developing (TD) peers (Tierney et al, 2016; O’Hagen & Hebron, 2016; Cage et al., 2016). Tierney et al. (2016) found that young autistic girls could recognise emotionally-intimate qualities of female-to-female friendships, however they often found that they did not understand, and therefore could not abide by, the covert rules within these relationships. O’Hagan and Hebron (2016) interviewed parents of autistic males, who reported that their sons did not understand friendships in the same way that they did. This finding suggests that there may be differences in the meaning and nature of friendship for those with an ASC, without implying that such relationships are inferior. This finding was supported by Cage et al. (2016), who found that Learning Support Assistants (LSAs) observed that autistic young people’s friendships had different qualities to typical students’ friendships. However, Sedgewick et al. (2016) found that the relationally aggressive behaviours characteristic of many typical female friendships (see Nichols, Moravcik & Tetenbaum, 2009), such as gossiping, being excluded, and having trust betrayed, were discussed repeatedly by their autistic female participants. It is worth noting that the autistic girls who described these incidents did not see their friendships as being characterized in this way overall.

Important qualities of friendship.Many autistic adolescents identified important qualities of friendship, such as having shared interests (O’Hagen & Hebron, 2016; Howard et al., 2006; Daniel & Billingsley, 2010; Foggo & Webster, 2016; Sedgewick et al., 2016), offering help and support, and trust (Howard et al., 2016; Foggo & Webster, 2016). O’Hagan and Hebron’s (2016) participants discussed the importance of common interests, which were often related to computer games. In this study, parents of autistic youth spoke about internet friends and their potential advantages, such removing the pressure of interpreting subtle social cues required in face-to-face contact, and associated disadvantages, such as online bullying.

Foggo and Webster’s (2016) participants spoke about the importance of sharing activities, particularly less structured and social activities, like shopping and going to the cinema. Sedgewick et al.’s (2016) participants noted that not having the same interests could be a barrier to being friends, which was similar for both non-autistic and autistic boys, suggesting commonalities in the nature of friendship. They also noted humour as an important aspect to friendship. Howard et al.’s (2016) case study of one male participant highlighted other factors that were considered important in friendship, such as offering help and support to each other, caring and responding, and seeing friends regularly. However, as this participant had attended some social skills training, it is difficult to ascertain where these ideas about friendship came from. Foggo and Webster’s (2016) participants highlighted trust, support and respect as important aspects of friendship. Although it appears autistic adolescents are able to describe qualities of a good friend, Cage et al. (2016) highlighted that these descriptions are often limited and do not include all three dimensions of friendship (i.e. affection, intimacy and companionship) outlined by Bauminger and Kasari (2000). The students’ lack of discussion of intimacy as a defining feature of friendship may also go towards explaining why, despite describing features of friendship, the students’ parents and teachers felt that they did not have a fully developed understanding of friendship (O’Hagan & Hebron, 2016).

### Having and Wanting Friends

**Box 2: Having and Wanting Friends**

**Desire for friendships**

“Tom has always wanted to connect with peers. He is very hopeful. He looks for ways to connect.” (YP’s mother; Howard et al., 2006)

“Yes, I think having friends around to make you happy is awesome. If you didn’t have friends around, which was the case with me for a while, you feel alone and feel as though the whole world is against you.” (YP; Foggo & Webster, 2016)

“Some people are lonely and need friends’’ (YP; Sedgewick et al. (2016)

“He mentions it, that he’d like to have a friend come over to play with or to talk to or hang around with […] I’d probably say he mentions it once a month.” (YP’s father; O’Hagan & Hebron, 2016)

“I definitely couldn’t be some kind of hermit. As much as I would like to be able to I don’t think it would be good for me at all.” (YP; Tierney et al., 2016)

**Having friends**

“She’s been my friend ever since I was very, very little.” (YP; Daniel & Billingsley, 2010)

“He’s got a natural group that he sits with but it’s a group enforced by the resource rather than created by himself.” (LSA; O’Hagan & Hebron, 2016)

“He found it nearly impossible to make friends, and he was very much if there was somebody crossing the road, they would be his friend even if he had never seen them before.” (YP’s mother; O’Hagan & Hebron, 2016)

**Box 2 (continued): Having and Wanting Friends**

**Reputation concerns**

“He still prefers to be in his main school form than to come back here [to the autism provision] for form time. He sees it as more of a stigma coming back here. He wants to be seen as everyone else.” (LSA; Cage et al., 2016)

“I don’t really know the rules. I just do not really care about being cool” (YP; Cage et al., 2016)

“They think I’m weird because I don’t act, talk walk speak and gossip the way they do but I’m proud to be me” (YP; Foggo & Webster, 2016)

Desire for friendships.The reviewed studies indicated that most autistic adolescents had a desire to form friendships (Howard et al., 2016; Foggo & Webster, 2016; Sedgewick et al., 2016; Tierney et al., 2016), and many have experienced loneliness through that desire not being fulfilled (Sedgewick et al., 2016; O’Hagen & Hebron, 2016l; Tierney et al., 2016). That said, the majority of the young people interviewed across all included studies did have friends. In Howard et al.’s (2016) case study, the participant chose having good friends as one of his top priorities and described close friendships with four other adolescents. His mother reinforced that he had always had a desire to connect with peers. All bar one of Foggo and Websters’s (2016) participants indicated that it was important to have friends. Sedgewick et al. (2016) looked at the difference between male and female autistic youths in this domain, and found autistic girls showed similar motivation and friendship quality to non-autistic girls, whereas autistic boys reported having less motivation for social contact relative to boys without autism and to girls with and without autism. Five out of 23 of their autistic participants reported that they would like to have more friends than they had. O’Hagan and Hebron (2016) highlighted that autistic adolescents’ desire for friendships was not always fulfilled, and they found that all of their participants reported loneliness. A similar finding came from Tierney et al.’s (2016) paper, as they found that autistic adolescents were motivated to have friendships, therefore obstacles to making friends caused discomfort or distress.

Having friends.Most of the autistic adolescents studied had friends, often formed at school, and maintained these friendships despite various challenges, such as school transition (Daniel & Billingsley, 2010; O’Hagen & Hebron, 2016). Daniel and Billingsley (2010) interviewed male autistic adolescents who all reported having friends, and they identified school as the primary place for making friends. Other places included extra-curricular activities, neighbourhoods, family friends, church and holidays. Four boys maintained friendships despite school transitions and family moves, but this was reported to be difficult, therefore only the closest friendships remained. O’Hagan and Hebron’s (2016) findings revealed that autistic adolescents tended to have more friendships with other autistic individuals than with their TD peers, which may be because they attended a resource provision that facilitated bonding with autistic peers. Parent perspectives on their children’s friendships tended to differ to the young people’s perspectives. This highlights a potential issue with interviewing only young autistic people about friendship, as their perception of their own friendships may be different to the perspectives of others, which was highlighted by a mother who noted that her son would approach someone crossing the road, whom he had never seen before, and consider him his friend (O’Hagan & Hebron, 2016).

Reputation concerns. The topic of reputation was most prevalent in Cage et al.’s (2016) study, in which autistic adolescents highlighted the difficulty with understanding social rules and conventions, which at times made it hard to fit it. Participants were capable of being concerned about their reputation, and some of the young people used their understanding of “being cool” to change their behaviour, in order to impress others. This desire to adapt oneself to impress others emphasised the desire that many young autistic people have to be accepted socially. Participants were aware that others might describe them differently to how they would describe themselves, which demonstrates an awareness of the concept of reputation. Reports from staff supported the findings that autistic young people generally have a desire to fit in with their peers. Foggo and Webster (2016) looked specifically at autistic girls and found that, in contrast to perceptions about their own characteristics, participants were much less aware of what peers thought about them. Three of the participants either stated that they did not know what others thought of them or left the question blank. The other four participants suggested that they were perceived by peers in a negative light due to their refusal to act the way others did.

### Challenges of Peer Relationships

**Box 3: Challenges of Peer Relationships**

**Making friends**“ No, I don’t find it easy at all ‘cause you’ve got to like, closely watch what they’re doing or else they’ll probably exploit you later on… It’s better to just have acquaintances sometimes. [Because], I don’t know. I just don’t like people to become more intimate, unless I actually want them to…” (YP; Daniel & Billingsley, 2010)

“I look at them and see if I could be their friend. See if they’re worthy enough to like my stuff as much as them. […] But the problem is he might get sick of me. And he probably has other friends, probably. So I think, oh, I don’t think so …. Because I think he might not like me as much and he might not know...how to say no.”(YP; Daniel & Billingsley, 2010)

“Talking to people, being with people; he does try to, he probably tries too hard, which is why he annoys people so much because he doesn’t understand the rules” (Head of autism resource; O’Hagan & Hebron, 2016)

“[I worry about] people liking me, and my friends never invite me to places. They always use the excuse that I am not allowed” (YP; Cage et al., 2016)

“Yes, I struggle to know how to socialise with people and what is appropriate. Meeting new people in a different place is so hard. Starting conversations and knowing what to say makes me feels really awkward and embarrassed.” (YP; Foggo & Webster, 2016)

**Age**I think when she started secondary she was more aware . . . that she couldn’t keep a friend. (YP’s mother; Tierney et al., 2016)

“He’s probably become more socially isolated over the four years because of a developing awareness that they’re not very nice to him, without a developing awareness of how to change that relationship.” (Support worker; O’Hagan & Hebron, 2016)

**Box 3 (continued): Challenges of Peer Relationships**

**Group Interaction**“With a group, there’s loads of different people all at different times and it turns into a murder mystery game of Cluedo where somebody made this go wrong, we’ve got to find out who it is, people blaming each other, splitting each other up and just wrecking everything. I don’t like it at all.” (YP; Tierney, Burns & Kilbey, 2016)

“Yes, when you are sorting of sitting there and you feel like everyone else is good friends with each other and you are just sitting there” (YP; Foggo & Webster, 2016).

**Peer rejection and victimisation**“I have to be really careful when I’m talking to her cos . . . otherwise I’ll . . . slip up or say something stupid or misinterpret it.” (YP; Tierney, Burns & Kilbey, 2016)

“It feels like in my classroom that I’m surrounded by lions…I feel like a mouse and everyone else is like a giant cat or something” (YP; Tierney et al., 2016)

“I did get bullied quite severely by most of the school actually, well by most of my grade in school” (YP; Fisher et al., 2015)

“I’m easy to aggravate, pretty much. At times, at least. Um, yeah. I was way too easy to target, I was easy pickings is the word.” (YP; Fisher et al., 2015)

**Identity**“[you are] generally wanting to fit in with your peers, but you have the added stress of being autistic.” (LSA; Cage et al., 2016)

“I think I had a sort of identity crisis really because I wasn’t quite sure who I was anymore because I was so used to…pretending to be the same as everyone else when really I knew I wasn’t.” (YP; Tierney et al., 2016)

Making friends.Autistic adolescents experienced a number of challenges in making and keeping friends (Daniel & Billingsley, 2010; O’Hagen & Hebron, 2016; Cage et al., 2016; Sedgewick et al., 2016). Daniel and Billingsley (2010) identified making new friends as the most difficult aspect of friendship for autistic adolescents. These difficulties varied with each boy they interviewed; some did not know how to approach others, another worried about trusting others. One participant, however, was enthusiastic about approaching new people to make friends, though with some reservations; he worried that people would be bothered by his talkative nature and knew that this could be difficult, therefore distanced himself from peers in order not to disturb them. O’Hagan and Hebron (2016) identified that one of the predominant challenges in making and keeping friends was the difficulty these young people experienced in understanding social conventions. Cage et al’s (2016) study highlighted that concerns about others liking them made it difficult to make new friends. In terms of maintaining friendships, Sedgewick et al., (2016) found autistic girls in particular may struggle with identifying and dealing with conflict in their social lives.   
 Age.Multiple studies noted that making and keeping friends became more difficult for these young people as they became older (Tierney et al., 2016; O’Hagen & Hebron, 2016). Tierney et al. (2016) found that changes in expectations as people got older prompted difficulties to emerge or become more problematic, for example school transition may result in changes in expectation and etiquette, which may be particularly challenging for autistic young people. O’Hagan and Hebron (2016) found that forming and maintaining friendships seemed to become more difficult as their participants got older. One support worker identified the factor of age and its association with growing awareness of difference between the young autistic person and their peers. She observed that some of her students had become more socially isolated over the four years they had been at the school, possibly because of a developing awareness that others were not very nice to them, without developing awareness of how to change that relationship.   
 Group interaction.It emerged that autistic adolescents tended to find group interactions particularly difficult (Cage et al., 2016; Tierney et al., 2016; Foggo & Webster, 2016). Cage et al. (2016) identified that strangers’ observations could cause anxiety to autistic adolescents, for example when doing things in a group setting. Tierney et al. (2016) also found that group communication was considered challenging by all of their participants. Foggo and Webster (2016) showed that autistic adolescents often found social interaction difficult, and managing conflict in group interactions especially so. Such challenges often arose from differences of opinion and general conflict, described by a young person as “when some people want one thing and the rest want another”. Only one participant across all studies claimed there were no negatives to socialising with a group of friends. Group interactions were also linked by participants of this study to feelings of social exclusion and the majority of participants reported that they had felt socially excluded from a group at some time.   
Peer rejection and victimisation.Many autistic adolescents had experienced peer rejection or victimisation (O’Hagen & Hebron, 2016; Tierney et al., 2016; Fisher et al., 2015), and subsequent feelings of sadness or anxiety (Tierney et al., 2016; Cage et al., 2016; Fisher et al., 2015). Some of the perceived reasons for such behaviours related to core autism difficulties, with a few participants blaming themselves. O’Hagan and Hebron (2016) found that peer rejection was experienced by all students they interviewed. Tierney et al. (2016) investigated this topic in more depth and found that when autistic adolescents broke the social rules they were singled out and consequently experienced peer rejection. This led to these young people feeling unable to fit into social situations. Participants attributed some of their experiences of peer rejection to their core autism difficulties, which are characterized by difficulties with social communication. Tierney at al. (2016) noted that when participants began to struggle to cope with extra demands placed on their socio-communication skills as they were expected to make new friends, often secondary mental health difficulties (e.g. affective disorders) emerged. Cage et al’s (2016) study also highlighted the difficulty with managing social reputation when others might respond negatively to the individual being autistic.   
 The type of victimisation experienced by autistic adolescents included verbal victimisation (reported most often), physical victimisation, relational victimisation and unspecified (reported bullying but with no specific details; Fisher et al., 2015). Most participants in Fisher et al.’s (2015) study had experienced some form of peer victimisation. Reasons for bullying included personal attributes, such as the individual blaming themselves, seeing themselves as easy targets, or bullies targeting them for being autistic, and others’ opinions of them, for example others not wanting to be around them. Some adolescents expressed annoyance with bullies. It is worth noting that few studies mentioned bullying explicitly, due to it not being the main focus of their paper. Fisher et al.’s (2015) paper was the only paper identified to qualitatively explore peer victimisation in this group.  
 Identity. Autistic adolescents often had constructed an understanding of their autism, with some accepting and others rejecting it as part of their identity (Humphrey & Lewis, 2008; Cage et al., 2016; Tierney at al., 2016). Identity development is a challenge faced by all adolescents but may be particularly more challenging for autistic individuals, who might feel somewhat different to their peers. Humphrey and Lewis (2008) found autistic young people were faced with the task of constructing an understanding of autism, and some talked about themselves and their autism in negative terms. Others, however, thought autism was simply part of ‘who they are’. Characteristics of autism were recognized as making life in school more difficult, for example social naivety can be exploited by other pupils. In Cage et al.’s (2016) study, staff recognized the challenge of being autistic in a neurotypical world. Tierney et al. (2016) highlighted that autistic young peoples’ social-communicative difficulties were a barrier to developing friendships, as mutual misunderstandings made bonding difficult. Participants were often aware of this, making it at times difficult to accept and embrace being autistic.

Overcoming Challenges

**Box 4: Overcoming Challenges**

**Adapting behaviour  
“**Yes, my phone’s already going “ring, ring” and then I pick up, “Hello,” and it’s like, “Gosh, not you again!” And then, “ring, ring” . . . “ring, ring” . . . Gosh! . . . And my phone bill’s already far too high.” (YP; Carrington et al., 2003) (*Given as* *example of masquerading)*

“I have a very good memory so I can… relate that to a situation the other person’s in… I sort of used that memory and just associated with what she knew” (YP; Tierney et al., 2016)

“I see how other people act first then copy them in my own way…I change it a little bit so it’s not like I’m really copying them.” (YP; Tierney et al., 2016)

‘Sometimes it’s like, “make me normal’’’ (YP; Humphrey & Lewis, 2008)

**Support from others**

“There was something about them that was more like mothering rather than like “oh, get out of here, you’re strange, we don’t want anything to do with you” (YP; Tierney et al., 2016)

“My mom tries to help me be a good friend” (YP; Howard et al., 2006)

**Responding to bullies**

“I first ignore them, they’re very persistent. Very persistent. And you can’t ignore it when it’s physical” (YP; Fisher et al., 2015)

“Um, my responses were at times not the best. [Ok, why do you say that?] Well, threatening to cut someone up and describing in detail of what you would do, not the smartest thing to do. I have a very active imagination, not the best at times, especially when you’re really angry and you want to scare someone.” (YP; Fisher et al., 2015)

Adapting behaviour.Concern for reputation and awareness of their social communication difficulties led many of the interviewed autistic adolescents to develop strategies for overcoming the challenges they experienced with peer relationships (Carrington et al., 2003; Tierney et al., 2016; Humphrey & Lewis, 2008; Howard et al., 2006). The coping strategies that were discussed in the reviewed papers included ‘masquerading’; pretending to know how social situations work and adapting behaviour accordingly to mask difficulties. In Carrington et al.’s (2003) study, the authors talked about how participants told stories about the numbers of friends they had and how easy interactions with them were as a way of masking their social communication and interaction difficulties with their peers, though authors did not provide credible evidence to support the assumption that participants were not being truthful about their interactions with peers. Tierney et al.’s (2016) participants described a range of sophisticated strategies that the autistic adolescents had developed, which utilised innate strengths and enabled them to appear socially-competent to observers, and not stand out to others. For example, one young person spoke of showing empathy by matching corresponding memories to another person’s situation in order to create a concrete reference point. Another spoke about pretending to be occupied, whilst observing others to later imitate them. Tierney at al. (2016) considered that, based on the young people’s reported experiences, these strategies had negative repercussions on the psychological wellbeing of the majority of participants. For example, autistic adolescents adopting these strategies might have felt as though they were not being true to themselves, which might have hampered access to support, as their difficulties were being hidden. Other, less explicit, ways of adapting the self were mentioned in the reviewed studies. Humphrey and Lewis (2008) talked about their participants having to negotiate ‘difference’, meaning that autistic students felt forced to adapt themselves to submerge in the social world of the school. Howard et al.’s (2006) case study revealed that Tom recognised sometimes he had to put his own interests aside and ‘get interested in others’ interests’, since he and his friends did not always have the same interests. Tierney et al. (2016) also noted that their participants tried to choose friends who would nurture them, for example autistic adolescents often described female peers who had supported them in their acquisition of social skills. Support from others.It was reported in multiple studies that sometimes parents and school staff could be used to facilitate autistic adolescents’ social relationships (Tierney et al., 2016; Howard et al., 2006). Tierney et al. (2016) found that initiating friendships might be facilitated by parents. Similarly, in Howard et al.’s (2006) case study, both Tom and his mother described that Tom’s mother facilitated his social relationships by providing opportunities for Tom to meet and engage with people, and by offering advice to help him succeed in his friendships.Responding to bullies.In response to difficulties with peer victimisation, reactions varied. In Fisher et al.’s (2015) study, some autistic adolescents said that they would report incidents of bullying to a member of staff, to try and gain their support, whereas others tried to adapt their own behaviour instead. Many tried to ignore bullies and tried to control their emotions, though some found this difficult to achieve. There were also reports of autistic adolescents trying to retaliate against bullies, whereas others tried to work on making themselves more intimidating in the future. It was also reported that some participants added qualifiers to try and minimize the seriousness of the situation, for example when one adolescent was describing how a peer tied his shoes together, he stated dismissively, “I know, poor me”.

## Discussion

### How Do Autistic Adolescents Experience Peer Relationships?

Autistic adolescents understood the concept of friendship, though this understanding was somewhat limited in content and different to how their peers or others might describe friendship. This supports research by Bauminger and Kasari (2000), who found autistic young people aged 8 to14 had less complete understandings of friendship and loneliness than their TD peers; our findings suggest this extends to older adolescents (Carrington et al., 2003; Sedgewick et al., 2016; Tierney et al., 2016). The current review identified that descriptions of friendship may appear scripted or learned and other informants agreed that autistic adolescents’ friendships had different qualities to typical friendships. Many of the young people interviewed said that they struggled with understanding covert social rules and that sometimes, even if they were able to identify the rules, individuals were not able to follow them. Ruffman et al.’s (2001) and Senju et al’s (2009) research similarly demonstrates that many autistic youths have difficulty with automatically working out another’s perspective to establish what is expected of them in social situations.

Autistic adolescents could identify qualities that they would find important in a friend, though there tended to be more emphasis on shared interests and activities than on intimate qualities of friendship, such as affection and emotional support. The absence of intimacy in descriptions of friendships was also found in Bauminger and Kasari’s (2000) paper, who saw a low frequency of affective dimensions (affection and intimacy) in the definitions of a friend provided by autistic adolescents compared to TD adolescents.

Importantly, this review highlighted that most of the autistic adolescents had a desire for friendships. This desire was often met, but it also sometimes led to feelings of loneliness, when it was difficult to achieve. Quantitative research also shows autistic adolescents do have and want friends (e.g. Orsmond et al., 2004; Bauminger & Schulman, 2003). One of the reviewed studies looked at gender differences, which highlighted that autistic girls may be more socially motivated than autistic boys. Most of the interviewed young people considered school the best place to make friends, and some friendships were facilitated by an in-school autism resource centre. This meant that autistic adolescents tended to have more autistic friends than their TD peers, though this is an area that warrants further research. Autistic adolescents made lasting friendships, though their parents and teachers often had a different perspective on the quality and quantity of these relationships.

Autistic adolescents were aware that they had a reputation and understood the concept of others viewing them differently to how they viewed themselves. Some were more concerned about this than others, supporting previous research into how autistic individuals construct their autistic identity (e.g. Baines, 2012; MacLeod, Lewis & Robertson, 2013). There were reports of individuals wanting to adapt themselves to try and appear ‘cool’, whereas others were intent on staying true to themselves. Not understanding social rules and conventions can make it difficult for autistic young people to manage their reputation and fit in with peers. Some believed they were perceived by others in a negative light, due to their refusal to act like others did.

Autistic adolescents faced multiple challenges in negotiating peer relationships. Some young people identified making friends as the hardest part, providing reasons such as not knowing how to approach others and not trusting others. Misunderstanding social conventions was identified multiple times as something that makes it hard to form and maintain friendships, which has been shown previously (Kunce & Mesibov, 1998). Another factor that might affect autistic adolescents’ ability to maintain friendships is their difficulty with understanding and dealing with conflict in social settings. It was noted in multiple studies, either by the young people themselves or by related informants, that these challenges become more difficult to manage, or more prevalent, with age. Reasons for this were given, such as there being changes in etiquette and expectations due to school transition, or due to growing awareness of difference and victimisation. This supports other research, such as Kuusikko et al. (2008) and Adreon and Stella (2001), who identified adolescence as a particularly difficult time for autistic people, as social expectations increase and peer relations become more complex. It is understandable that autistic adolescents would find the impact of these challenges upsetting, given that intimate peer relationships are known to become increasingly valuable for adolescents (Janowski et al., 2014). Group interactions were identified as being especially difficult for autistic adolescents. Some reported managing multiple views and conflicts as stressful, others linked group settings to feelings of social exclusion. It was also reported that group social interaction could cause anxiety due to the feeling of being watched by multiple people at once; this should be considered when developing group-based social skills interventions with this population (see Rao, Beidel & Murray, 2008).

Peer rejection and victimisation was found to be common towards autistic adolescents, resulting in negative consequences such as sadness and anxiety, as supported by quantitative research findings (e.g. Cappadocia, Weiss & Pepler, 2012; Shtayermman, 2007). Many young people blamed themselves or being autistic for the treatment they received. Some accepted and others rejected being autistic as part of their identity in social settings, viewing it either in negative terms or as part of ‘who they are’, but most young people recognized that characteristics of autism made school life and social interaction more difficult. Peer rejection was perceived to result from autistic adolescents breaking social rules, which supports findings by Kloosterman et al. (2013). The type of victimisation received by the young people varied, with verbal victimisation being reported as most common. Autistic adolescents often viewed themselves as easy targets and felt others did not want to be around them, which is why they rejected or bullied them. This supports research findings by Delfabbro et al. (2006), who found that autistic young people may be vulnerable to victimisation and abuse of power by peers due to being marginalized and unprotected within the social group. It is also known that victimisation further exacerbates social difficulties (Van Roekel et al., 2010), making it difficult for these young people to break the cycle of being victimised. The same authors linked frequent victimisation to many mental health problems in autistic young people, as rated by parents, which was also a notion that emerged from the reviewed studies.

Despite facing multiple challenges in peer relationships, the autistic adolescents interviewed in the reviewed studies showed resourcefulness and resilience in their efforts to overcome these challenges. Some reported strategies such as masquerading; trying to mask difficulties with social interaction by presenting themselves as especially socially competent and popular. Examples of masquerading relate to the literature on camouflaging in autistic adults (e.g. Hull et al., 2017; Lai, Lombardo, Auyeun, Vhakrabarti & Baron-Cohen, 2017).

Autistic adolescents in the reviewed studies reported studying the behaviour of others to copy them and learn how they handled social situations. Some participants were able to use sophisticated strategies, such as linking their current experience to a memory of a similar past event, to try and empathize with the person in front of them. Autistic adolescents spoke about choosing friends who nurtured them and supported their social skills acquisition. Parents and teachers may also help these young people with their social relationships, which supports previous quantitative findings (e.g. Bauminger & Shulman, 2003). Responses to bullies varied, with some reporting incidents to teachers or parents, and others trying to ignore bullies. Other strategies for responding to victimisation included minimising the seriousness of the incident, intimidation and adapting one’s own behaviour to try and stop the bullying from happening in the future. These strategies varied in how adaptive they seemed to be, with some of them being perceived as helpful, and others having the potential for negative psychological consequences. For example, autistic adolescents masking their difficulties might limit access to support and prevent them from feeling able to be themselves and know themselves (Schroeder et al., 2014).

### Study Limitations

All of the studies in this synthesis obtained the perspective of autistic youth about their experiences of peer relationships, however only one study (Sedgewick et al., 2016) also interviewed TD adolescents to ascertain whether autistic adolescents’ experiences were different to typical adolescent experiences. In a few of the reviewed studies (Howard et al., 2006; O’Hagan & Hebron, 2016; Daniel & Billingsley, 2010; Cage et al., 2016) other informants were interviewed, for example teachers and parents, in an attempt to gain their perspectives on the young people’s friendships, however no one interviewed the friends in question, to explore and validate the experience of a friendship with an autistic adolescent, as a reciprocal relationship.

It is important to consider the possible effect of combining studies from different settings, theoretical backgrounds and with different quality ratings. Most studies recruited their samples from mainstream school settings, although there were also studies which recruited from specialist educational settings (Sedgewick et al., 2016) and another was a case study of a boy who had been home schooled (Howard et al., 2006). It would be ideal to treat these participants separately and compare their responses and experiences, however that was beyond the scope of this review. Studies looking at bullying and those looking at friendships were also pooled together for the purpose of the review, and it is arguable that these concepts should be treated separately.

More generally, the pooling of qualitative findings is subjective, due to there being multiple approaches to data synthesis, multiple perspectives involved in the review and varying study quality. We recognize the usefulness of alternative interpretative approaches, such as meta-ethnography, as well as narrative synthesis and thematic analysis. For example, the usefulness of meta-ethnography lies in its ability to generate theoretical understandings that may or may not be suitable for testing empirically. Thematic synthesis is of use in drawing conclusions based on common elements across otherwise heterogeneous studies. We consider, however, that these approaches do not seek to provide guidance for action and aim only to ‘anticipate’ what might be involved in analogous situations and to understand how concepts connect and interact. Meta-aggregation is the preferred approach for developing recommendations for action.

### Implications for Policy and Practice

A clear finding from this review is that there are additional challenges with regards to peer relationships for autistic adolescents, compared to their typical peers. Autistic adolescents may require additional support from school staff and parents to help them to understand social rules, build and maintain friendships, and manage bullying. Schools may consider offering social skills training groups, which have shown preliminary efficacy with autistic youth, according to a review by Cappadocia and Weiss (2011). However, Carrington et al.’s (2016) findings highlighted that, while some autistic adolescents perceived the support they received as appropriate and as helping ease their anxieties about school, others felt the ‘visibility’ of additional support provided often made pupils feel their differences were accentuated. Any interventions that are offered or developed should therefore consider how the young people feel about being supported and should be developed in a way that is as low-key, and de-stigmatising as possible.

The finding that autistic adolescents tend to mask their difficulties with social interaction or develop strategies to help them ‘fit in’ with their peers, is important to consider in future policy and practice developments for this group. School staff and parents may perceive autistic adolescents to be coping better than they are and masking their difficulties may contribute to these young people developing emotional difficulties. Perhaps if efforts were made, in schools and in public awareness campaigns, to increase the understanding and acceptance of autism, young people would feel less pressure to hide their true selves. Schools provide a good platform to foster inclusiveness and encourage understanding of difference, and this should be a priority for schools that wish to support the healthy social-emotional development of autistic young people. Increased awareness and understanding of difference amongst school pupils may increase acceptance, which in turn could reduce bullying and victimisation experienced by autistic adolescents. Humphrey and Hebron (2015) highlighted that research on anti-bullying interventions for autism is in its relative infancy. Current available evidence (e.g. Cappadocia and Weiss, 2011; Myers, Ladner and Koger, 2011; Locke, Ishijima, Kasari & London, 2010) suggests that a multi-level, comprehensive approach to intervention that offers parallel foci on autistic children and young people, their peers, teaching and support staff, and the broader school ethos and climate is warranted. Interventions should acknowledge the elevated risk experienced by this group and should be tailored to their specific needs.

### Implications for Research

Based on the findings of this synthesis we believe that further research is needed both to develop understanding of autistic young people’s experiences of peer relationships, and to test recommendations and practical strategies that might facilitate meaningful social inclusion for this group. An evident gap in the literature is exploring experiences of peer relationships with autistic adolescents from the peers’ perspective. Building a clearer understanding of the nature of the friendships experienced by these young people from both sides would help in the development of strategies to help facilitate these friendships. For example, if autistic young people are experiencing friendships in a way that is different to how those named friends would describe the relationship, it would be important to be aware of this. On the other hand, if autistic adolescents tend to perceive their friendships similarly to their named friends, this would suggest that recognising genuine friendship is not an area that requires additional support.

More qualitative research should be undertaken to explore autistic adolescents’ experiences of bullying and victimisation, particularly given its known association with mental health difficulties (Van Roekel et al., 2010). In the reviewed study by Fisher et al. (2015), both playful and harmful teasing was reported by autistic adolescents. More could be done to explore whether autistic adolescents are able to distinguish between the two, and how they cope with or tolerate each type of teasing. Additionally, given the reported instances of masquerading and reputation management, it is possible that participants across the reviewed studies did not report some of the victimisation they may have been experiencing.

There is distinct need for further research on a larger scale in this area, in order to develop effective practice. Pellicano, Dinsmore and Charman (2014) investigated the views of the UK’s autism community on the nature of research currently conducted and priorities for future research. Their results suggested that autistic adults, family members, practitioners and researchers felt that priority should be given to the management of practical, social and emotional issues in autistic people of all ages. Autistic adults, parents and practitioners were all concerned that there is insufficient understanding about autism, including both limited expert knowledge and a lack of accurate public awareness. There is guidance (e.g. Department for Education and Skills, 2002) on how to deliver good practice to autistic children and young people, however there has been some concern expressed about the extent to which it is utilized in schools (House of Commons Education and Skills Committee, 2006). Therefore, schools in particular would benefit from research and knowledge transfer that gives indication of what works, how it works, and in what contexts it works, in this area. Such research would benefit from comparing male and female autistic adolescents, as this review has highlighted they may experience and understand peer relationships differently, which therefore has implications for developing targeted interventions.

### Conclusions

This synthesis indicates that autistic adolescents have and want friends. There are a number of difficulties they face with making and keeping friends, primarily due to their difficulty with understanding social rules and conventions or knowing how to conform to them. Perhaps due to their perceived ‘difference’, rejection and peer victimisation is commonly experienced by autistic adolescents, which can cause anxiety, upset and feelings of loneliness. Some autistic adolescents care about being ‘cool’ and adapting their behaviour to fit in. Others wish to stay true to themselves, even if that means they are not accepted by their peer group. School staff and parents should make efforts to increase general understanding and acceptance of the social difficulties faced by autistic adolescents, to reduce incidences of peer victimisation. Additional support should be offered to autistic adolescents to support the development of their social skills and awareness; further research is needed to establish how this could be done most effectively.

## Part Two: Empirical Paper.

# ‘Who Am I?’ Do Conceptions of Personal Identity and Acculturation Relate to Psychological Wellbeing and Positive Self-concept in Autistic Adolescents?

## Abstract

Autistic adolescents are at increased risk of experiencing mental health difficulties in adolescence. One factor that might contribute to this is the task of identity development; working out ‘who am I?’ and ‘where do I fit in?’ There has been recent interest and development in the idea that autistic people are building an emerging culture with its own unique identity, and qualitative studies have suggested there is variation in how autistic adolescents relate to autistic culture. The current study therefore aims to explore the relationship between personal identity, acculturation (alignment to autistic and non-autistic culture) and psychological wellbeing, including positive self-concept, in autistic adolescents. Twenty-nine (male = 27, female = 3) adolescents with a diagnosed autism spectrum condition completed self-report measures investigating personal identity, acculturation and psychological wellbeing. Findings revealed that psychological wellbeing was not related to personal identity strength. Desrciptive data indicated that those who aligned themselves only to non-autistic culture appeared to have better psychological wellbeing scores and were able to generate a higher proportion of positive statements about themselves than those who aligned themselves to neither culture. Only a small number of participants aligned only to autistic culture, which raises questions about the process and trajectory of acculturation for autistic adolescents. Findings suggest that autistic adolescents should be helped and encouraged to explore both autistic and non-autistic culture, and what autism means to them, so that they can make choices and commitments regarding their cultural identity.

## 

## Introduction

### Autism and Adolescence

Over the past decade and worldwide, estimates of increases between 50% to over 2000% in cases of autism diagnoses have been charted, studied and discussed (Centers for Disease Control and Prevention, 2009), making the search for greater understanding and awareness of its complexities essential. Adolescence can be especially difficult for individuals on the autism spectrum, as social expectations increase and peer relations become more complex (Adreon & Stella, 2001). Autistic adolescents face multiple additional social challenges in adolescence, which are described in detail in the current literature review (Part One, pp.14-16), including increased bullying and peer victimization (Sterzing et al., 2012; Kuusikko et al., 2008).

### Autism and Psychological Wellbeing

Research has shown that autistic individuals are at higher risk of developing psychiatric difficulties, particularly anxiety and depression symptoms (e.g. Tantam, 2000; Ghaziuddin et al., 2002), and this increased vulnerability is particularly prominent during adolescence amongst autistic individuals (e.g. Vickerstaff et al., 2007; Lecavalier, 2006). There is evidence that autistic children and adolescents tend to have differences in self-perceptions relating to competencies, with young autistic people being less likely to perceive themselves as socially or physically competent and reporting poorer ratings of global self-worth compared to typically developing peers (Capps, Sigma & Yirmiya, 1995).

Strang et al. (2012) conducted a large-scale study looking at autistic children and adolescents and found that 40% of their sample had borderline or clinical levels of depression and/or anxiety symptoms. More specifically, the prevalence rates for anxiety and depressive disorders have been found to be 41–42% and 6-10% respectively in this population (Gjevik, Eldevik, Fjaeran-Granum & Sponheim, 2011; Mattila et al., 2010). Chiang and Gau (2016) found that comorbid psychiatric conditions (e.g. anxiety/depression, inattention and oppositional behaviour) mediated the link between autistic symptoms and social difficulties, suggesting that psychiatric comorbidity might exacerbate an autistic adolescent’s psychosocial functioning.

Although it can be unreliable to depend on one type of methodology (e.g. parent report, clinical ratings) to arrive at a complete understanding of the behaviours and symptoms present in autistic adolescents (Lord, Corsello & Grzadinzinski, 2014), there is substantial evidence to suggest that psychiatric comorbidity is a common and important problem in autism, which is likely to negatively impact upon an autistic individual’s experience of adolescence.

### Identity Development and Psychological Wellbeing

Given the prevalence of comorbid mental health difficulties amongst autistic adolescents, it is important to examine factors that might contribute to the development of such problems. One key task that takes place during adolescence is identity development, whereby an individual begins to question and distance themselves from the expectations, values and identities handed down to them from their parents (Marcia, 1980). Identity can be defined as the way a person understands and views him or herself, and is often viewed by others (Holland, 2001).

James Marcia (1980) developed identity status theory, the core idea of which is that one’s sense of identity is determined largely by the choices and commitments made regarding certain personal and social traits. Marcia (1890) proposed that a well-developed identity comprises of a sense of one’s strengths, weaknesses, and individual uniqueness. Two processes of identity development were proposed: exploration and commitment. Exploration referred to some period of thinking through and trying out various roles. Commitment referred to the degree of personal investment the individual expressed in a course of action or belief (Kroger & Marcia, 2011).

Identity status theory has been criticised and developed, for example by Weinreich and Saunderson (2005), who argued that individuals transition between exploration and commitment at different and multiple times in their lives, depending on biographical experiences and resolution of conflicted identifications situated in various contexts; it is not a linear or fixed process. Additionally, it has been proposed that the theory does not relate to identity development in non-White populations due to them not being adequately represented in the research upon which it was developed (Sneed, Schwartz, Cross & William, 2006). Similarly, there is no evidence that autistic samples were specifically used to develop or test this theory, however that is not to say that these ideas may not relate to autistic individuals.

Erikson (1968) introduced the idea that a relationship exists between identity development and psychological wellbeing. Research using general population samples shows that adolescents with high anxiety struggle more with identity development (Crocetti, Rubini, Luyckx & Meeus, 2008) and those who have not made a commitment, according to Marcia’s (1980) theory, tend to have higher depressive symptoms in adolescence (Meesus, van de Schoot, Keijsers & Branje, 2012). In a review of 12 studies, Meesus, Iedema, Helsen and Vollebergh (1999) found that those who were actively exploring their identity had higher scores than those who had made commitments with regards to various development domains, with or without exploration, on various indicators of internalizing problems such as anxiety, negative affect, tendency to worry, and depression.

The process of identity development can be particularly difficult to navigate when an individual has a disability or neurodevelopmental condition, such as autism (Gill, 1997). Any awareness of being different, and of being stigmatised, could have an impact on the development of the self-concept and self-esteem of the individual, which has been demonstrated amongst deaf adolescents (Cornell & Lyness, 2005). Perhaps the individual recognises and shares the negative representations that others associate with their ‘differentness’ (Corrigan, Kerr & Knudsen, 2005; Link & Phelan, 2001). If identity development is more difficult for autistic individuals, and there are identified links between difficulties with identity development and psychological wellbeing (e.g. Meeus et al., 1999, Crocetti et al., 2008), then identity development might contribute to explaining increased mental health comorbidity amongst autistic adolescents.

### Autism and the Self-concept

Self-concept, a term used to refer to how someone thinks about, evaluates or perceives themselves, has widely been considered as a reflection of an individual’s perceptions about how they appear to others, an idea known as the “looking glass self” (Cooley, 1902). Cooley (1902) posited that the self is inseparable from social life and necessarily involves some reference to others. If social relationships play a key role in the development of the self-concept, then frequent victimisation, teasing or physical bullying often experienced by autistic adolescents might lead a person to internalise a negative view of the self (Tantam, 1992). Additionally, autistic individuals have known difficulty with automatically considering someone else’s perspective, motives, thoughts and feelings (Ruffman, Garnham, & Rideout, 2001; Senju, Southgate, White, & Frith, 2009), which is likely to influence their social relationships (Attwood, 1997), and in turn their self-concept (Lee & Hobson, 1998).

Global self-concept has been found to be the most powerful intrapersonal correlate of life satisfaction and happiness in reports from adults and children in the general population (Diener, 1984; Huebner, 1991). Individuals with a positive self-concept evaluate themselves positively and are likely to make favourable inferences about themselves (Baumeister, 1997). Beck (1967) has postulated that depressive individuals carry with them a depressive self-schema that continually distorts self-relevant thoughts, and research shows that depressed individuals think more negatively about themselves than about others (Derry & Kuiper, 1981; Ingram, Smith & Brehm, 1983). It is therefore important to consider positive and negative self-concept when examining identity (Markus & Wurf, 1987).

Autistic adolescents not only negotiate forming their personal identity, but they also start to question their social identity and where they fit in, in terms of their minority group status within the majority culture of non-autistic peers (Ozonoff, Dawson & McPartland, 2002). Social Identity Theory (Tajfel & Turner, 1979) assumes that one part of the self-concept is defined by our belonging to social groups. If group membership provides individuals with a sense of meaning, purpose, and belonging, it can have positive psychological consequences (Haslam, Jetten, Postmes & Haslam, 2009). A sense of shared social identity can be protective against the negative consequences of marginalisation, by members of the disadvantaged group coming together to buffer the effects of difference (Blaine & Crocker, 1995; Postmes & Brandscombe, 2002). Autistic adolescents must define how this cultural aspect of their identity informs who they are, which has been documented as a process that happens amongst other minority groups, such as ethnic minorities (Adams, Gullotta & Montemayor, 1992).

### Autistic Culture

To understand the process of identity formation in autistic adolescents, we must look to research that seeks to understand how autistic people view themselves and their autistic social identity. Acculturation refers to the process of cultural and psychological change that occurs following the meeting between cultures (Sam & Berry, 2010). Berry (1986) describes four acculturation types: marginalised (alignment to neither cultural group), bicultural (alignment to both cultural groups), assimilated (alignment to majority group, rejecting own minority culture) and separated (alignment solely to those from own minority culture). Whether to align oneself to an autistic culture or not might be a complex negotiation faced by many autistic adolescents. It could be considered a process of identity exploration, leading towards commitment when the individual aligns themselves to autistic culture or not, as per Marcia’s (1980) identity status theory.

There has been recent interest and development in the idea that autistic people are building an emerging culture with its own unique identity (Dekker, 1999). For example, Kenny et al. (2016) found that autistic adults and their families preferred the term ‘autistic’ to ‘person with autism’, as they felt that autism was not something that can be removed or outgrown and it forms an integral part of who that person is. In the 1990s, some parents of autistic people responded to the perceived marginalisation of their autistic children by initiating the neurodiversity movement, which advocates self-identification as autistic and viewing autism as a positive identity that needs no cure (Chamak, 2008; Ortega, 2009). This movement was considered an antidote to the medical model, which aspires toward normalisation, symptom reduction, and elimination of conditions identified based on deficits said to cause functional impairment in major life activities (American Psychological Association, 2000; Baker, 2011).

It should be noted that the brain-based difference championed by the neurodiversity movement rests on a body of uncertain and contested neuroscientific data, as there is not yet a consensus on the aetiology of autism (Nadesan, 2005). Nonetheless, support for this movement comes from a body of psychological evidence, suggesting that that some autistic adolescents take pride in being different (e.g. Cage et al., 2016). Humphrey and Lewis (2008) interviewed autistic young people about their experiences of autism and a subset of pupils saw autism simply as part of ‘who they were’; they had come to accept and even celebrate their differences. One participant commented, “I like being like this you know, that’s the way it is.”

However, there is also evidence to suggest that some autistic young people distance themselves from their autistic identity (Baines, 2012; Huws & Jones, 2008) and hold negative perceptions of their differences, along with showing concern for not ‘fitting in’ (Humphrey & Lewis, 2008). Carrington and Graham (2001) interviewed two autistic adolescents about their experiences of autism, which highlighted the possibility that not accepting autism as part of one’s identity could negatively affect an individual’s psychological wellbeing. The study demonstrated that some autistic individuals become more aware as they grow older of their ‘differentness’; they want to ‘fit in’ but do not know how. The emotional stress associated with the basic need to belong (Baumeister & Leary, 1995) is evident in one of the participants’ interview quotes, “When the other kids listen to you, they tease you. Sometimes I wish I didn’t have Asperger’s. I wish I wasn’t autistic.” Although it is difficult to draw strong conclusions from a sample of only two individuals, these findings indicate it may be important for the wellbeing of autistic adolescents to have a positive sense of group belonging.

Cooper, Smith and Russell (2017) conducted a large-scale study that examined measures of self-esteem, depression, anxiety and autism social identification in autistic adults. Results of the study indicated that less autism identification related to more anxiety and depression symptoms, which was mediated through increases in collective self-esteem (perceived positivity of autism identity) and personal self-esteem. This finding suggests having a positive autistic social identity might offer a protective mechanism against psychological difficulties for autistic adults.

### The Current Study

Mental health in autism is a recognised problem and research can help in its understanding, treatment and prevention. Given that identity development has been found to relate to mental health outcomes in the general population (Crocetti et al., 2008; Meeus et al., 2012), and that identity concerns are prevalent amongst autistic adolescents (Cage et al., 2016; Baines, 2012; Huws & Jones, 2008), it is worth further exploring the relationship between identity development and psychological wellbeing in autistic adolescents. The current study aims therefore to build on findings by Cooper et al. (2017), who have highlighted the potential importance of investigating the link between sense of autistic identity and its relation to psychological wellbeing. These authors used an online sample of adults who self-identified as autistic, which could mean that not all participants met full diagnostic criteria. The current study will focus on a different sample group, adolescents, with a formal diagnosis of autism. Furthermore, Cooper et al. (2017) looked at autism identification, whereas the current study will be an exploratory study, investigating acculturation, thus looking not only at how autistic adolescents identify with and align themselves to autistic culture, but also how they relate to non-autistic culture. The measure used in the current study (Autism Identity Scale; Jarrett, 2014) considers multiple aspects relating to autistic and non-autistic social identity, including cultural identity, cultural involvement, cultural preference and cultural competence.

### Hypotheses

First, we propose that there will be positive a relationship between strength of personal identity and psychological wellbeing in autistic adolescents (H1). Second, we predict that those who align to only autistic or non-autistic culture will have better psychological wellbeing outcomes than those who align to both or neither cultures (H2). Finally, it is anticipated that those who align to only autistic or non-autistic culture will have more positive self-concepts than those who align to both or neither cultures (H3).

## 

## Method

### Participants

Participants were recruited through four mainstream secondary schools in London, and through a specialist service for autistic adolescents and their parents. The researcher had existing relationships with a senior staff member from each school, who were contacted and each agreed to disseminate the project information to all parents of autistic children at their school. Recruitment through the specialist autism service took place via a senior member of the organisations disseminating the study information to their parent database via e-mail. Interested parents then got in touch with researcher, either directly or through a named staff member. To meet eligibility for the study, individuals had to be aged 12 to18, and have a clinical diagnosis of an ASC. Non-verbal individuals, or individuals with a diagnosed learning disability, were not eligible for participation due to the nature and complexity of the concepts being explored.

Ethical approval was obtained from Royal Holloway University of London’s Research Ethics Committee. The study was first proposed to parents via letters sent home, and consent for their child’s participation was requested. The researcher then arranged to meet each consented young person, either at home or at school, to explain the project and obtain the young person’s written consent on the day of testing.

A-priori power was calculated using Cohen’s Power Primer (Cohen, 1998). Performing a multiple regression analysis at significance level α = 0.05, expecting a large effect size (*f2=0.1;* based on previous comparable literature e.g. Umana-Taylor and Updegraff, 2007; Latrofa, Vaes, Pastore & Cadinu, 2009*)* and using up to three predictor variables (identity strength, autistic acculturation, psychological wellbeing), Table 2 of Cohen (1998) indicated that a sample size of 34 was required. The final sample (n=29) included males (n=26) and females (n=3) between the ages of 12 and 18 (M= 13.8, SD = 2.30). Five participants were excluded from the analysis due to either verbal Intelligence Quotient (IQ) scores below 70 (n=3) or incomplete data across all measures (n=2). Age, gender and verbal IQ were controlled for in the analyses due to their potential influence on identity development (Carrington & Graham, 2001; Lai et al., 2015; Grotevant, 1987; Braverman, 2016). All participants had a formal diagnosis of an ASC (including Autism Spectrum Disorder and Asperger’s Syndrome), confirmed via parent report. The Social Communication Questionnaire (SCQ; Rutter, Bailey and Lord, 2003), completed by parents, was used to confirm ASC diagnoses; all participants scored above the clinical cut-off score of 15 (M=20.5, SD = 4.12, range = 15-27).

### Materials and Procedure

Consideration was given to the use of self-report measures with autistic adolescents, particularly those requiring identification of thoughts and feelings, as data collection through self-report can be problematic (Sofronoff, Attwood, & Hinton, 2005). Nonetheless, it has been shown that young autistic people can use structured measures to undertake self-reflection (Knott, Dunlop, & Mackay, 2006). Jones, Sensenig and Haley (1974) noted problems with “rating” methods to measure identity, as they restrict individuals to pre-determined items and may not provide categories that accurately define an individual in a way that is meaningful to their set of self-concepts. Alternative methods that are more open-ended, allowing individuals to describe fully their sense of self, were considered as the most appropriate way of measuring a construct as complex and multidimensional as “the self” (McGuire & Padawer-Singer, 1976).

Sessions lasted 40 to 60 minutes and began with the researcher explaining that some of the questions would address sensitive subject areas, and that participants should not feel obliged to answer any questions that made them feel uncomfortable. The researcher emphasised that all responses would be kept anonymous and confidential. Visual cards illustrating the words ‘Stop’, ‘Pause’ and ‘Take a Break’ were presented to participants on a desk in front of them, to which they could use at any time. The following measures were administered verbally in the order that they are presented below.

Wechsler Abbreviated Scale of Intelligence (WASI). The WASI (Wechsler, 1999) is a reliable measure of intelligence. The test is nationally standardized and yields verbal, performance and full-scale IQ scores. Only verbal tests, Vocabulary and Similarities, were used in this study due to the relevance of verbal IQ to understanding and articulating the concepts explored in the study. The Vocabulary subtest required the participant to verbally define orally and visually presented words, while the Similarities task necessitated an explanation of the similarity between two orally presented word pairs. The current sample had a mean verbal IQ score of 103.85 (SD=24.19; range = 70-147).

Twenty Statements Task (TST). The TST (Kuhn & McPartland, 1954) is a measure used to assess how individuals define themselves using their own words. The task requires participants to respond to the question ‘Who am I?’ by writing down up to 20 self-concepts, in a way that best defines their long-term identity (e.g. ‘I am a thrill-seeker’, ‘I am autistic’). The TST was administered verbally, including prompts indicating possible response types (e.g. characteristics, roles, abilities), to ensure that autistic individuals understood adequately what the task required of them. See Appendix 4 for an example TST response.

Each response was coded according to a coding scheme used by Rhee, Uleman, Lee and Roman (1995), which provided three separate scores for each participant: identity strength, identity complexity and identity quality. Identity strength was the total number of statements produced, up to a maximum of 20. Identity complexity was the number of different categories produced, out of a possible seven (social identity, physical descriptions, personal identity, personal qualities, interests and activities, relationships and environment). Identity quality was the proportion of specific items (i.e. qualified with some specific detail; e.g. “I have 3 sisters”), as opposed to abstract items (i.e. responses that are general or reflective and lacking specific details; e.g. “I am kind”). Marcia’s (1980) identity theory posits that well-developed identity comprises of a sense of one’s strengths and weaknesses (captured by identity strength and complexity scores), and one’s individual uniqueness (captured by identity quality score), therefore all three scores were included in the analysis independently to capture strength of personal identity.

Nonsense responses and repeated responses were not coded. Adults from the autism community were consulted on how to use the TST data to measure self-concept and they suggested calculating percentage of positive and negative statements produced in each TST. A coding scheme was developed to identify positive (e.g. ‘I enjoy…’, ‘I am good at…’ etc.), negative (e.g. ‘I am not good at…’, ‘I am a failure’ etc.) and neutral statements (‘I am calm’, ‘I have friends’ etc.) (Appendix 5). Each participant generated scores for percentage positive and percentage negative statements produced (the remaining statements were neutral). An independent rater also coded the responses. Inter-rater correlations were calculated for all TST scores, with the resulting coefficients ranging from 0.71 to 0.93, which are similar to those reported by Rhee et al. (1995; from 0.76 to 1.00).

The TST has been used with adolescent cultural minority groups (Cousins, 1989) and autistic adults (Tanweer, Rathbone & Souchay, 2010). Though it has not yet been used specifically with autistic adolescents, Carpenter and Meade-Pruitt (2008) summarise the breadth of studies that have used the TST to investigate self-concept and recognise that its ease of use and simplicity mean it can be used across cultures and with varying participant groups.

Autism Identity Scale (AIS). The AIS (Jarrett, 2014) was developed based on the Deaf Acculturation Scale (DAS; Maxwell-McCaw & Zea, 2011). The AIS looks at whether or not an individual aligns themselves more to an autistic or non-autistic culture, by asking questions related to cultural preference, knowledge, involvement and identification. The AIS has two scales (autistic (AIS1) and non-autistic (AIS2) acculturation) and it makes use of a 5-point likert scale (from strongly disagree (1) to strongly agree (5)). Jarrett (2014) tested the AIS with autistic adolescents on two occasions and found the measure to have moderate consistency over time (r = 0.50, *p* = 0.007); minor inconsistencies could be explained by the instability of the identity concept over time during adolescence (Klimstra, Hale, Raajmakers, Branje & Meeus, 2009). Internal consistency for AIS1 was acceptable (α= 0.63) and good for AIS2 (α=0.82), using the current data. Half of the participants received the AIS1 first, and the other half received AIS2 first, which was randomly assigned to minimise order effects.

Following the methodology of Jarrett (2014), data obtained from the AIS were organised into seven deciles, which were used to obtain cut-off scores to categorise each participant into one of four acculturation groups: marginalised (AIS1 score <48, AIS2 score <55), bicultural (AIS1 score > 48, AIS2 score > 56), assimilated (AIS1 score < 48, AIS2 score > 56) or separated (AIS1 score > 48, AIS2 score < 55). These groups were used to explore H2 and H3, which look at the relationships between acculturation type, psychological wellbeing, and positive self-concept. Group characteristics for the current sample are detailed in Table 1. No significant differences exist between groups on verbal IQ (F(3,23)=.12, *p* =.95) or age (F(3,23) 1.31, *p* =.30).

Table 1

*Sample Characteristics for Each Acculturation Group*

|  |  |  |  |
| --- | --- | --- | --- |
|  | Age  Mean (SD) | Verbal IQ  Mean (SD) | Gender (male:female) |
| Marginalised (alignment to non-autistic culture; n=7) | 13.00 (2.00) | 105.71 (24.10) | 6: 1 |
| Bicultural (alignment to both cultures; (n=7) | 14.57 (2.37) | 111.57 (20.86) | 6: 1 |
| Assimilated (alignment to neither culture; n=7) | 14.29 (2.69) | 110.29 (18.29) | 6: 1 |
| Separated (alignment to autistic culture; (n=3) | 12.00 (.00) | 111.67 (3.06) | 3: 0 |

Strengths and Difficulties Questionnaire (SDQ). The SDQ (Goodman, 1997) is a 25-item emotional and behavioural screening questionnaire. The self-report version, suitable for 11 to18 year olds, was administered to participants. Items are divided between five scales of five items each, generating scores for Behaviour Problems, Hyperactivity, Emotional Problems, Peer Problems, and Prosocial Behaviours. The first four subscales are added to provide a Total Difficulties Score (internal reliability =.82; Goodman, 2001), which will be used in the current analyses as a measure of psychological wellbeing as it was highly correlated with the emotional problems score (r(22)=.87, *p* <.001) and incorporates other aspects that contribute to psychological wellbeing, such as behavioural problems and hyperactivity (Goodman, 2001).

The SDQ has been shown to possess acceptable reliability and validity when assessing adaptation and psychopathology in children and adolescents (Goodman, 2001; Goodman & Goodman, 2009). The SDQ has been used as a measure of psychological wellbeing in typical adolescents (e.g. Ussher, Owen, Cook & Whincup, 2007) and of psychiatric problems in autistic adolescents (Simonoff et al., 2013).

Social Communication Questionnaire (SCQ). The SCQ (Rutter, Bailey & Lord, 2003) is a 40-item parent-report questionnaire, which provides useful information about a child’s characteristic autistic behaviour. Each item is scored 0 or 1, with 1 being the score for endorsement of each symptom of autism. Total scores can range from 0 to 39 (the first item is a language screening question that is not included in the total score). The recommended cut-off score for an ASC is 15. The SCQ was either completed by parents concurrently, in the case of home visits, or was sent home and returned to the researcher at a later date. 22 of 29 parents returned completed SCQs.

Participants and parents were debriefed at the end of the session and the researcher responded to any questions they had. Participants were also provided with a handout containing information about where to go for support if they were experiencing emotional difficulties.

### Design

An exploratory research design, which is predominantly interested in discovery (Davies, 2006) was used. The study was a cross-sectional, single group, correlational study, with strength of identity (as measured by the TST) and alignment to autistic culture (as measured by the AIS) as the predictor variables, and psychological wellbeing (as measured by the SDQ) and positive/negative self-concept (as measured by percentage positive and negative statements derived in TST) as the dependent variables. Verbal ability, as measured by the verbal tests of the WASI, age and gender were control variables.

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## Results

Data from the scales were analysed using the ‘Statistical Packages for the Social Sciences’ (SPSS). Data screening revealed conditions for parametric testing were met (homogeneity of variance, normal distribution, and no extreme scores).

### Descriptive Statistics

The means and standard deviations of the SDQ scale scores; TST scores, including percentage positive and negative statements; and the AIS scale scores (AIS1 = autistic scale, AIS2 = non-autistic scale) are presented in Table 2. The table includes the general population means for SDQ scale scores (Meltzler, Gatward, Goodman & Ford, 2000) to illustrate that the current sample had high levels of self-reported difficulties; there was a significant difference between the sample SDQ total difficulties score, and the general population mean (t(23)=5.92, *p*<.001). In line with previous research (e.g. Strang et al., 2012), 41.6% of the current sample of autistic adolescents had borderline or clinical levels of emotional and behavioural problems, as measured by the self-reported SDQ total difficulties score (scores greater than 16).

Table 2

*Means and Standard Deviations for Strengths and Difficulties Questionnaire, The Twenty Statements Task and the Autism Identity Scale*

|  |  |  |  |
| --- | --- | --- | --- |
|  | N | Sample Mean (SD) | General Population Mean |
| *SDQ scale items* |  |  |  |
| Total Difficulties | 24 | 14.4 (6.01) | 7.1 |
| Emotional problems | 24 | 3.8 (2.26) | 1.6 |
| Behavioural problems | 24 | 2.3 (2.26) | 1.3 |
| Hyperactivity | 24 | 4.9 (2.29) | 2.8 |
| Peer Problems | 24 | 3.4 (1.79) | 1.4 |
| Prosocial\* | 24 | 6.6 (2.28) | 8.6 |
|  |  |  |  |
| *TST scores* |  |  |  |
| Identity strength | 24 | 11.4 (4.77) |  |
| Identity complexity | 24 | 3.8 (1.55) |  |
| Identity quality | 24 | 0.8 (0.22) |  |
| % positive statements | 24 | 36.8 (25.78) |  |
| % negative statements | 24 | 19.3 (25.5) |  |
|  |  |  |  |
| *AIS scale scores* |  |  |  |
| AIS1 | 24 | 46.8 (7.05) |  |
| AIS2 | 24 | 56.2 (9.64) |  |

\* Higher Prosocial scores indicate better prosocial functioning.

*Notes*: Range of SDQ scale scores: total difficulties = 0-40; emotional problems, behavioural problems, hyperactivity, peer problems, prosocial = 0-10. Range of TST scale scores: identity strength =0-20; identity complexity = 1-7; identity quality =0-1. Range of AIS scores = 0-80.

Regarding the TST, although participants were asked to produce 20 statements, the average amount they produced was 11.4 (SD=4.77). Participants typically provided multiple categories in their identity descriptions, which also generally contained specific detail, rather than abstract statements. More positive (36.8%) than negative (19.3%) statements were produced in the TST task; the remaining statements were neutral (M=43.8%, SD = 23.45). Ten participants mentioned autism in their TST responses. Average scores on the AIS2 were higher than the AIS1, indicating autistic adolescents typically felt more aligned to non-autistic, than autistic, culture (Table 2).

### H1: There will be a positive relationship between strength of personal identity and psychological wellbeing in autistic adolescents.

Zero-order correlations illustrating the relationships between identity strength (TST strength, complexity and quality), SDQ total difficulties score, age and verbal IQ are reported in Table 3. Age and verbal IQ were significantly positively correlated with identity quality, and identity strength and quality were positively correlated with identity complexity.

Table 3

*Zero-order Correlations Between Personal Identity Scores on the Twenty Statements Task (strength (TSTs), complexity (TSTc) and quality(TSTq)) and SDQ Total Difficulties Score (TSTtd) in Autistic Adolescents (n=24)*

|  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- |
|  | Age | Verbal IQ | TSTs | TSTc | TSTq | SDQtd |
| Age | 1.00 | -.07 | .12 | .12 | **.45\*** | -.13 |
| Verbal IQ |  | 1.00 | .24 | .20 | **.48\*** | -.16 |
| TSTs |  |  | 1.00 | **.61\*\*** | .22 | -.10 |
| TSTc |  |  |  | 1.00 | **.48\*** | .07 |
| TSTq |  |  |  |  | 1.00 | -.09 |
| SDQtd |  |  |  |  |  | 1.00 |

\*. Correlation is significant at the 0.05 level (2-tailed)\*\*. Correlation is significant at the 0.01 level (2-tailed).

A hierarchical multiple regression was conducted using psychological wellbeing (SDQ total difficulties score) as the outcome variable and strength of personal identity (TST strength, complexity and quality) as predictors. Results of this analysis are reported in Table 4. Age, gender and verbal IQ were controlled in the first step of the analysis. Tests were conducted using Bonferroni adjusted alpha levels of 0.02 (.05/3) due to multiple comparisons. The results of the regression indicated the personal identity scores did not explain a significant amount of the variance in psychological wellbeing (F(3, 23) = .30, *p*=.93; R2 =.09, adjusted R2 = -.23). Neither identity strength, complexity nor quality, as measured by the TST, were significant predictors of psychological wellbeing, as measured by the SDQ total difficulties score, after controlling for age, gender and verbal IQ (all *p*s>.55).

Table 4

*Summary of Hierarchical Regression Analysis for Personal Identity Variables Predicting Psychological Wellbeing in Autistic Adolescents (n=24)*

|  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- |
|  | **Model 1** | | | **Model 2** | | |
|  | **B** | **SE B** | **β** | **B** | **SE B** | **β** |
| Age | -26 | .59 | -.98 | -.27 | .71 | -.10 |
| Gender | 3.59 | 4.16 | .20 | 3.35 | 5.26 | .19 |
| Verbal IQ | -.02 | .08 | -.06 | -.02 | .09 | -.06 |
| TST strength |  |  |  | -.23 | .39 | -.18 |
| TST complexity |  |  |  | .67 | 1.44 | .17 |
| TST quality |  |  |  | .52 | 10.45 | .02 |

*Note*. Model 1: R2=.07, F(3, 20)=.48, *p*=.70; Model 2: R2=.09, F(3, 17) =.17, *p*=.92

No relationship was found between strength of personal identity and psychological wellbeing, therefore H1 has not been supported.

### H2: Those who align to only autistic or non-autistic culture will have better psychological wellbeing outcomes than those who align to both or neither cultures.

Due to insufficient power, inferential statistics could not be conducted and descriptive data was used to examine the current hypothesis. The means and standard errors for the four groups are displayed in Figure 1. Those who aligned themselves more to neither non-autistic nor autistic culture (marginalised; n=7; M=18.6, SD=2.13) had the highest SDQ total difficulties scores, indicating poorer psychological wellbeing, followed by those who aligned themselves to both autistic and non-autistic culture (bicultural; n=7; M=14.9, SD=2.15), then those who aligned themselves only to autistic culture (separated; n=3; M=14.2, SD=3.38) and the lowest scores were found in those who aligned themselves only non-to autistic culture (assimilated; n=7; M=9.8, SD=2.12).

*Figure 1*. Bar graph demonstrating mean SDQ total difficulties score according to acculturation group (marginalised = alignment to non-autistic culture; bicultural = alignment to both cultures; assimilated = alignment to neither culture; separated = alignment to autistic culture).

H2 has not been supported due to insufficient power to test this hypothesis with inferential statistics. However, descriptive statistics indicate that marginalised participants tended to have higher SDQ total difficulties scores than assimilated participants.

### H3: Those who align to only autistic or non-autistic culture will have more positive self-concepts than those who align to both or neither cultures.

Due to insufficient power, inferential statistics could not be conducted and descriptive data was used to examine the current hypothesis. Figure 2 illustrates the mean percentage of positive and negative statements generated in each group. As shown in Figure 2, those in the assimilated group (M=57.7%, SD=7) generated a higher proportion of positive statements about themselves than the other groups, in particular the marginalised group (M= 17.2%, SD=7). The assimilated group (M=12%, SD=8.8) also generated a lower proportion of negative statements about themselves, particularly in comparison to the marginalised group (M=29.6%, SD=8.9). Those who aligned themselves only to non-autistic culture were able to generate a higher proportion of positive and a lower proportion of negative statements about themselves than those who aligned themselves to neither culture. Though there is a small *n* for the separated group, this group generated the second highest proportion of positive statements about themselves, and the second lowest proportion of negative statements.

*Figure 2*. Bar graph demonstrating mean TST % positive and % negative statements produced according to acculturation group (marginalised = alignment to non-autistic culture; bicultural = alignment no both cultures; assimilated = alignment to neither culture; separated = alignment to autistic culture).

H3 could not be supported due to insufficient power to use inferential statistics. However, descriptive statistics indicated a relationship between acculturation type and self-concept in autistic adolescents, whereby those who aligned themselves only to non-autistic culture or autistic culture appeared to generate a higher proportion of positive, and fewer negative, statements about themselves than those who aligned to neither culture or both cultures.

## Discussion

The aim of the current study was to explore relationships between identity, including personal identity and acculturation, and psychological wellbeing in autistic adolescents. The first hypothesis proposed that there would be a relationship between strength of personal identity and psychological wellbeing in autistic adolescents. No evidence was found to support this, as participants’ scores on measures relating to personal identity strength, complexity and quality did not significantly predict scores of psychological wellbeing. Second, it was hypothesised that those who aligned to only autistic or non-autistic culture would have better psychological wellbeing outcomes than those who aligned to both or neither. This hypothesis could not be tested using inferential statictics, however descriptive statistics indicated that those who aligned themselves to neither non-autistic nor autistic culture (marginalised) tended to have poorer psychological wellbeing sores than those who aligned themselves only to non-autistic culture (assimilated).

The final hypothesis predicted that those who aligned to only autistic or non-autistic culture would have more positive self-concepts than those who aligned to both or neither cultures. This hypothesis could not be tested using inferential statitsics, however descriptive data indicated marginalised or bicultural groups tended to generate fewer positive statements about themselves than assimilated or separated groups. Aligning oneself only to non-autistic culture may relate to being able to generate positive statements about the self, indicating a more positive self-concept, than aligning to neither culture. These results should be treated with caution, but they may imply that aligning oneself more to one cultural group and committing to it, rather than aligning to neither group, may have benefits for psychological wellbeing and positive self-concept.

The current sample had poorer levels of psychological wellbeing compared to general population means, which is consistent with previous research with autistic adolescents (e.g. Vickerstaff et al., 2007; Lecavalier, 2006). In general, participants felt more aligned to non-autistic culture than autistic culture and less than half (10 out of 24) of the current sample mentioned autism in their identity descriptions, suggesting perhaps many autistic adolescents had not yet considered autism as part of their identity.

### Interpretation of Findings

One of the key aims of the current study was to contribute to understanding of the development of poor psychological wellbeing amongst autistic adolescents. Identity development was identified as an area that might impact upon psychological wellbeing, based on previous literature amongst minority groups (e.g. Cornell & Lyness, 2004). Developing a strong sense of identity, irrespective of autism, was not found to relate to psychological wellbeing. Previous research has suggested that individuals might find it difficult to establish a strong self-concept and self-esteem if they have an awareness of being different (Corrigan et al., 2005), which is something many autistic adolescents have reported (Humphrey & Lewis, 2008), and thus it is interesting to find that identity development might not have a negative impact on psychological wellbeing in this group. Conclusions should be drawn carefully, however, due to the subjectivity of measuring identity, and future research should seek to replicate this finding with a larger sample size.

Findings of the current study indicated that those who felt aligned only to non-autistic culture (assimilated) may have been able to generate more positive statements about themselves than those who aligned to neither culture and the same group appeared to have better psychological wellbeing scores. Those who aligned themselves to autistic culture (separated) generated the second highest proportion of positive statements about themselves and had second highest psychological wellbeing scores. Marcia’s (1980) identity status theory can be used to explain such findings, whereby commitment refers to the degree of personal investment the individual expressed in a course of action or belief (Kroger & Marcia, 2011). Those in the marginalised or assimilated groups may have explored and committed to an identity, whereas those in the bicultural or separated groups (alignment to both or neither culture) may not yet have achieved commitment and thus an established sense of identity. Minority group research supports this, which has shown that ethnic identity (the process of exploring and committing) can serve a protective role for individuals’ self-esteem; individuals who have explored and resolved issues pertaining to the group they identify with may feel more confident and have the tools to discuss issues regarding their group identity (Phinney, 2003).

Alignment to autistic culture has been encouraged amongst the autistic community in recent years, via the neurodiversity movement, which advocates self-identification as autistic and viewing autism as a positive identity that needs no cure (Chamak et al., 2008; Ortega, 2009). It is important to note the small number in the current sample of those who aligned only to autistic culture, which might suggest that exploring and committing to autistic identity is rare amongst young autistic adolescents, and may take time, which is particularly indicated by the relatively low mean age of the current sample (M=13.8), given identity development is known to continue into young adulthood (Kroger, Martinussen & Marcia, 2010). Cooper et al. (2017) found positive associations between autism identification and psychological wellbeing, however did not comment on the proportion of their adult sample who positively identified as autistic, which would be useful data for comparison with the current sample.

### Theoretical Implications

The finding that those who aligned to non-autistic culture may have had a more positive self-concept than those who aligned to neither culture shows support for previous group identity literature, which suggests group membership can have positive psychological consequences, for example by providing a sense of meaning, purpose and belonging (Haslam et al., 2009). Specifically, ethnic identity literature has highlighted that having a strong sense of social identity in adolescence can contribute to better self-esteem and fewer depressive symptoms (Umana-Taylor & Updegraff, 2007), which might help to explain why those who felt aligned to non-autistic culture seemed to have more positive self-concepts. Research on biculturalism has provided mixed findings, with some arguing that self-esteem and good psychological health are directly associated with minority group university students’ sense of biculturalism (i.e. belonging to both the majority culture of their peers and their minority culture; Cornell & Lyness, 2004). Others have found that those who feel caught between two cultures, feeling alienated from both cultures or feeling somewhat aligned to both, can develop mental health problems (e.g. Yeh, 2003), which supports the current finding that those who aligned to neither culture (assimilated) showed the least positive self-concepts and appeared to have poorer psychological wellbeing outcomes.

Research examining the development of a sense of autistic social identity, or alignment to autistic culture, have been mixed, which is reflected in the current findings. For example, Carrington and Graham’s (2001) qualitative study indicated that not accepting autism as part of one’s identity could negatively affect an individual’s psychological wellbeing, with some participants expressing a desire to ‘fit in’ but now knowing how. Perhaps these individuals are represented in the marginalised group (alignment to neither culture), who had the most negative and least positive self-concept in the current study. The current findings cannot contribute to understanding about whether some autistic adolescents take pride in being autistic (e.g. Cage et al., 2016) and whether autism identification can have positive effects on mental health and self-esteem (Cooper et al., 2017), given the low number of those who aligned only to autistic culture. However, our findings suggest that there is individual variation, whereby some may benefit psychologically from aligning themselves to non-autistic culture. It is not known if members of this group hid their autism to fit in with the majority group, a concept known in autism literature as “camouflaging” (Hull et al., 2017) and has been shown to be associated with negative psychological wellbeing (Bagatell, 2007; Cage, Di Monaco & Newell, 2017), as marginalised participants may have accepted being autistic yet still preferred to align to non-autistic culture.

### Limitations

Some caution must be taken when interpreting the findings due to the exploratory nature of the study and the small sample. Attempts were made to enlarge the sample, including increasing travelling distance and recruitment time, and expanding recruitment sources beyond schools. However, the time scale and strict inclusion criteria, as well as the opt-in consent required from parents *and* young people, restricted the possibility of a larger sample. The sample used is also at risk of bias as opt-in consent may have meant those with poorer psychological wellbeing were unlikely to agree to take part; this was certainly feedback from several non-participating parents, who feared participation would exacerbate their child’s current mental health symptoms. Other parents verbalised that they provided consent on the grounds that they felt their child had some difficulties relating to identity, thus there is possibility of sample bias in this domain. Additionally, all participants attended mainstream secondary schools and therefore the experiences of those in alternative settings, such as specialist provisions or home education, are not explored, and these have been shown to vary in terms of outcomes of behaviour and socialisation for autistic adolescents (Reed, Osborn & Waddington, 2012).

Identity-based research has generated great interest, which has resulted in many different ways of studying identity, including a variety of definitions of the concept and a wide variety of research methodologies (Abdelal, Herrera, Johnston & Martin, 2001). Two measures were used to investigate different aspects of identity in the current study, however both had methodological limitations and highlight the subjective nature of measuring such a broad construct. The TST is a qualitative measure that is coded quantitatively, which has the potential to lessen the accuracy of analysis and miss some of the meaning and value gained in qualitative responses (Kracauer, 1952), although it has advantage in allowing for quantitative comparison with other variables. Coding schemes and multiple raters were used in attempt to overcome issues of subjectivity and interpretation bias, by aiming to represent a reality within a certain threshold of consistency, accuracy, and attention to subjectivity and reflexivity of the researcher as instrument (Mays & Pope, 2000).

The AIS measure had not been widely used and the internal consistency for the autistic scale was acceptable using the current sample, which raises issues of reliability. Stebbins (2001) argues that within exploratory research, methodological issues are likely to arise and be improved upon over a number of studies in a new area. Furthermore, the method of analysis for this measure, suggested by Jarrett (2014), involved separating participants into four acculturation groups. This further reduced the sample sizes in each comparison group, which meant that the study did not have enough power to conduct inferential statistics.

Lastly, there are issues with applying the acculturation model to the autistic population, despite strong supporting arguments presented by Myers et al. (2011), who make links between autistic and deaf minority groups, and describe the successful outcomes that have arisen using the acculturation model with deaf individuals. The model is based on feelings of alignment to majority and minority groups (Berry & Sabatier, 2011) and the difficulties autistic individuals often have with social interaction and communication can impact on their ability to form relationships in groups (Foggo & Webster, 2016), therefore lack of alignment to one or both groups could reflect a social communication difficulty rather than the individual’s cultural preference and how they identify themselves. There is also ongoing discussion as to whether autism should be considered a minority group, and Jaarsma & Welin (2012) argue independent autistic culture might be limited to those who are highly verbal, which warrants further exploration in future research. Despite the limitations outlined, the current study serves to highlight avenues for intervention and raise the profile of considering identity development and acculturation amongst autistic adolescents.

### Implications for Practice and Research

There are currently several initiatives to help autistic adolescents with their personal and social development, often delivered in school, including social skills development (see White, Koenig & Scahill, 2007, for a review) and more holistic approaches such as ILAUGH (Winner & Crooke, 2009), which incorporates aspects such as developing conceptual processing and abstract thinking. However, few of these approaches address identity development, or actively help young people to explore their personal and social identity preferences, in order for them to establish what autistic culture means to them.

Myers et al. (2011) recommend that individuals should be encouraged to explore their autistic identities when appropriate, rather than having to hide their autism and present as neurotypical in aspects of their life. This has been supported by adult autism literature, showing that acceptance from others significantly predicts stress and experiences of “camouflaging” could relate to higher rates of depression in autistic adults (Cage et al., 2017). The current findings suggest there is likely to be individual difference between acculturation preference and how adaptive that alignment is, however it appears that alignment to one culture may be more adaptive than aligning to neither autistic or non-autistic culture. Autistic adolescents should therefore be helped to explore their cultural identity, through exposure to both groups, and by providing knowledge and information of each group, necessary to form a cultural preference. This could be done in school, at home and with support from specialist autism services.

Less than half of participants mentioned autism in their identity descriptions in the TST, which is interesting considering recent efforts to encourage self-identification as autistic by the neurodiversity movement (Chamak et al., 2008; Ortega, 2009). There may be several reasons for this, and why more people aligned themselves to non-autistic, rather than autistic, culture, such as variation in exposure to other autistic individuals (Petalas, Hastings, Nash, Dowey & Reilly, 2009), discourses in the home around autism (Dale, Jahoda & Knott 2006), age of diagnosis (Coo, Ouellette-Kuntz, Lam & Yu, 2012), and personal perception of autism (Humphrey & Lewis, 2008). Future research should aim to examine this further, as it will help to build an understanding of how autism identity development and acculturation manifest in adolescence.

Identity development is not necessarily a fixed process; it is likely to be fluid and developed over time (Weinreich & Saunderson, 2005). Therefore, this field of research would benefit from longitudinal data, mapping identity development and acculturation over time, perhaps from a starting point of receiving an autism diagnosis. Documenting mental health symptoms alongside this, using a large sample, would help to bolster the current findings, infer cause and effect, and further explore the relationship between these concepts. The current findings give rise to more questions, which is to be expected in exploratory research (Stebbins, 2001), which provides a good starting point for further research into this topic area. Replication of these finding in different settings, with more female participants and with a large overall sample, is essential.

### Conclusions

Autistic adolescents face the task of working out who they are and where they fit in, in relation to their autistic and non-autistic peers. There was no evidence to suggest personal identity development, relating to identity strength, complexity and quality, relates to psychological wellbeing in this group, which is a novel finding in this area that would benefit from replication. In relation to acculturation, it appears as though those who aligned themselves only to non-autistic culture (assimilated) tended to have better outcomes of psychological wellbeing, than those who aligned themselves to neither culture (marginalised), and assimilated autistic adolescents seemed to have a more positive self-concept than marginalised autistic adolescents. The separated group, those who aligned to autistic culture, had the second best psychological wellbeing and positive self-concept scores. Further research is needed to strengthen and build upon these exploratory findings. However, they have important implications for the development of strategies to help autistic adolescents explore autistic and non-autistic culture, in order to commit to a preferred group identity, which may benefit their psychological wellbeing and positive self-concept.

# Part Three.

# Integration, Dissemination and Impact Summary

## Integration

### Aim

The overall aim of the current research was to investigate psychological wellbeing and factors that might influence it in autistic adolescents. More specifically, the theme of the project is identity, focusing on how the questions of ‘who am I?’ and ‘where do I fit in?’ relate to psychological wellbeing. Both questions were explored quantitatively amongst autistic adolescents in the empirical paper (Part Two), and to gain a fuller understanding of how autistic adolescents experience themselves and others during their school years, a systematic review of the literature relating to experiences of friendships, peer victimisation and loneliness was completed (Chapter One).

Childhood friendships provide an important context for social, emotional and cognitive development (Helm, 2005) and become increasingly important and valuable with age for adolescents (Jankowski et al., 2014). A key characteristic of autism is difficulty with social communication, which can make social interactions, and particularly building and maintaining friendships, particularly challenging (Koning & Magill-Evans, 2001). Autistic children and adolescents are common targets of bullying during their school years (e.g. Cappadocia et al., 2012), with this group being up to four times more likely to experience bullying than their typically developing peers (Sterzing et al., 2012). Increased risk of developing psychiatric difficulties, which has been shown consistently amongst the autism population (e.g. Tantam, 2000), is especially prominent during adolescence (e.g. Vickerstaff et al., 2007) and this has been linked to experiences of frequent peer victimisation (Van Roekel et al., 2010). Any awareness of being different, and of being stigmatised, could have an impact on the development of the self-concept and self-esteem of the individual, perhaps due to the individual recognising and sharing the negative representations that others associate with their ‘differentness’ (Corrigan et al., 2005; Link & Phelan, 2001). More generally, experiences of friendships and peer relationships have been found to influence mental health outcomes (e.g. Kupersmidt, Coie & Dodge, 1990) and identity formation (e.g. Rutland et al., 2012) in minority groups, therefore further exploration of these ideas amongst autistic adolescents was indicated.

### How this was accomplished.

A systematic review of the qualitative literature examining autistic adolescents’ perspectives of their experiences of peer relationships, including the rewards and challenges, was completed. Ten journal articles were reviewed, and findings related to four main themes: understanding friendship, having and wanting friends, challenges of peer relationships and overcoming challenges. The review findings are relevant to and informed the empirical study by providing insight into how autistic adolescents navigate the process of developing relationships with peers, and how this can relate to their relationship with autism (e.g. perceiving that they are being bullied because of their autism; Tierney et al., 2016), their own personal identity (e.g. “I’m proud to be me”; Foggo & Webster, 2016) and their desire to “fit in” (e.g. many autistic adolescents had and wanted friends, though many found the process difficult due to not understanding social rules and conventions; O’Hagan & Hebron, 2016).

The empirical study began with a literature review of autistic adolescent mental health and identity literature, attending to group identity and its potential influence on psychological wellbeing. The study introduced and explored the idea of autistic acculturation, which is the process of alignment to autistic and/or non-autistic culture and an idea that relates to the systematic review findings around “fitting in” with peers (e.g. Cage et al., 2016). One of the key findings of the empirical study was that autistic adolescents tended to align themselves more to non-autistic culture than autistic culture, and those who felt aligned to only non-autistic culture appeared to have a more positive self-concept. This connects to findings in the systematic review, which focused on articles investigating relationships between autistic adolescents and typical peers, as it suggests that many autistic adolescents are capable of “fitting in” with their typical peers (e.g. Daniel & Billingsley, 2010; Howard et al. 2016; Cage et al., 2016) and, when this is achieved, it may have a positive effect on psychological wellbeing (Foggo & Webster, 2016).

A further finding linking the systematic review to the empirical article is that group settings were identified in the review as especially difficult for making friends (e.g. Cage et al., 2016; Foggo & Webster, 2016). Perhaps, then, acculturation itself is a challenging task for autistic adolescents, as it may require interaction and engagement with other members of the group, such as attending culture-specific events or gatherings, which might be difficult for individuals who prefer more individualised contact. However, the empirical study found that those who aligned themselves to neither autistic nor non-autistic culture seemed to have the least positive self-concepts. It may therefore be worth providing additional support to facilitate group interactions, for example in school, to encourage alignment to a preferred cultural group, which could have potential psychological benefits.

A future avenue for further linking these areas of research would be to consider if and how experiences of peer victimisation differ according to acculturation type. The systematic review findings might suggest that those who experience severe peer victimisation may be deterred from aligning to autistic culture (as autism can be perceived as the reason for the bullying; Tierney et al., 2016) and non-autistic culture (as the bullies might suggest that the autistic adolescent does not fit in amongst typical peers; Fisher et al, 2015). Those who aligned to neither culture (marginalised) appeared to have the least positive self-concept in the empirical study, therefore it is worth investigating if this could relate to experiences of peer victimisation.

### Challenges and Reflections

One of the key challenges experienced in conducting the empirical study was in recruitment, specifically in recruiting mainstream schools to advertise the study to parents. Some schools expressed initial interest and then did not engage in follow-up correspondence, others claimed to be too restricted in time and resource to facilitate involvement, and some expressed concern that talking about mental health issues with their autistic pupils, many of whom experienced high levels of emotional problems, would increase levels of distress. The latter point is important to consider, as it could be a factor that impedes the progression of research in this area, when it is truly needed (White, Oswald, Ollendick & Scahill, 2009). Self-selection biases may have resulted in a group of more distressed autistic adolescents not being recruited for the study, which limits the utility and generalisability of the findings to some degree. The systematic review suffered less from this limitation, due to the diversity and multiple recruitment approaches used in the reviewed studies. For example, the reviewed articles explored attitudes in an equal proportion of male and female participants and from different educational settings; two factors the empirical study could not achieve.

Recruitment difficulties shifted what was understood initially to be a realistic goal, in recruiting a large and representable sample, and attempts were made to overcome this by expanding recruitment sources, geographical radius and approach. Perhaps using an ‘opt-out’, as opposed to ‘opt-in’, recruitment strategy might have helped to increase numbers, but this was considered less ethical given the potential vulnerability of the studied group. An implication of this limitation for the overall project is that some of the ideas identified in the systematic review could not be investigated, such as the differences in perspective between autistic males and females.

Conversations with teachers and parents that took place during the recruitment phase of the empirical study highlighted the need for greater attention, in research and practice, to this topic area. Multiple teachers and parents commented that they have observed in some autistic adolescents a difficulty with working out how to make sense of their autism diagnosis and how they fit in, both with peers in an autism provision and with mainstream peers, which relates both to experiences of peer relationships and acculturation. It would be interesting for future research to further build on exploring these two areas in tandem, for example by asking autistic adolescents in each acculturation group about how they experience relationships with both autistic and non-autistic peers and comparing responses. The systematic review highlighted the paucity of qualitative research exploring autistic friendships within autistic culture; there is mostly a focus on autistic adolescents’ relationships with typical peers in the current literature. Further exploration is indicated to build upon the current empirical study’s aim of investigating the effect of acculturation on psychological wellbeing.

## Impact

There is potential for the current project to have significant impact at multiple systemic levels. Firstly, there has been recent attention and focus amongst the autism community on celebrating autism, encouraging self-identification as autistic and embracing autism as an integral part of who that person is (Kenny et al., 2016; Ortega, 2009). Myers et al. (2011) advocates for autistic individuals to be supported to succeed in mainstream schools by being encouraged to explore and celebrate their autistic identity. The current systematic review provides some evidence that support this view, for example that some autistic adolescents embrace their autism and would like to be accepted by peers for who they truly are (Cage et al., 2016), however it also provides indication that some make concerted efforts to “fit in” with their mainstream peers (Tierney et al., 2016) and many have and want non-autistic friends in a mainstream school environment (Foggo & Webster, 2016; Howard et al., 2006).

Furthermore, participants in the empirical study aligned more, on average, with non-autistic than autistic culture and the group who aligned only to non-autistic culture appeared to have a more positive self-concept than those who aligned to neither culture, which suggests that for some people embracing autistic culture is not essential to fostering positive psychological wellbeing. This finding by no means provides substantial evidence to suggest that efforts should not be made to help individuals to explore their autistic identity, however it does suggest that it might be adaptive for some autistic adolescents to fully integrate with TD peers. It is not known whether this would mean rejecting their autistic identity and autistic culture altogether, which should be further explored. Approaches in schools could be developed that encourage autistic individuals to spend time exploring both autistic and non-autistic cultures, by learning about each group and spending time in both mainstream and specialised autism settings, to establish a preference and fit in terms of their acculturation type.

The current project will increase awareness relating to the idea of “autistic culture”, which could potentially be a conceptualisation that schools, families and services could use to help autistic adolescents understand their autism and what it means to them. For example, schools could use the Autism Identity Scale (Jarrett, 2014) with pupils to help staff and students better understand how they identify with autistic and non-autistic communities. Scale items, which require a likert scale response from strongly disagree to strongly agree, relate to cultural identity (e.g. ‘I call myself autistic’), cultural involvement (e.g. ‘I enjoy going to events for people with autism’), cultural preference (e.g. ‘I would prefer my closest friend(s) to have autism’) and cultural competence (e.g. ‘I know lots of other teenagers with autism’). Responses could provide insight into how much an individual aligns with autistic and non-autistic culture, which might facilitate conversations about whether a young person would like things to be different in these areas, and how staff, parents or peers could support this. The measure is available online and copies could be included when disseminating project findings.

Findings from the systematic review indicate a need for increased support in schools with regards to helping autistic adolescents develop their social skills so that they feel more comfortable in social situations, and better able to form and maintain meaningful friendships. Social skills training can be effective in supporting autistic adolescents to feel more socially competent (see Cappadocia and Weiss, 2011, for review), as can other programmed that incorporate aspects such as developing conceptual processing and better abstract thinking (Winner & Crooke, 2009). The current systematic review impacts upon the further development of such programmes, and supports their wider use in schools, by highlighting the concern that many autistic adolescents still do not feel socially competent.

The empirical study findings suggest that, as well as helping autistic adolescents improve upon their social skills and awareness, school staff, autism services, parents and wider society should increase awareness and understanding of autism, to help autistic adolescents with acculturation. Those who had not aligned to either autistic or non-autistic culture in the current empirical study seemed to have a less positive self-concept than those who aligned to non-autistic culture, thus presenting an argument for providing support to help autistic individuals understand and embrace a culture of preference, which should first involve access to information and exploration of both cultures. Such support might involve having taught classes on the history of autism, providing reading materials by both autistic and non-autistic authors, and about autism and the neurodiversity movement (e.g. *Neurodiversity: Discovering the extraordinary gifts of autism, ADHD, dyslexia, and other brain differences*. Armstrong, 2010), and organising events that encourage interaction with both autistic and non-autistic peers.

Schools should link up with local National Autistic Society (NAS) services, who may host events and be able to provide relevant and current autism resources for young people. A position statement of the Autistic Self-Advocacy Network (ASAN; 2015) stated, “Many of the barriers faced by Autistics and others with disabilities arise not from the condition itself, but from prejudice and stereotypes that have the effect of excluding us from full participation as citizens with equal rights and responsibilities in society.” According to this view, the barriers to inclusion will be reduced when mainstream culture accommodates the different ways that autistic people function socially (Robertson & Ne'eman, 2008). More work is therefore needed with typical adolescents and society at large to encourage better understanding and acceptance of autism, in order to help autistic adolescents understand and accept who they are and where the fit in. Accordingly, Cage et al. (2017) found that acceptance from others links to mental health symptoms and stress, with experiences of not feeling accepted negatively impacting autistic adolescents.

Another way in which the current findings could impact society more generally is by bringing the idea of identity development in autistic adolescents to the forefront of thinking. Increasing numbers of autistic pupils are being educated in mainstream settings (Dybvik, 2004), however Humphrey and Lewis (2008) describe this as one of the most complex and poorly understood areas of education. It is not clear at present that supporting identity development in autistic pupils is high on the agenda for schools, indicated by the lack of support programmes that have been designed and implemented in this area (Gobbo & Shmulsky, 2016). Identity development in the general population is a key process of adolescence (Marcia, 1980) however it has been argued that it is during the university years that the greatest gains in identity formation appear to occur (Waterman, 1982). Of 11 disability categories, autism was in the lower third of university enrolment and graduation (Sanford et al., 2011), which has implications for identity development as very few autistic individuals may benefit from the opportunity to further explore and make identity commitments through university experiences. Gelbar, Shefcyk and Reichow (2015) surveyed autistic students who currently and previously attended university, to find that there was little support to integrate autistic individuals into their campus communities, and there were high reported rates of anxiety, depression and loneliness. Thinking about identity should therefore begin early, in schools, services and at home, which might have potential benefits for psychological wellbeing, but also future educational experiences and life satisfaction.

Finally, but by no means exhaustively, the current project has community impact by strengthening the idea that, similar to racial, ethnic and sexuality minority groups, autistic individuals develop identity within a culture that may not understand or accept their distinct ways of being, and that the problem and the solution are not within an individual, but rather in the person-environment fit (Gobbo & Smulsky, 2016). In line with the neurodiversity movement, the current project addresses the idea that autism can be viewed as its own independent culture that can be accepted, accommodated and embraced rather than a condition that must be cured. Emerging voices of autistic people and allied educators are discussing signs of autistic culture. For example, autistic bloggers and Facebook groups pages are numerous, including Lydia X. Z. Brown (writer of Autistic Hoya), Autism Friendly UK, and internationally published autistic author Jon Elder Robinson. Groups such as the ASAN, Autism Women’s Network (AWN) and ‘Aspies for Freedom’ support autistic individuals via the internet from a non-cure point of view. Movements like these help to strengthen the value in autistic culture, and more resources designed specifically for young people might help to encourage exploration of autistic culture. The low number of participants who aligned themselves only to autistic culture in the current empirical study could be explained by the idea of autistic culture being in its early stages of conceptualisation (Jaarsma & Welin, 2012), rather than because of a preference towards non-autistic culture, therefore efforts should be made to encourage positive autism identification and understanding, with careful monitoring of effects on psychological wellbeing over time.

### Pathways to Impact

Actions will be taken to disseminate the project (detailed below), via presentations at autism conferences, reporting findings via groups on social media, and through journal submission. These actions will result in increased awareness and recognition of the topic, findings and areas for further development, which will expand the potential impact of the project, through alerting relevant people and professionals to the need to make changes in schools and services. The current project highlights multiple avenues for future research, both in the areas of peer relationships and autistic identity development.

Involvement from autism community members took place at multiple phases of the project, to maximise the potential benefit and impact. Thornicroft and Tansella (2005) present ethics-based and evidence-based reasons why it should be necessary and advantageous to involve users of research in mental health research. For example, they argue that community-based mental health support should be established upon the foundation of key principles, such as autonomy, effectiveness, comprehensiveness and accountability, and users of research have vital contributions to make in defining each of these principles, and in honouring these principles in their operation. Formative evaluation from members of the autistic community helped to shape the project, in the form of feedback on the initial proposal and on how to capture data from particular measures used in the empirical study. This approach ensured that the perspectives of the community were heard, and that the project remained relevant and useful to the population group from the start, thus strengthening pathways to impact.

Process evaluation explored what worked well and what could be done differently to improve future, similar research in this topic area. Evaluation involved keeping a reflective journal, asking for structured feedback from participating schools and community representatives, and gaining immediate feedback from participants, parents and teachers on how they experienced involvement with the project. Feedback and reflection ensured that the project met stated objectives in a way that would be meaningful and relevant to the autism community and wider services.

## Dissemination

Dissemination can be defined as a planned process that involves consideration of target audiences and the settings in which research findings are to be received and, where appropriate, communicating and interacting with wider policy and health service audiences in ways that will facilitate research uptake in decision-making processes and practice (Wilson, Petticrew, Calnan & Nazareth, 2010). A theoretically-informed approach to research dissemination will be adopted, based on a systematic scoping review by Wilson and colleagues (2010), which aimed to identify and describe any conceptual/organising frameworks that could be used by researchers to guide their dissemination activity.

The strategy that appeared most often in the reviewed frameworks (Wilson et al., 2010) was persuasive communication (McGuire, 1969), principles of which will therefore be used to inform the dissemination of the current project. The Persuasive Communication Matrix (McGuire, 1969) is guided by five variables that influence the impact of persuasive communications. These variables are: the source of communication, the message to be communicated, the channels of communication, the characteristics of the audience and the setting in which the communication is received. Each will be discussed with reference to the current research project.

### The Source of Communication

The first input to the influence process is that communication about the project findings is presented by a particular source. The primary source may be the researchers, who have the principal power and opportunity to disseminate the findings, however other sources may have greater impact, such as parents, teachers or policy makers (Petty, Gleicher & Jarvis, 1993). It is therefore important to disseminate the project findings not only to those who may benefit directly, but also to those who may become a future source for continued and sustainable dissemination, such as the teachers who were involved in recruitment for the empirical paper. The source provides some information, the message, and this message can then be spread amongst the autism and wider communities.

### The Message to be Communicated

The message to be communicated, primarily, is that efforts should be made to support autistic adolescents to explore their personal and cultural identity, to help them to commit to an identity of preference, and to provide further support in developing their social relationships at school. Identity exploration might involve exposure to both autistic and non-autistic groups, and information being communicated with regards to each culture, for example its history, practices and aspects often celebrated by the cultural community. Support should also be offered routinely in schools to help autistic adolescents with their development of social skills, via increased and reliable delivery of social skills support programmes (Cappadocia & Weiss, 2011)

### Channels of Communication

Efforts are being made amongst the autism community to encourage identity exploration (Bagatell, 2010), for example through aforementioned online support forums and blogs. In the past, families have contributed to expert understanding of autism and directed avenues of research through advocacy and fundraising for autism research (Silverman & Brosco, 2007). It is therefore important that scientific research is not viewed as disconnected from the divergent ways to think about and respond to autism in society. Involving members of the autism community in dissemination, obtaining their feedback, and acknowledging that the message to be communicated may be one, scientific, perspective that should act to increase awareness and support ongoing action in this area can help to .

Channels of communication will include: social media, via known autism support groups; handouts, which can be developed to communicate key messages from the project and disseminated in schools who participated in the research, and schools in the wider community; submission of both the systematic review and empirical project to established autism journals (e.g. *Research in Autism Spectrum Disorder*s; *Autism*); and presentation of the findings at relevant research conferences, including Autistica’s 2018Autism Annual Research Conference. Petty et al. (1993) argue that stakeholder engagement is the primary facilitator for enhancing impact of research and its translation. Key stakeholders such as policy makers, with regards to schools and autism service provision, will therefore be informed of the current project findings, and encouraged to engage with their dissemination, via a research summary written for a specialised autism blog known to the researcher.

### Characteristics of the Audience

Interaction with the end-user is key to successful dissemination of findings (Wilson et al., 2010). The characteristics of the audience will vary due to the potentially broad impact of the project. Autistic and typical adolescents could benefit from better understanding the concept of acculturation and its potential benefits, as well as the difficulties faced by some autistic adolescents with regards to peer relationships; inviting all adolescents to take interest in the findings could help with wider attitude change, autism acceptance and support for acculturation. Parents and schools who participated in the research will be presented with the findings via a written summary in letter format, and encouraged to disseminate these further to known peers, colleagues and organisations. Parents and schools may benefit from increased understanding about autistic adolescents’ peer relationships, identity development and the potential role of acculturation.

### The Setting in which Communication will be Received

Communication will be primarily received in schools, homes of participating families and specialist services. Social media (e.g. Facebook, Twitter) will be used to expand upon the geography and scope of settings in which the project findings could be communicated, by presenting key messages to related groups and organisations.

## Summary

The current project has highlighted and discussed some of the difficulties faced by autistic adolescents, specifically relating to identity development and peer relationships, and the potential impact of such challenges. It is important that the project findings are carefully disseminated, using a theoretically-informed approach, to maximise the potential impact they could have at multiple systemic levels, including for autistic adolescents, their mainstream peers, their families, schools and society at large. The message to be communicated, principally, is that more should be done, both in research and practice, to heighten awareness of and examine ideas of autistic acculturation and to help autistic adolescents to consider their personal identity and what autism means to them.

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## Appendices

### Appendix 1: JBI QARI Critical Appraisal Checklist for Interpretive & Critical Research

Reviewer Date

Author Year Record Number

|  |  |  |  |
| --- | --- | --- | --- |
|  | Yes | No | Unclear |
| 1. Is there a congruity between the stated philosophical perspective and the research methodology? |  |  |  |
| 2. Is there a congruity between the research methodology and the research question or objectives? |  |  |  |
| 3. Is there a congruity between the research methodology and the methods used to collect the data? |  |  |  |
| 4. Is there a congruity between the research methodology and the representation and analysis of data? |  |  |  |
| 5. Is there a congruity between the research methodology and the interpretation of results? |  |  |  |
| 6. Is there a statement locating the researcher culturally or theoretically? |  |  |  |
| 7. Is the influence of the researcher on the research, and vice versa addressed? |  |  |  |
| 8. Are participants, and their voices, adequately represented? |  |  |  |
| 9. Is the research ethical according to current criteria or, for recent studies, is there evidence of ethical approval by an appropriate body? |  |  |  |
| 10. Do the conclusions drawn in the research report flow from the analysis, or interpretation, of the data? |  |  |  |

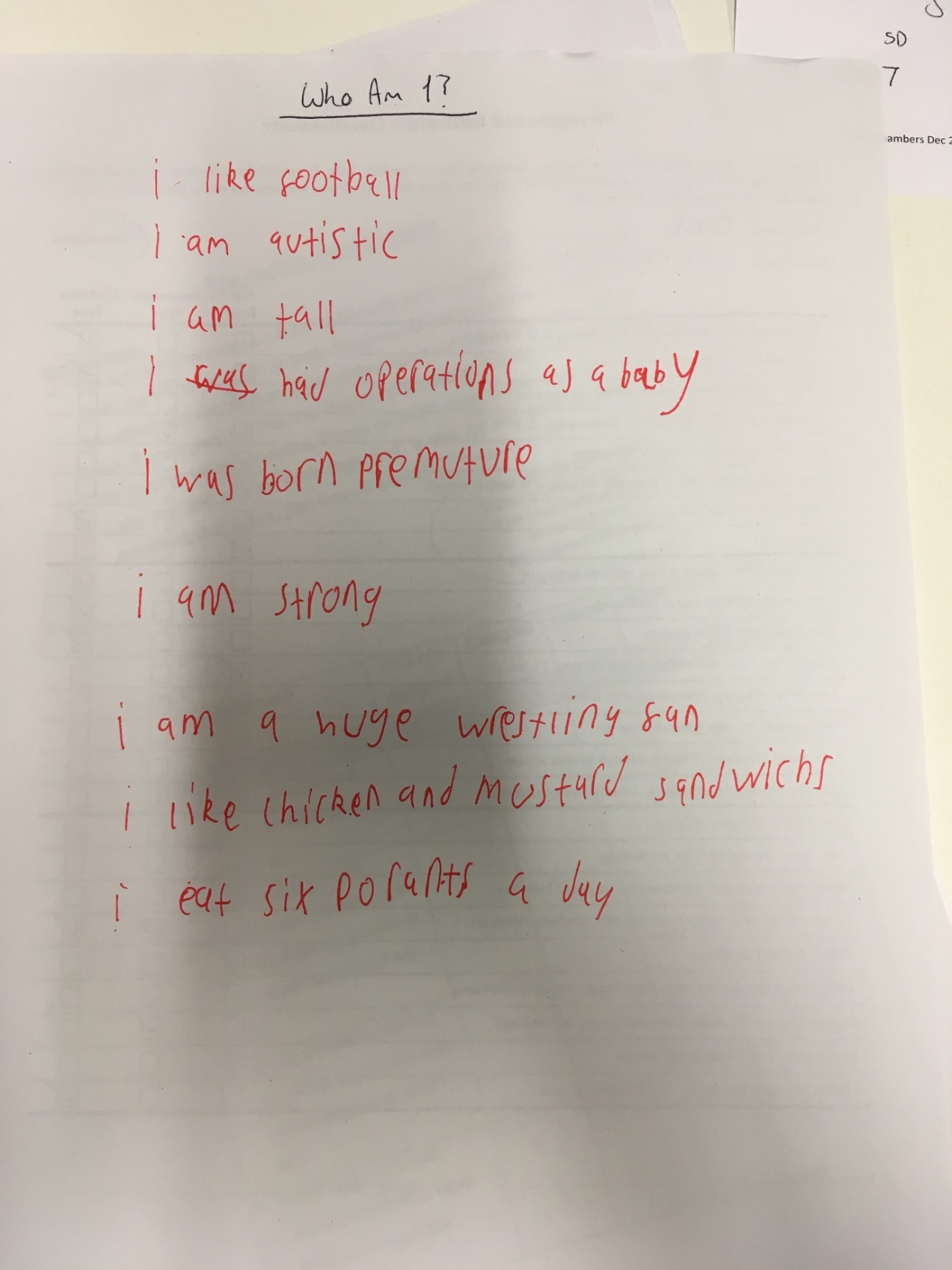
Overall appraisal: Include Exclude Seek further info

Comments (including reasons for exclusion):

### Appendix 2: Quari-view graph

|  |  |  |  |  |
| --- | --- | --- | --- | --- |
| **Finding**  ***Une = unequivocal***  ***P = plausible***  ***Uns = unsupported*** | | | **Category** | **Synthesised finding** |
| Difficulty in talking about friendships in an in-depth way, recognising friendship language (Carrington et al., 2003) (Une) | | Autistic adolescents do have some understanding of what is friendship, drawing on their own experiences, but it may be limited and difficult to describe verbally. | | Understanding friendships:  Autistic adolescents are able to understand and describe friendships, though this may be in a slightly different way to their peers. They can verbalise the qualities they would want in a friend, and express desire to have friends. |
| Understanding of acquaintance in unemotional terms – easier than describing a friend (Carrington et al., 2003) (Une) |  | | |  |
| Ps were better able describe characteristics of peers who would not be friends (Carrington et al., 2003)  (Une) |  | | |  |
| Ps reported their own experiences of when things have gone wrong in friendships, often rigidity (Carrington et al., 2003) (Une) |  | | |  |
| Various descriptions were provided of what is a friend, generally found it difficult to explain (Carrington et al., 2003) (Une) |  | | |  |
| The relationally aggressive behaviours characteristic of many typical female adolescent friendships (see Nichols et al. 2009) such as gossiping, being excluded, and having trust betrayed were discussed repeatedly by the autistic girls: “basically just backstabbing, bitchin’…people go and say something to one people and the other person goes around and tells another person” (AG) It is worth noting that the autistic girls who described these incidents did not see their friendships overall as being characterized in this way. (Sedgewick et al. 2016) (Une) |  | | |  |
| Ps recognized emotionally-intimate quality of peers’ female-female friendships and often found that they did not understand, and therefore could not abide by, the covert rules within these relationships. (Tierney, Burns & Kilbey, 2016) (Une) | Autistic adolescents may understand and experience friendships differently to others | | |  |
| Parent interviews revealed parents believe their sons’ did not understand friendships in the same way was them – definitions may not reflect experience. (O’Hagan & Hebron, 2016) (Une) |  | | |  |
| LSAs reported autistic young peoples’ friendships had different qualities to typical student’s friendships (Cage et al., 2016) (Une) |  | | |  |
| Common interests – often computer games. Pros and cons of internet friends (O’Hagan and Hebron, 2016; Howard, Cohn & Orsmond, 2006) (Une) | Autistic adolescents identified important qualities in friendship, such as having shared interests, offering help and support, and trust. They also identified the importance of doing activities together. | | |  |
| Spoke of activities with friends x2 (Daniel & Billingsley, 2010) (Une) |  | | |  |
| All informants said that sharing interests and participating in common activities are part of friendship x3 (Daniel & Billingsley, 2010) (P) |  | | |  |
| Proximity – Tom identified seeing friends regularly as important, but you also need more than that to be a true friend. (Howard, Cohn & Orsmond, 2006) (Uns) |  | | |  |
| Help and support – the quality of helping and supporting one another were identified as reciprocal elements of friendship (Howard, Cohn & Orsmond, 2006) (Une) |  | | |  |
| Caring and responding, forgiveness and reciprocity were also important. (Howard, Cohn & Orsmond, 2006) (Une) |  | | |  |
| Friendship qualities include trust, support and respect (Foggo & Webseter, 2016) (Une) |  | | |  |
| Sharing experiences was important – particularly less structured and social activities, e.g. shopping, cinema (Foggo & Webseter, 2016) (Une) |  | | |  |
| Ps were able to define friendships and desirable characteristics of a good friend – limited and often not including 3 dimensions (affection, intimacy, companionship) (O’Hagan & Hebron, 2016; Cage et al., 2016) (Une) |  | | |  |
| All students reported loneliness (O’Hagan & Hebron, 2016) (P) | Many autistic adolescents have a desire to form friendships, and many have experienced loneliness through that desire not being fulfilled, which can be difficult. | | | Having and wanting friends:  Autistic young people do have and want friends, though this is not always easily achieved. They are often aware that they have reputation and some are more concerned about this desire to fit in and manage their reputation than others. |
| Students had a great desire for friendships that was not always fulfilled (O’Hagan & Hebron, 2016) (P) |  | | |  |
| Ps were motivated to have friendships, therefore obstacles to making friends caused discomfort and distress (Tierney, Burns & Kilbey, 2016) (P) |  | | |  |
| Tom chose having good friends as one of his top priorities, and described close friendships with four other adolescents. (Howard, Cohn & Orsmond, 2006) (Une) |  | | |  |
| Social interactions are important – all bar one p indicated it was important to have friends (Foggo & Webster, 2016) (Une) |  | | |  |
| Autistic girls showed similar motivation and friendship quality to non-autistic girls (Sedgewick et al., 2016) (Une) |  | | |  |
| Autistic boys reported having both qualitatively different friendships and less motivation for social contact relative to boys without autism and to girls with and without autism (Sedgewick et al., 2016) (Uns) |  | | |  |
| All boys reported having friends (Daniel & Billingsley, 2010) (P) | Most autistic adolescents do have friends, often formed at school, and are able to maintain these friendships despite obstacles such as school transition. Students may be more likely to have friends that are autistic than TD peers. Parent perspectives may differ. | | |  |
| School as primary place for making friends, other places included extra-curricular activities, neighbourhoods, family friends etc. (Daniel & Billingsley, 2010) (P) |  | | |  |
| Four boys maintained friendships despite school transitions and family moves, but it was hard to do and usually only the closest friendships remained. (Daniel & Billingsley, 2010) (P) |  | | |  |
| Students had more friendships with other people with ASC than TD peers (O’Hagan & Hebron, 2016) (Une) |  | | |  |
| Pupils’ relationships with peers proved to be both a barrier and an enabler to their successful inclusion in school (Humphrey & Lewis, 2008) (Une) |  | | |  |
| Parent perspective often differed to student’s perspective (O’Hagan & Hebron, 2016) (Une) |  | | |  |
| Variability in the extent to which adolescents were concerned about their reputation – desire to be true vs. difficulty understanding social rules and conventions (Cage et al., 2016) (Une) | Many autistic adolescents are aware that they have a reputation and are aware, despite some difficulty in understanding social conventions, of what it is to be cool, though some are less concerned about it than others. Some have a desire to ‘fit in’, whereas others prefer to be true to themselves. | | |  |
| Ps were capable of being concerned about their reputation, understanding what it is to be cool, changing behaviour toy impress others etc. (Cage et al., 2016) (Une) |  | | |  |
| Difficulty understanding social rules could contribute to reputation concerns (Cage et al., 2016) (Une) |  | | |  |
| Ps were aware that they have a reputation, with others describing them differently to how they would describe themselves. They do have a self-concept. (Cage et al., 2016) (P) |  | | |  |
| Perception of others – Ps were much less aware of what peers thought of them and when asked what they believed other girls liked, they described interests that didn’t appear to interest them (Foggo & Webseter, 2016) (Une) |  | | |  |
| Staff reported their students have a desire to fit in (Cage et al., 2016) (Une) |  | | |  |
| Making new friends was the most difficult aspect to friendship (Daniel & Billingsley, 2010) (P) | Autistic adolescents find it particularly difficult to make friends and keep friends, for reasons such as difficulties in understanding social conventions, not knowing how to approach others, not living near friends, worries about others liking them and difficulty with dealing with conflict. These difficulties may increase with age, as social expectations change. | | | Challenges of peer relationships:  Autistic adolescents experience a number of challenges in making and keeping friends. Many have experienced peer victimisation and loneliness. They may find group interaction particularly difficult, and often have some reputation concerns. These difficulties are likely to relate to their characteristic social-communication difficulties, and may become increasingly difficult with age. |
| Difficulties varied with each boy – some didn’t know how to approach others, another worried about trust (Daniel & Billingsley, 2010) (P) |  | | |  |
| One of the predominant challenges was difficulty in understanding social conventions (O’Hagan & Hebron, 2016) (Une) |  | | |  |
| Forming and maintaining friendships seemed to become more difficult as they got older (O’Hagan & Hebron, 2016) (P) |  | | |  |
| Worries about others liking them making it hard to make new friends (Cage et al., 2016) (Une) |  | | |  |
| Changes in expectations as people got older prompted difficulties to emerge or become more problematic (e.g. school transition – changes in social expectation and etiquette) (Tierney, Burns & Kilbey, 2016) (P) |  | | |  |
| All students described the distance they lived from school as the reason they didn’t see friends outside of school (O’Hagan & Hebron, 2016) (Une) |  | | |  |
| Girls on the autism spectrum in particular may struggle with identifying and dealing with conflict in their social lives. (Sedgewick et al., 2016) (P) |  | | |  |
| Strangers observations could cause anxiety (e.g. doing things in a group setting). (Cage et al., 2016) (Une) | Autistic adolescents find group interaction particularly difficult. | | |  |
| Group communication was found challenging by all. (Tierney, Burns & Kilbey, 2016) (Une) |  | | |  |
| Social interactions are difficult – managing conflict in group interactions especially so… all Ps felt they had stopped being friends with someone at some point. (Foggo & Webseter, 2016) (Une) |  | | |  |
| Peer rejection was experienced by all students (O’Hagan & Hebron, 2016) (Une) | Many autistic adolescents have experienced peer rejection or victimisation, and subsequent feelings of sadness or anxiety. Perceived reasons for such behaviours may relate to core ASC difficulties, with some blaming themselves. | | |  |
| When Ps broke the rules, they were identified as different and consequently experienced peer rejection. This led to Ps feeling unable to fit into social situations (Tierney, Burns & Kilbey, 2016) (P) |  | | |  |
| Core ASC difficulties resulted in frequent peer-rejection and loneliness. This led to a number of Ps developing secondary MH difficulties (Tierney, Burns & Kilbey, 2016) (P) |  | | |  |
| Verbal victimisation – reported most often (9/30), physical victimisation (6/30), relational vicitmization (4/30) and unspecificed – bullied but no specific details (7/30) – most had had some experience of victimisation (Fisher et al., 2015) (Une) |  | | |  |
| Reasons for bullying included personal attributes (Ps blamed themselves, seen as easy targets, bullies target their disability), and others’ opinions of them (e.g. others didn’t want to be around them) (Fisher et al., 2015) (Une) |  | | |  |
| Some adolescents expressed annoyance with bullies (Fisher et al., 2015) (Une) |  | | |  |
| Constructing an understanding of AS – talking about themselves and their AS in negative terms (Humphrey & Lewis, 2008) (Une) | Autistic adolescents often had constructed an understanding of their autism, with some accepting and others rejecting of it. Characteristics associated with ASC were identified as contributors to their difficulties with peers. | | |  |
| Some pupils thought AS was simply part of ‘who they are’ (Humphrey & Lewis, 2008) (Une) |  | | |  |
| Characteristics associated with AS and life in school – social naivety can be exploited by other pupils (Humphrey & Lewis, 2008) (Une) |  | | |  |
| Staff recognised the challenge of living with autism in a neurotypical world` (Cage et al., 2016) (Une) |  | | |  |
| Ps social-communicative difficulties were a barrier to developing friendships as mutual misunderstandings made bonding difficult. (Tierney, Burns & Kilbey, 2016) (Une) |  | | |  |
| *\* Repeat* Core ASC difficulties resulted in frequent peer-rejection and loneliness. This led to a number of Ps developing secondary MH difficulties (Tierney, Burns & Kilbey, 2016) (Une) |  | | |  |
| Coping with social deficits by masquerading (Carrington et al., 2003; (Tierney, Burns & Kilbey, 2016)) (P) | Some autistic adolescents have developed coping strategies to mask or cope with their difficulties with peer relationships, such as masquerading, adapting themselves and using past experiences. Sometimes these techniques had negative repercussions. | | | Overcoming challenges**:** Many autistic adolescents have developed ways of overcoming or masking difficulties with peer relationships, such as by imitating others. There are also various ways they might respond to peer victimisation. Some of these coping styles can have a negative impact. Others are sometimes used to help facilitate social relationships. |
| Ps might choose friends who nurtured them; Ps often described female peers who had supported them in their acquisition of social skills. (Tierney, Burns & Kilbey, 2016) (Une) |  | | |  |
| Most Ps developed sophisticated strategies which utilized innate strengths and enabled them to appear socially-competent to observers, and not stand out to others. (Tierney, Burns & Kilbey, 2016) (Une) |  | | |  |
| e.g. empathy informed by memory – matching corresponding memories to another person’s situation in order to create a concrete reference point (Tierney, Burns & Kilbey, 2016) (Une) |  | | |  |
| e.g. sophisticated levels of peer-imitation, sometimes pretending to be occupied and actually observing others in order to intimidate them (Tierney, Burns & Kilbey, 2016) (Une) |  | | |  |
| For the majority, these strategies had negative repercussions on the psychological wellbeing and hampered access to support as difficulties were hidden. (Tierney, Burns & Kilbey, 2016) (P) |  | | |  |
| Tom recognised sometimes he had to put his own interests aside or ‘get interested in others’ interests’ since he and his friends did not always have the same interests. (Howard, Cohn & Orsmond, 2006) (Une) |  | | |  |
| Negotiating ‘difference’ – pupils with AS feel forced to adapt themselves in order to submerge themselves in a social world of the school (Humphrey & Lewis, 2008) (Une) |  | | |  |
| Many tried to ignore bullies, some were unable to, try to control emotions (Fisher et al., 2015) (Une) | In response to difficulties peer victimisation, reactions varied. Some tried to ignore bullies, others would try to retaliate or minimise the seriousness of the situation. | | |  |
| Some responded by trying to retaliate, others tried to make themselves more intimidating in the future (Fisher et al., 2015) (Une) |  | | |  |
| Some Ps added qualifiers to try and minimise the seriousness of the situation (bullying) (Fisher et al., 2015) (P) |  | | |  |
| Initiating friendships might be facilitated by parents (Tierney, Burns & Kilbey, 2016) (Une) | Sometime parents and school staff can be used to facilitate autistic adolescents’ social relationships, or how they cope with bullying. | | |  |
| Some reported the incident, others tried to change their behaviour (Fisher et al., 2015) (Une) |  | | |  |
| Tom and his mum described that she facilitated his social relationships by providing opportunities for Tom to meet and engage with people, and by offering advice to help Tom succeed in his friendships. (Howard, Cohn & Orsmond, 2006) (Une) |  | | |  |

### Appendix 3: Example TST response



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### Appendix 4: TST positive/negative self-concept coding scheme.

|  |  |  |
| --- | --- | --- |
| Code | Description | Example |
| Positive | Positively connoted adjectives (e.g. beautiful, funny, etc.)  Indication of liking/being good at s’thing | “I am kind a friendly”  “I am good at maths”  “My favourite colour is Blue” |
| Negative | Negatively connoted adjectives (e.g. ugly, stupid etc. )  Indication of disliking, not being good at s’thing | “I am lonely”  “I don’t like school”  “I am really bad at sitting still.” |
| Neutral | Facts, descriptive statements.  Where there is doubt about connotation, rate as neutral | “I have a big family”  “I am autistic”  “ I do a lot of different activities” |

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### Appendix 5: Autism Identity Scale (Jarrett, 2016)

**The Autism Identity Scale**



**Instructions:**

* The scales below include a list of statements about how you see yourself and what you like to do. If you strongly disagree, tick this box. If you disagree with the statement, tick this box. If you neither agree nor disagree, tick the ‘neutral’ box. If you agree, tick this box. If you strongly agree, tick this box. **There are no right or wrong answers.** Please complete scale 1 **and** scale 2.
* Only tick **one** box for each statement. **If you do not want to answer a question, that’s fine, just leave it blank**.

Scale 1 (Autistic Scale).

|  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- |
| **Statement** | **Strongly disagree** | **Disagree** | **Neutral** | **Agree** | **Strongly agree** |
| Cultural Identity | | | | | |
| I call myself autistic or say I have Asperger syndrome. |  |  |  |  |  |
| Being involved with people who have autism or Asperger syndrome is an important part of my life. |  |  |  |  |  |
| Being autistic or having Asperger syndrome is an important part of who I am. |  |  |  |  |  |
| I feel that I fit in with other people who have autism or Asperger syndrome. |  |  |  |  |  |
| I am comfortable with other people who have autism or Asperger syndrome. |  |  |  |  |  |
| Cultural Involvement | | | | | |
| I enjoy reading books /magazines/information written by authors who are autistic or have Asperger syndrome or that are about autism or Asperger syndrome. |  |  |  |  |  |
| I enjoy going to events/parties/gatherings for people with autism or Asperger syndrome. |  |  |  |  |  |
| I enjoy talking to other young people with autism or Asperger syndrome online. |  |  |  |  |  |
| I enjoy taking part in activities that promote the rights of people with autism or Asperger syndrome. |  |  |  |  |  |
| Cultural preference  **If you could have it your way, what would you prefer the following situations in your life to be like?** | | | | | |
| I would prefer my education to be at a school with only people with autism or Asperger syndrome. |  |  |  |  |  |
| I would prefer my closest friend(s) to have autism or Asperger syndrome. |  |  |  |  |  |
| I would prefer my family members to have autism or Asperger syndrome. |  |  |  |  |  |
| Cultural competence | | | | | |
| I know lots of other teenagers with autism or Asperger syndrome. |  |  |  |  |  |
| I know lots of names of well-known people who have autism or Asperger syndrome. |  |  |  |  |  |
| I know lots about important events in the history of autism or Asperger syndrome. |  |  |  |  |  |
| I know of clubs run by and for people with autism or Asperger syndrome. |  |  |  |  |  |

**Scale 2 (Non-autistic scale).**

|  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- |
| **Statement** | **Strongly disagree** | **Disagree** | **Neutral** | **Agree** | **Strongly agree** |
| Cultural Identity | | | | | |
| I don’t call myself autistic or say I have Asperger syndrome. |  |  |  |  |  |
| Being involved with people who do not have autism or Asperger syndrome is an important part of my life. |  |  |  |  |  |
| I often wish I could become non-autistic or not have Asperger syndrome. |  |  |  |  |  |
| I feel that I fit in with other people who do not have autism or Asperger syndrome. |  |  |  |  |  |
| I am comfortable with other people who do not have autism or Asperger syndrome. |  |  |  |  |  |
| Cultural Involvement | | | | | |
| I enjoy reading books /magazines/information written by people without autism or Asperger syndrome. |  |  |  |  |  |
| I enjoy going to events/parties/gatherings for people who don’t have autism or Asperger syndrome. |  |  |  |  |  |
| I enjoy talking to other young people without autism or Asperger syndrome online. |  |  |  |  |  |
| I enjoy taking part in school events with people who don’t have autism or Asperger’s syndrome. |  |  |  |  |  |
| Cultural preference  **If you could have it your way, what would you prefer the following situations in your life to be like?** | | | | | |
| I would prefer my education to be at a school with people with and without autism or Asperger syndrome like now. |  |  |  |  |  |
| I would prefer my closest friend(s) to **not** have autism or Asperger syndrome. |  |  |  |  |  |
| I would prefer my family members to **not** have autism or Asperger syndrome. |  |  |  |  |  |
| Cultural competence | | | | | |
| I know lots of other teenagers without autism or Asperger syndrome. |  |  |  |  |  |
| I know lots of names of well-known people without autism or Asperger syndrome. |  |  |  |  |  |
| I know lots about important events in world history. |  |  |  |  |  |
| I know of clubs run by and for all young people |  |  |  |  |  |

**Thank you for completing this questionnaire!**

**Scoring** (Not shown to participants)

1. Strongly disagree (2) Disagree (3) Neutral (4) Agree (5) Strongly agree

**Biculturalism** =High score on both scales- bicultural

**Separated** = High Autism score, low non-autistic score

**Assimilated** = High non-autistic score, low autistic score

**Marginalised**= low scores on both scales

### Appendix 6: Parent Information Sheet

**Exploring identity and mental health in adolescents on the autism spectrum**

Dear parent/guardian,

I am writing to invite your child to be involved in a new research project which looks at the relationship between personal identity and mental health in adolescents on the autism spectrum.

During the teenage years, young people, including those on the autism spectrum, try to make sense of “who they are” – their personal identity. My research will look at how adolescents on the autism spectrum understand who they are, whether they see autism as part of who they are, and whether this all relates to feelings of anxiety and low mood.

I very much hope that you would like your child to take part. The more we understand about the experiences of young people on the autism spectrum, the more we can do to support them during adolescence and into adulthood. After reading this information sheet, please discuss with your child whether she/he wants to take part.

**Who is conducting this project?**

Lily Cresswell, a doctoral student in Clinical Psychology, under the supervision of Dr Eilidh Cage, will be conducting this study.

**What will happen if my child takes part?**

If you agree for your child to take part in the study, I will explain the study clearly to him/her at school and see if he/she would like to participate. Young people who agree will be seen once for a session lasting 30-40 minutes, which will be arranged with their teacher to ensure that learning at school is not disrupted. During this sessions I will help your child to complete a number of straightforward tasks, to gather information about their sense of personal and any feelings of anxiety or low mood.

I have experience working both with individuals on the autism spectrum and those with mental health problems, therefore I understand these topics can be difficult to talk about for some people. Importantly, young people are assured that they are free to take a break or withdraw at any time. As the child’s parent, you will be asked to complete two brief questionnaires; one about your child’s behavioural and emotional strengths and difficulties, and the other about your child’s symptoms of autism.

**What should I do next?**

If you would like your child to take part in this study, please fill in the enclosed form and return it to [teacher’s name]. Please keep this letter for your reference. If you agree to your child taking part, I will then meet with your child at school and discuss the project in detail with them, and find out if they are happy to take part in the project. If you would like to discuss the research at any time, please do not hesitate to contact us using the details below.

Very best wishes,

|  |  |
| --- | --- |
| **Lily Cresswell**  [**Lily.cresswell.2015@live.rhul.ac.uk**](mailto:Lily.cresswell.2015@live.rhul.ac.uk)  **Trainee Clinical Psychologist** | **Dr Eilidh Cage**  [**Eilidh.Cage@rhul.ac.uk**](mailto:Eilidh.Cage@rhul.ac.uk)  **Supervisor** |

|  |  |
| --- | --- |
|  |  |

**CONSENT FORM: ADOLESCENTS WITH AUTISM**

**Researcher copy -** Please return this copy to [name]

I have read the information sheet about the research and discussed the project with my child. I am happy for my child to be asked whether he/she would like to take part in the study.

I understand that participation is voluntary and that my child is free to withdraw at any time, without giving any reason and without my child’s education being affected in any way.

I understand that I can contact Lily Cresswell ([lily.cresswell.2015@live.rhul.ac.uk)](mailto:lily.cresswell.2015@live.rhul.ac.uk)) to discuss this study at any time.

I am happy to be contacted about future research projects

**Yes  No**

**Yes  No**

**Yes  No**

**Yes  No**

Name of child: \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_ \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_  (Male)  (Female)

(Forename) (Surname)

**Date of Birth**:­­­­­­­­­­­­­ \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_ **School**:\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

**Contact email: \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_**

**Contact phone: \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_**

**Name of parent/guardian (please print):\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_**

**Signature: \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_ Today’s date:\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_**

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### Appendix 7: Ethical Approval Letter



1. The term ‘autistic’ is used instead of first person language (i.e. *a person with autism)*, as identity-first language was found by Kenny et al. (2016) to be preferred by the majority of people on the autistic spectrum. [↑](#footnote-ref-1)