Title: An exploration of identity formation in autistic adolescents, its relationship with psychological wellbeing, and the role of mainstream education provision in the identity formation process.

Submitted by Hayley Jarrett to the University of Exeter as a thesis for the degree of Doctor of Educational, Child and Community Psychology in May 2014.

I certify that all material in this thesis which is not my own work has been identified and that no material has previously been submitted and approved for the award of a degree by this or any other University.

Signature: ……………………………………………………………………..

Acknowledgements

I would like to acknowledge a number of people for their support in the completion of this research.

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Abbreviations

Table 1: Abbreviations used within paper one and two

Abbreviation	Meaning
DfE	Department for Education
TEP	Trainee Educational Psychologist
LEA	Local Education Authority
RQ	Research Question
EP	Educational Psychologist
EPS	Educational Psychology Service
ICD-10	International Statistical Classification of Diseases and Related Health Problems 10th Revision
DSM-V	Fifth edition of the Diagnostic and Statistical Manual of Mental Disorders
DAS	Deaf Acculturation Scale
NAS	The National Autistic Society
SENCO	Special Educational Needs Coordinator
AIS	Autism Identity Scale
SCAS	Spence Children's Anxiety Scale
SPSS	Statistical Packages for the Social Sciences
BPS	British Psychological Society
BERA	British Educational Research Association
CRB	Criminal Records Bureau
SEN	Special Educational Needs
Ofsted	Office for Standards in Education, Children's services and Skills
DSM-5	Diagnostic and Statistical Manual 5th Edition
DVD	Digital Versatile Disc
UK	United Kingdom
TA	Teaching Assistant
PSHE	Personal, Social, and Health Education
EHC	Education, Health, and Care Plan

Thesis introduction

Research context

The following research was conducted whilst I was working as a Trainee Educational Psychologist (TEP) in a large local authority (LA) in the south of England. Both papers allowed for exploration of an area of interest, identity formation, whilst supporting a priority area for the LA, autism. Conducting research within this field also provided an opportunity for professional development, advancing personal knowledge and gaining experience of working with a population with whom I have had minimal experience of working with.

Area of focus

The focus of this thesis is an exploration of identity formation in autistic adolescents, its relationship with psychological wellbeing, and the role of mainstream education provision. This is an under researched area (Bagatell, 2007).

The thesis consists of two papers (figure one, p.6). An exploratory research design, utilising mixed methods, is employed within paper one. This draws on a theory first developed in relation to ethnic minorities, and later used within those with hearing impairments, looking at identity formation in relation to four acculturation types (assimilation, separation, marginalisation, and biculturalism) (Berry, Trimble, & Olmedo, 1986; Phinney, 1990).

Paper two utilises a qualitative approach to explore the theme of identity formation in relation to the perceived contextual factors within mainstream education. The methods used enabled the voice of adolescents with and without autism to be heard. This is particularly important given the increasing number of autistic adolescents now attending mainstream provision (Department for

Education (DfE), 2011, 2013) and research suggests that this group can find this environment particularly challenging (Humphrey & Lewis, 2008; Myers, Ladner, & Koger, 2011).

Figure 1: Overview of thesis

Title: An exploration of identity formation in autistic adolescents, its relationship with psychological wellbeing, and the role of mainstream education provision in the identity formation process.

Exploration of literature (Literature Review)

Aim: Paper one: To explore identity formation in autistic adolescents and the relationship between this and aspects of psychological wellbeing.

Research questions:

RQ1: What are the relationships between a ‘bicultural identity’ and psychological wellbeing in autistic adolescents in mainstream settings?

a) Is there a relationship between anxiety and self-esteem?
b) Is there a relationship between a ‘bicultural identity’ and self-esteem?
c) Is there a relationship between a ‘bicultural identity’ and anxiety?

RQ2: What are the perspectives of autistic adolescents in mainstream settings regarding their identity (including: cultural identification, cultural involvement, cultural preference, and cultural competence) in relation to their acculturation type (marginalised, assimilated, separated, and bicultural)?

Aim: Paper two: To explore the perceived contextual factors that relate to identity formation of autistic adolescents attending mainstream education provision.

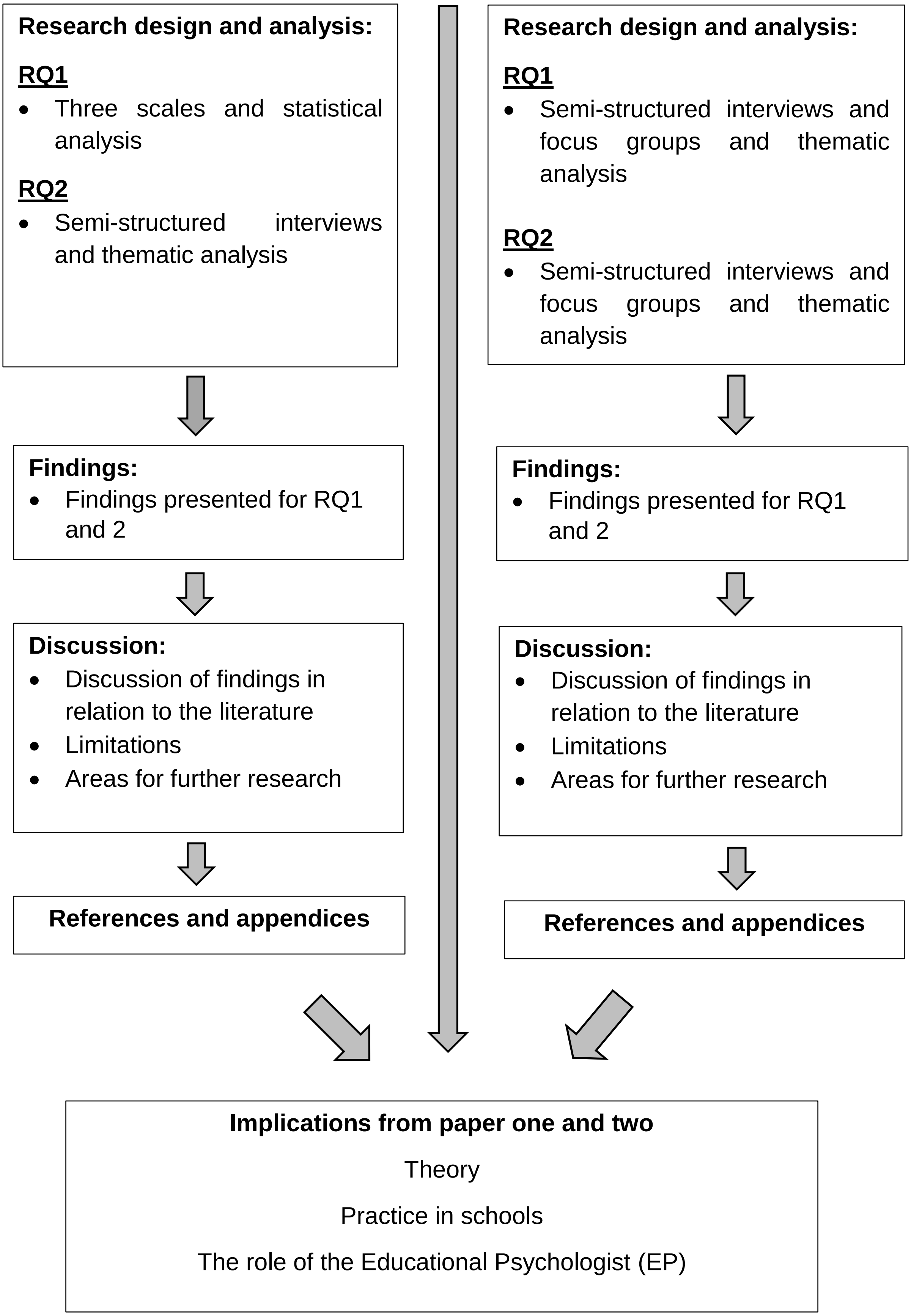
Research questions:

RQ1: What are the views of adolescents with and without autism regarding contextual factors in their mainstream provision related to identity formation?

a) What are their views about understanding and raising awareness of autism?
b) What are their views about disclosing diagnoses?
c) What are their views regarding relationships with peers?
d) What are their views about adaptations made for young people with autism?

RQ2: What suggestions do these adolescents with and without autism in mainstream settings make in relation to changing provision as regards to autism identity formation?

Continued overleaf



Research design and analysis:

RQ1
- Three scales and statistical analysis

RQ2
- Semi-structured interviews and thematic analysis

Findings:
- Findings presented for RQ1 and 2

Discussion:
- Discussion of findings in relation to the literature
- Limitations
- Areas for further research

References and appendices

Research design and analysis:

RQ1
- Semi-structured interviews and focus groups and thematic analysis

RQ2
- Semi-structured interviews and focus groups and thematic analysis

Findings:
- Findings presented for RQ1 and 2

Discussion:
- Discussion of findings in relation to the literature
- Limitations
- Areas for further research

References and appendices

Implications from paper one and two

Theory

Practice in schools

The role of the Educational Psychologist (EP)

Key findings

Paper one:

- The mean anxiety and self-esteem scores for participants fell within the ‘normal range’.
- No statistically significant relationship between a bicultural identity and self-esteem or anxiety was found, although average psychological wellbeing scores were better for those with bicultural and marginalised identities.
- Key similarities across the acculturation types: most perceived they had minimal knowledge about autism; none had relationship preferences; and all reported neutral to positive feelings about their autism.
- Key differences exist between the acculturation types, although most of these relate to the marginalised participant only.
- The prevalence of similarities suggests the acculturation types within autism may not be as distinct as within other minority groups and this therefore might explain the findings within RQ1.
- Negative treatment and difficulties with social interaction found within young people with autism may impact on the effect the acculturation type has within this population.

Paper two:

- Non-autistic participants, as well as some autistic, think student understanding of autism is low, and this can result in wariness and negative treatment of students with the condition. Participants from both groups called for an improvement in the future, although non-autistic participants more so.
- Means for finding out about autism, including discussions, are limited and both sets of participants suggested ways to improve this.
- Autistic participants generally reported disclosing their diagnosis, although fear of negative treatment, embarrassment, and poor representations of autism in the media are reasons for not disclosing.
- Autistic students can be seen as going against the ‘norm’ and can be treated differently, including bullying and notions of ‘help’.
- Autistic participants generally know peers with the condition and half valued this.
- Autistic participants generally appeared content with adaptations, but some non-autistic participants felt these could cause them to stand out or become separated, things they wanted to reduce.

Paper One

Paper one abstract

The aim of paper one was to explore identity formation in autistic adolescents and the relationship between this and aspects of psychological wellbeing. Twenty-two participants (aged 11-18) with a diagnosis of autism from nine mainstream secondary schools completed scales on anxiety, self-esteem, and acculturation into autistic and non-autistic identities (cultural competence, identification, preference, and involvement). Nine of these participants also participated in a semi-structured interview to elicit in-depth perspectives in relation to aspects of acculturation listed above. Statistical analysis revealed no statistically significant relationship between measures of psychological wellbeing and acculturation types (bicultural, assimilated, separated, and marginalised), although descriptive statistics showed bicultural and marginalised participants had the greatest psychological wellbeing. The interviews were analysed thematically and data from six were separated into participants' acculturation type. Findings revealed differences between the types; however, the large number of similarities was felt to suggest that the acculturation types are not as distinct within autism as other minority groups. Additionally, the impact of negative treatment and difficulties with social interactions within autism were felt to contribute to the lack of a statistically significant relationship between biculturalism and psychological wellbeing within this population. These findings are discussed in relation to other studies exploring identity formation and psychological wellbeing in minority groups, with limitations and suggestions for further research included.

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2.2 Participants

Chapter 3: Findings

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1. Introduction

1.1 Rationale

Bagatell (2007) suggests there is a lack of research into identity formation within autism as deficit based views of the condition have commonly prevailed and therefore identity is seen as an insignificant issue. Despite a call for further research utlising participant voice (Billington, McNally, & McNally, 2000; Gilling, 2012), it appears that understanding of autism from people with the condition remains limited (Kapp, Gillespie-Lynch, Sherman, & Hutman, 2013).

Autism is an ongoing focus of the work of EPs (Gilling, 2012), and thus it is both pertinent for my own professional development and for others in the field. LA data indicates approximately 120 young people in the authority receive a diagnosis of autism every year and therefore increasing knowledge is important to ensure the diverse needs of these young people are met. The exploration of mental health issues for these adolescents within mainstream settings is also particularly salient as a review conducted by the Educational Psychology Service (EPS) found professionals were particularly worried about this.

1.2 Review of literature

1.2.1 Introduction

The following section will provide a summary of the literature in which paper one is situated (see appendix one for full review).

There is a large amount of literature within the field of autism. As a result it was necessary to focus on that relating to identity, found within social psychology. The method for conducting the review was informed by a narrative approach, whereby the range of literature covered was broad with less restrictions placed upon the studies included (Collins & Fauser, 2004). A distance to close strategy, as proposed by Rudestam and Newton (2001), structured it, ensuring transition from the general to specific.

The search occurred through three phases:

1. General search of practitioner texts; internet search engines; and peer-reviewed journals.
2. Greater specificity, focusing upon acculturation types in minority groups (Berry et al., 1986) and using search engines (such as EBSCO- E-Journals, PsycINFO, and ERIC) including key terms (such as autism and identity, biculturalism, and acculturation). A paper on the relationship between identity formation and psychological wellbeing in autism was identified (Myers et al., 2011).
3. In-depth exploration of identity in autistic adolescents using literature sourced from the above search engines as well from references within these. Due to the limited research available date limits were not set for the searches performed.

1.2.2 Definitions

The following definitions are used within both papers:

Autism

“Autism is a lifelong condition, which affects how a person communicates, interacts socially, and can present difficulties or differences for the person in their thinking, imagination and sensitivity of their senses” (Autism Initiatives, 2014, Autism spectrum condition, para.1). Defining autism as a condition, rather than a disorder, fits my personal views and recently noted movements within the field (Russell & Norwich, 2011).

Autism is characterised within the International Statistical Classification of Diseases and Related Health Problems 10th Revision (ICD-10) (World Health Organisation, 2010) by the presence of the following: development which is abnormal or impaired before three years; and qualitative abnormalities in communication, reciprocal social interaction, and restricted, stereotyped, or repetitive behaviour which cannot be attributed to other disorders or difficulties. The definition for Asperger syndrome matches this although a general delay in language or cognitive development is removed. The Fifth edition of the Diagnostic and Statistical Manual of Mental Disorders (DSM-V) (American Psychiatric Association, 2013) provides a similar definition although Asperger syndrome as a separate diagnosis has been removed, with the umbrella term 'Autistic Spectrum Disorder' used instead.

The terms 'autism' and 'autistic' are used throughout both papers to reflect all aspects of the spectrum, including Asperger syndrome. Participants were recruited on the basis of having a diagnosis: this paper will not explore the particular definitions on which this was made. Diagnoses were purposefully not checked by myself as questioning their validity was contradictory to the aims of the project.

Identity

The definition utilised is: "…the way a person understands and views himself, and is often viewed by others…" (Holland, Lachicotte Jr, Skinner, & Cain, 1998, p.68). This was selected as it highlights the importance of the individual within their environment.

1.2.3 Identity formation

Identity formation is said to be a fundamental task for young people during their adolescent years in western societies (Grotevant, 1992). This is a time during which they must make decisions regarding their values, career, and beliefs (Erikson, 1980). Erikson (1968, 1980) proposed an eight stage model of psychosocial development which emphasised the importance of the interaction with society and the need to search for one's sense of self. His ideas were built upon by Marcia (1980), who developed four identity statuses based on the type of exploration done in order to empirically study identity theory. Over time, interest has grown in the elements of identity people do not have control over, including ethnicity (Grotevant, 1992).

Identity formation and minority groups

An important concept within ethnic identity is acculturation, defined as the "... process of cultural and psychological change that results following meeting between cultures" (Sam & Berry, 2010, p.472). Berry et al. (1986) describe four acculturation types that relate to the value the person places on maintaining their cultural customs and upholding relationships with people from different groups to their own (figure two, overleaf). These have been further explored by Phinney (1990).

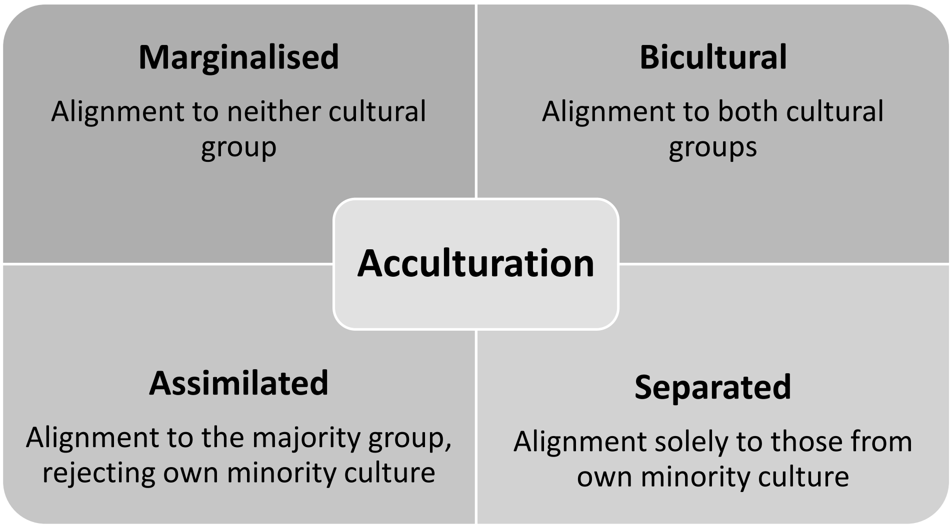

Figure 2: Four types of acculturation

Myers et al. (2011) claim the same concept can be applied to other minority groups and scales employed in research with ethnic minorities have been adapted for use with participants with hearing impairments (Glickman & Carey, 1993; Maxwell-McCaw & Zea, 2010). For example, the Deaf Acculturation Scale (DAS) measures acculturation across five areas (cultural involvement, cultural knowledge, language competence, cultural identification, and cultural preferences) on hearing and deaf identity sub-scales (Maxwell-McCaw & Zea, 2010). Nevertheless, sole reliance on self-report scales is at risk of response bias (Hammond, 2006).

Identity formation and autism

Interest in aspects of identity which are assigned, such as ethnicity, developed over twenty years ago (Grotevant, 1992); however, exploration within autism remains limited. Bagatell (2007) suggests this is linked to deficit based views of the condition, including difficulties with social interaction. Enright and Deist (1979) argue social perspective taking, the ability to see things from others’ points of view, is key to the development of identity, a skill people with autism can have difficulties with (The National Autistic Society (NAS), 2014b). Bagatell indicates the focus on these difficulties may have led to identity formation in individuals with autism being seen as less important. Nonetheless, research with small samples has begun to demonstrate the active role of these individuals in this social process, including positioning themselves to be viewed positively (Baines, 2012).

Papers exploring identity formation in autism have slowly begun to emerge and many demonstrate difficulties adolescents can have in accepting autism as part of their identity. This can be expressed as a desire to fit in and appear normal (Carrington & Graham, 2001; Humphrey & Lewis, 2008). Some also distance themselves from their autistic identity (Baines, 2012; Huws & Jones, 2008) or search for a cure (Bagatell, 2007). Such difficulties are said to lead to poor psychological wellbeing (Carrington & Graham, 2001). One suggestion for these findings is that autism is not viewed as a valid identity by society, demonstrated through the use of therapeutic interventions to correct ‘deviant’ behaviour (Brownlow, 2010). This concurs with notions of stigma (Edgerton, 1967). Nonetheless, advocates of neurodiversity have begun to challenge such practices (Jaarsma & Welin, 2012; Jordan, 2010). Additionally, Humphrey and Lewis (2008) describe participants who had accepted their autism, although do not detail how they came to this or the impact.

Research in the area predominantly uses qualitative methods, which provide in-depth personal perspectives, as advocated by Billington et al. (2000); however, this limits sample sizes and has resulted in a paucity of direct measures.

1.2.4 Psychological wellbeing

The psychological wellbeing of young people with autism is a concern, with over 70% of this population reported to experience mental health problems (NAS, 2010). Such worries are mirrored within the LA, as data from an EPS review revealed professionals were concerned regarding the levels of anxiety experienced by autistic students in mainstream settings.

Anxiety within this population is well documented (Gillott, Furniss, & Walter, 2001; Van Steensel, Bögels, & Perrin, 2011); however, research looking at anxiety in relation to mainstream education settings and identity is limited. A similar issue exists for self-esteem, despite recognition that this can be a difficulty for young people with autism and claims that this links to other aspects of psychological wellbeing (Myers et al., 2011).

Psychological wellbeing and identity in minority groups

The idea that a relationship exists between identity and psychological wellbeing stems back to Erikson (1968, 1980). Research with minority groups has demonstrated such a relationship, predominantly using quantitative data to do so (Cornell & Lyness, 2004; Rivera-Sinclair, 1997; Smokowski & Bacallao, 2007). A meta-analysis of 83 studies revealed biculturalism had the strongest link to positive psychological adaptations in ethnic minorities (Nguyen & Benet-Martinez, 2013). Similarly, Hintermair (2008) compared data from the DAS and Rosenberg self-esteem scale (SES), amongst others, and found biculturalism was the best outcome for participants with hearing impairments. Nonetheless, Schwartz and Unger (2010) suggest biculturalism is not always an advantage when the minority culture experiences discrimination and Hintermair reports those in the marginalised group could also develop good self-esteem.

Additionally, Rudmin (2003) argues past research has failed to show strong empirical evidence that biculturalism is best.

Psychological wellbeing and identity in autistic adolescents

Similar research within autism was not uncovered; nevertheless, a number of personal accounts indicate such a relationship exists. A reoccurring theme is that hiding one's autism to fit with the majority group is associated with negative psychological wellbeing (Bagatell, 2007; Carrington & Graham, 2001). This is further reinforced by findings showing participants who celebrated their autism spoke positively about themselves (Humphrey & Lewis, 2008). Myers et al. (2011) claim identity formation in autism parallels that of individuals with hearing impairments and therefore biculturalism will have a positive relationship with psychological wellbeing in this population. Such claims lack empirical evidence and the differences that exist between minority groups can make direct comparisons difficult.

1.2.5 Limitations identified within the literature

A review of the literature revealed a paucity of research exploring identity formation in autism, despite the issue being raised seven years ago (Bagatell, 2007). Furthermore, within the limited research available, studies using quantitative approaches do not appear to exist. Similarly, the review revealed a need for further research exploring the link to psychological wellbeing. A number of papers highlighting personal accounts suggest such a relationship is present (Bagatell, 2007; Carrington & Graham, 2001); however, unlike with other minority groups (Cornell & Lyness, 2004; Hintermair, 2008), this has not been directly measured. This is despite a call for such research over 25 years ago (Weinberg & Sterritt, 1986). Studies with other minority groups have often solely relied on quantitative measures and therefore a mixed method design, as called for by Hintermair (2008), overcame this.

1.3 Research aim and questions

Aim

To explore identity formation in autistic adolescents and the relationship between this and aspects of psychological wellbeing.

Research questions (RQs)

RQ1: What are the relationships between a ‘bicultural identity’ and psychological wellbeing in autistic adolescents in mainstream settings?

a) Is there a relationship between anxiety and self-esteem?
b) Is there a relationship between a ‘bicultural identity’ and self-esteem?
c) Is there a relationship between a ‘bicultural identity’ and anxiety?

RQ2: What are the perspectives of autistic adolescents in mainstream settings regarding their identity (including: cultural identification, cultural involvement, cultural preference, and cultural competence) in relation to their acculturation type (marginalised, assimilated, separated, and bicultural)?

2 Methodology

2.1 Research design

An exploratory research design, which is predominantly interested in discovery (Davies, 2006), was selected. In addition, a mixed-methods approach was chosen to answer the RQs and overcome identified limitations. This is in line with the pragmatic philosophical perspective whereby the methods selected are those that will best answer the questions set (Robson, 2002; Tashakkori & Teddlie, 1998). This perspective is one that is concerned with ways of knowing which are shaped by the researchers' beliefs and values, rather than focusing on what is truth (Mertens, 2010). The methods selected, scales and semi-structured interviews, were deemed appropriate for achieving the above aims, allowing the perspectives of participants to be heard, as well as searching for relationships between aspects of identity.

2.2 Participants

2.2.1 Sampling strategy

A purposeful opportunistic sampling technique was used, whereby participants were recruited through contact with school staff (Robson, 2002). This technique is advocated as valuable when exploring complicated psychosocial issues (Marshall, 1996).

2.2.2 Recruitment and inclusion criteria

Nineteen secondary schools were identified using an online directory and via autism advisory teachers using the criteria overleaf. Letters or emails were sent to head teachers, special educational needs coordinators (SENCO), and/or autism coordinators. Follow up contact was made one week later (appendix two).

Table 2: Inclusion criteria

Schools	Participants
• Offer full-time secondary education in a mainstream setting; • Located within the LA and within one and half hours travel of my home.	• 11 -18 years old; • Attend the mainstream setting for at least 95% of their school day; • A formal diagnosis of autism that they know about.

2.2.3 Participant details

Schools

Nine mainstream secondary schools, including maintained and academies, across one county in the south of England agreed to participate.

Participants (appendix three)

Scales:

Invited to participate	66
Agreed to participate	31
Fully completed both the anxiety and self-esteem scales (RQ1a)	25
Allocated an identity group and completed the self-esteem scale (RQ1b)	21
Allocated an identity group and completed the anxiety scale (RQ1c)	18

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Semi-structured interviews: Nine of the above participants, aged 11 to 16 years (8 males, 1 female) with a mean age of 13.2, were invited to participate in an interview. Three did not fully complete the autism identity scale or their score fell at the median cut off point (see appendix thirteen) and therefore data from six was used to answer RQ2. Analysis from all nine participants can be found in appendix eleven.

The inequality in males to females reflects the inequality in ratios of males and females diagnosed with autism.

2.3 Scales (appendix four)

Consideration was given to the use of scales with autistic adolescents, particularly those requiring identification of feelings, as data collection through this means can be problematic (Sofronoff, Attwood, & Hinton, 2005). Nonetheless, it has been shown that young people with autism can use structured scales to undertake self-reflection (Knott, Dunlop, & Mackay, 2006) and this is said to improve with age (Kuusikko et al., 2008). Additionally, interviews were used to help overcome the disadvantages that accompany self-report tools, including the risk of response bias (Hammond, 2006).

Autism identity scale (AIS):

This was based on the Deaf Acculturation Scale (DAS) as no scales for measuring identity in autistic adolescents were available. The DAS measures whether participants feel more aligned to the deaf culture, hearing culture, both, or neither across five areas: cultural preference, cultural knowledge, cultural involvement, cultural identification, and language competence (Maxwell-McCaw & Zea, 2010). It has been proven reliable, with Cronbach's alpha coefficients between 0.91 and 0.95 showing internal consistency for the two scales. A former colleague and friend with Asperger syndrome was shown a draft of the scale and alterations were made following her feedback (appendix six). The AIS has two scales (autistic and non-autistic acculturation); makes use of a 5-point scale; and measures four of the five areas listed above, with language removed.

Rosenberg's self-esteem scale (SES):

This was selected to measure self-esteem, defined as "…a positive or negative attitude toward a particular object, namely, the self" (Rosenberg, 1965, p.30). High self-esteem is shown on the scale as a feeling of being good enough whilst low self-esteem reflects dissatisfaction and rejection of the self (Rosenberg, 1965). It was chosen because it has proven validity (Hintermair, 2008); it has a simple format reducing the burden on participants; and it is suitable for the age range involved in the research (Gray-Little, Williams, & Hancock, 1997; Rosenberg, 1965). Additionally, it has been standardised on a large adolescent population (Rosenberg, 1965). The scale is freely available online (http://personality-testing.info/tests/RSE.php).

Spence children's anxiety scale (SCAS):

This was employed to measure anxiety. It has been proven reliable and valid and suitable for the age of the participants (Spence, Barrett, & Turner, 2003). It has also been used successfully with autistic participants (Gillott at el., 2001; Hannah & Topping, 2012). The scale is free for researchers to download (http://www.scaswebsite.com/index.php?p=1_6).

2.4 Semi-structured interviews (appendix four):

The schedule was developed using questions from the three scales. As in the AIS, the identity aspect included four areas believed to be related to acculturation: cultural identity, involvement, preference, and competence (Maxwell-McCaw & Zea, 2010). Hierarchical focusing, as proposed by Tomlinson (1989), was used which aims to impose as minimal a frame as possible, allowing ideas to be lead from participants so that prompts are only employed when the aspect of the topic has not been raised.

2.5 Procedures

A timetable was created to ensure all of the procedures could be completed in the timeframe stipulated (appendix five).

Piloting

Prior to data collection, piloting took place with one interview participant and three for the scales, an important first step to overcome any issues (Robson, 2002). Additional piloting was desired but not possible due to limited numbers of participants. Minimal alterations were felt to be required as the instruments were deemed appropriate after testing (appendix six).

Scales

Participants completed the three scales in any order, taking 15 to 40 minutes to do so. Breaks, use of a computer, and adult support were offered to assist completion. As a result the conditions in which participants completed the scales may have altered slightly, although this was important to reduce the burden and ensure accessibility.

Semi-structured interviews

Semi-structured interviews were audio recorded and lasted 25-40 minutes. This approach was deemed suitable as it has been used effectively to seek the views of young people with autism (Beresford, Tozer, Rabiee, & Sloper, 2004; Humphrey & Lewis, 2008). As in the aforementioned studies, the procedure was tailored for each participant to make it as accessible and enjoyable as possible, including: avoiding face-to-face seating; careful use of language; support from a familiar adult; and implementation of preparation activities, all where appropriate (appendix seven).

2.6 Data analysis

Quantitative analysis:

Data from the scales were analysed using the Statistical Packages for the Social Sciences' (SPSS). This occurred in two stages:

1. Descriptive statistics for all three scales were produced.
2. Inferential statistics:
   1. Screening of the data from the SCAS and Rosenberg's SES was followed by a Pearson's product-moment correlation coefficient to explore the direction (positive or negative) and strength (weak, moderate, strong, or perfect) of any relationship.
   2. Data from the AIS were categorised into seven deciles with the middle group, who fell on the median cut-off, removed to ensure each participants' score from the autistic and non-autistic scales fell into one of four types (marginalised, assimilated, separated, or bicultural), utilising as much data as possible (appendix twelve). Data screening was performed before a One-Way ANOVA was undertaken on the acculturation types, SCAS, and Rosenberg's SES data to identify any difference. A post-hoc test (Tukey HSD) was used to identify where any difference occurred.

Qualitative analysis

An adapted version of the thematic analysis procedure outlined by Braun and Clarke (2006) was employed to provide a "thick description" and findings which are accessible to users (appendix eight). Extra stages were added to ensure the transcripts could be coded inductively and deductively, allowing themes to arise from the data whilst also acknowledging the theory underpinning the interview questions. Steps included:

1. Transcription and continual reading to ensure familiarity.
2. Initial coding of each transcript individually in Nvivo 10 and then further revision of these codes. Mapping out themes for each participant using an inductive approach.
3. Combining themes for each participant to create a set of themes across the group.
4. Re-coding of the transcripts in Nvivo 10, applying the group themes from step three and four themes underpinning the interview questions.
5. Repeated examination of the data and refining themes.
6. Reporting the findings.

Data from the analysis were separated into acculturation types utilising participants' AIS scores (appendix thirteen) and findings were compared for points of interest.

2.7 Reliability

Anxiety and self-esteem scales

Neither scale has been standardised on young people with autism and therefore semi-structured interviews employing similar questions were used to ensure triangulation. Interview responses related to anxiety and self-esteem were given a ranking of low, medium, or high and compared to scores achieved on the SCAS and Rosenberg (appendix thirteen). This revealed consistency of 66% for both scales. A sample of text was tested for inter-rater consistency by two raters which revealed agreement for 5/6 transcripts or 83% for anxiety and 4/6 transcripts or 66% for self-esteem (appendix nine).

AIS

The AIS was completed twice, with a three week minimum gap, to explore whether participants achieved the same results on two occasions (Dyer, 1995). Data screening (appendix twelve) was followed by a one-tailed Pearson's product- moment correlation co-efficient. This revealed a statistically significant moderate positive relationship between the first and second attempts at the autistic scale (r= 0.498, p= 0.007) and a weak non-statistically significant positive relationship between first and second attempts at the non-autistic scale (r= 0.027, p= 0.450) (table seventeen, appendix twelve). A related t-test revealed participants' answers on the first and second attempts at the autistic scale were not statistically significantly different, t (23) = -0.020, p 0.984. This was repeated for the non-autistic scale t (22) = -0.782, p 0.443 (table eighteen, appendix twelve). This shows the AIS demonstrates some consistency over time; moderate in the autistic scale and weak within the non-autistic scale.

2.8 Ethical considerations

Prior to data collection ethical approval was received from the University and LA (appendix ten). Participating schools and students were given information about the study, including their right to withdraw, and provided their consent on this basis (British Psychological Society (BPS), 2010), (see appendix ten for consent and information forms). One participant chose to withdraw after paper one but did not ask for their data to be removed.

Information about participants' right to confidentiality and the storage of data was provided to all (British Educational Research Association (BERA), 2011) (see information forms, appendix ten). Additional information was provided to one family who were unclear how data would be shared with the school (appendix ten). Participants were made aware that if safeguarding issues arose these would need to be shared.

3 Findings

RQ1: What are the relationships between a 'bicultural identity' and psychological wellbeing in autistic adolescents in mainstream settings?

1a. Is there a relationship between Spence anxiety and Rosenberg self-esteem?

Data screening:

Data screening revealed three of the four conditions for parametric testing were met (scale data, normal distribution, and no extreme scores) (table eleven, appendix twelve).

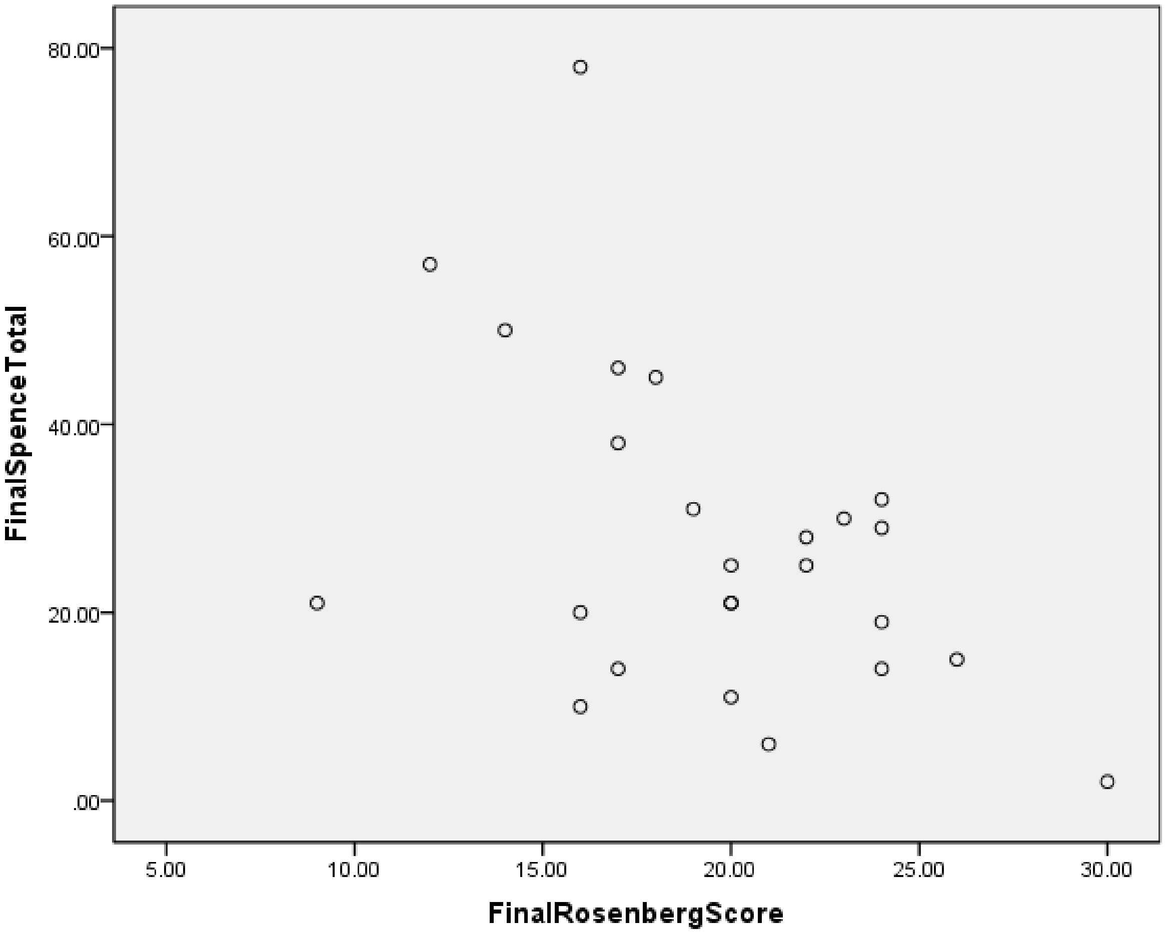
Descriptive statistics:

Table 3: Descriptive statistics for self-esteem and anxiety data

Scale	Number of participants	Mean	Standard deviation
Total Spence Anxiety Score	25	27.5	17.3
Total Rosenberg Self-esteem Score	25	19.6	4.6

The scatter graph (figure three, overleaf) revealed a negative relationship between participants' anxiety and self-esteem scores.

Figure 3: Scatter graph of self-esteem and anxiety data



Inferential statistics:

A one-tailed Pearson’s product- moment correlation co-efficient to explore the relationship between anxiety and self-esteem revealed a statistically significant moderate negative correlation between anxiety and self-esteem (r= -0.466, p= 0.009). This suggests that participants’ with higher self-esteem have lower anxiety.

Pearson correlation	**-.466**
Sig. (one-tailed)	**0.009**

1b. Is there a relationship between a ‘bicultural identity’ and Rosenberg self-esteem?

Data screening:

Data screening revealed three of the four conditions for parametric testing were met (scale data, normal distribution, and no extreme scores) (table twenty, appendix twelve).

Table 4: Descriptive statistics for the acculturation type and self-esteem data

Types	Number of participants	Mean	Standard deviation
Marginalised	5	20.40	2.5
Assimilated	6	17.66	4.8
Separated	3	19.00	5.1
Bicultural	7	22.14	4.8

The descriptive statistics showed the bicultural group had the highest self-esteem scores, followed by the marginalised group. The assimilated group had the lowest mean self-esteem score.

Inferential statistics:

A One-Way ANOVA uncovered no statistically significant relationships between the acculturation types and self-esteem, F (3, 20) = 1.146, p= 0.359.

1c. Is there a relationship between a ‘bicultural identity’ and Spence anxiety?

Data screening:

Data screening revealed three of the four conditions for parametric testing were met (scale data, normal distribution, and no extreme scores) (table twenty, appendix twelve).

Table 5: Descriptive statistics for the acculturation type and anxiety data

Types	Number of participants	Mean	Standard deviation
Marginalised	5	22.6	15.82
Assimilated	5	25.8	12.71
Separated	2	49.0	41.01
Bicultural	6	22.0	13.78

The descriptive statistics revealed the bicultural group had the lowest anxiety scores followed by the marginalised group. The separated group had the highest anxiety scores and greatest variation of scores, although data were only drawn from two participants.

Inferential statistics:

A One-Way ANOVA uncovered no statistically significant relationships between acculturation types and anxiety, F (3, 17) = 1.321, p= 0.307.

RQ2: What are the perspectives of autistic adolescents in mainstream settings regarding their identity (including: cultural identification, cultural involvement, cultural preference, and cultural competence) in relation to their identity type (marginalised, assimilated, separated, and bicultural)?

Thematic analysis was undertaken on the interview responses relating to identity which resulted in five salient themes (see appendix eleven for thematic analysis of all interview data). This analysis was separated into acculturation types. Four participants' AIS scores put them in the 'bicultural' group, one within the 'separated', and one within the 'marginalised'. Three interview participants did not have complete AIS data or their score fell at the median cut off and none fell within the 'assimilated' group (appendix thirteen).

Theme 1: Personal definitions of and perceived knowledge about autism (Cultural competence)

The table below summarises participants' definitions of autism and knowledge about the condition.

Level one sub-themes	Summary	Illustrative data
How participants define autism	**Bicultural:** Definitions included key information/facts and lacked personal references. Two included negative traits or a negative tone and two included benefits.	*"…problems with learning difficulties and reading language…"* (A17). "*…now I don't have to worry about my son or daughter getting it"* (A22). *"….most autistics are normally normally grow up and become*

		excellent engineers great artists…" (A5).
	Separated: Definition includes personal references and difficulties.	*"…I was just either talking gibberish or talking in opposites..like when I was really little sometimes I would be banging on the door…"* (A16).
	Marginalised: Definition includes a few facts and brief reference to self.	*"…like a mental condition then… sometimes high functioning…"* *"…apparently I am going to be somewhat smarter…"* (A28).
Perceived levels of knowledge about autism and related things	**Bicultural:** All provide some information but only one appeared confident. Participants know more about peers and famous people and less about history and organisations/clubs.	*"not much"* (A38). *"well I know a fair bit about it because XXX (family member)"* (A17). "…*Albert Einstein had autism…"* (A22).
	Separated: Reports having minimal knowledge but provides information about famous people, clubs, history, and peers.	*"I only know very basic information…"* *"I know Albert Einstein had autism…."* (A16).
	Marginalised: Reports having no knowledge. Does not distinguish whether people have autism.	"…*no I just usually regard the famous people as… just famous people"* (A28).

Theme 2: Cultural identification

The table below summarises participants' feelings about having autism; whether they fit in with others; and their disclosure of their diagnosis.

Level one sub-themes	Summary	Illustrative data
Feelings about autism	**Bicultural:** Having autism is important to half. Three listed benefits of having autism, although one also reported negatives.	*''…quite important cos that means I can put ideas I have onto paper…"* (A5). *"It's not really important to me it's something that is there…"* (A17). *"…sometimes it feels good because I've got a creative mind and it also feels bad at times cos cos people make fun of me…"* (A22).
	Separated: Feelings about autism have changed from trying to hide it in the past to feeling proud now. Lists benefits of having autism.	*"…I ended up like hating my autism and just try to push it aside…"* *"I have accepted my autism and I've come to be quite proud of it…"* (A16).
	Marginalised: Does not mind having autism but views it as a background thing.	*"…it's just like a background thing to me"* *"I don't really mind it…"* (A28).
Self in relation to others	**Bicultural:** None appear to spend much time making comparisons to others, although one reported difficulties fitting in. Three	*"…I don't really compare myself…"* (A17). *"…with my friends and stuff but not the other not the types of people who that are mean to me*

	listed benefits of spending time with autistic peers.	*and think I'm different…"* (fitting in) (A22). *"…I don't feel like I am on my own or you know I am not like the only one"* (A38).
	Separated: Fitting in has been an issue which resulted in them trying to hide their autism. Regularly makes negative comparisons to others. Identified benefits of spending time with autistic peers.	*"…X is doing better at school than me or whether you know X is more popular than me…"* *"…because the new friends I made I just wanted to be like them and I found it so hard to be like because of my autism"* (A16).
	Marginalised: Fits in and does not compare self to others, something which has improved over time. Spending time with autistic peers is not important.	*"I: do you think you fit in with others at school?* *A28: Yeh"* *"…I just generally hang out with people"* (A28).
Sharing diagnoses	**Bicultural:** Three have or would disclose their diagnosis, although two are cautious. One would not disclose and tried to present themselves so it could not be seen.	"…*defend off things*…" (A5). *"…I have Asperger but I don't really I try not to show it as much as I can"* (A38).
	Separated: Would disclose to others if asked but presents self to be viewed positively by others.	*"…I present myself so well to other people so they might not notice"* *"…if somebody asks me you know to describe myself I would definitely put autism there…"* (A16).

	Marginalised: Would not describe self as autistic.	*"…if people really ask I just refer to myself as just a person"* (A28).

Theme 3: Cultural involvement

The table below summarises participants' perspectives on their involvement with activities and autistic peers.

Level one sub-themes	Summary	Illustrative data
Feelings of involvement with things related to autism	**Bicultural:** Half felt involved, half did not comment on this.	*"…I don't really know really I think I am alright"* (A5). *"Fairly well involved…"* (A17).
	Separated: Not discussed although indicated they have attended clubs and read books about autism.	"*I used to go to this club called XXX… it was almost like a youth group but it was just for people with Asperger or autism…."* (A16).
	Marginalised: Does not feel very involved.	*"…I don't actually feel very… involved at all because I just usually…maybe just…..spending time with people"* (A28).
Involvement in activities/ events	**Bicultural:** All had sought or expressed an interest in seeking information about autism. This was usually through books (three had read at least one) or family members. Three do not attend clubs/events related to autism. In contrast, one	*"Yeh that's where I got most of the facts from a book in the library that's about autism… I found that by myself"* (A5). *"…I don't feel that much on you know chatting online, events or promoting rights or campaigns"* (A38).

	was involved through their family. Three chat online but not specifically to people with autism.	*“…sometimes I do some charity work with X (family member)…”* (A17).
	Separated: Has attended clubs for people with autism and those open to anyone. Chats online and has read books about autism but does not enjoy either. Attendance at events would depend on the environment.	*“…I have tried to read books about people you know you have been diagnosed but I have found them like difficult to read …”.* *Umm it depends what event it is if it is going to be crowdy or loud…”* (A16).
	Marginalised: Is not involved in any activities related to autism. Chats to people online but does not know if they have autism.	*“Um….I don’t really know who has and who hasn’t” (*A28).
Social relationships with autistic peers	**Bicultural:** All know at least one other student with autism; with half knowing many. Two reported having friends with the condition.	*“…a friend of mine called X has Asperger I know that….that’s about it”* (A5). *“Yeh I know pretty much everyone in the school with autism….I got to know them because most of us go to X (special educational needs (SEN) area) just to hang out…”* (A38).
	Separated: Has friends with autism but feels it is a person’s ability to have conversations that is important. Only knows autistic peers within SEN areas.	*“Only the people in here (SEN area) …”* *“I have very good friends who have got you know the same spectrum are on the same spectrum as me…”* (A16).

	Marginalised: Does not know autistic peers	*"Ummm…..no….I don't know…."* (A28).

Theme 4: Relationship preferences (Cultural preference)

The table below summarises participants' preferences as to whether peers and family members have autism or not and reasons behind this.

Level one sub-themes	Summary	Illustrative data
Preferences	**Bicultural, Separated and Marginalised:** None.	*"No I don't mind"* (A16). *"…fine either way"* (A28).
Reasons behind preferences	**Bicultural and Marginalised:** Whether friends, peers, or family members have autism does not matter.	*"…I treat them exactly the same they are still people"* (A17). *"….I don't really mind…"* (A28).
	Separated: Whether someone can have a good conversation is most important.	*"…if that person can make a good conversation with me about something then I would be perfectly happy to talk to them…"* (A16).

Theme 5: Negative treatment

Negative treatment was an additional theme that arose when participants spoke about their identity.

Summary	Illustrative data
Bicultural: One had experienced jokes made about them and another reported bullying. Both attributed this to their autism. Half did not report any negative treatment.	*"…pushed me shoved me called me names like stupid or ugly…"* (A22). *"…I think they sort of realised that and sort of joking really not really bullying but sort of jokes"* (A5).
Separated: Has experienced some teasing in the past due to their autism. Feels it could happen again if they disclosed but thinks most people would respect them.	*"…might you know tease me about it because they have in the past"* (A16).
Marginalised: Experiences some negative comments but has learnt to focus on the positive.	*"Um sometimes ? (inaudible) but usually I just ignore them…"*. *"…when I was younger I was just… learning to pay attention to good things"* (A28).

Comparisons within and across the acculturation types

The data were explored for similarities and differences within the bicultural group and across the three acculturation types in order to provide a deeper insight into the relationship between biculturalism and psychological wellbeing in autism explored within RQ1.

Table 6: Summary of key similarities and differences within the bicultural group

Themes	Similarities	Differences
Definitions and knowledge	• All knew famous people and autistic peers but lacked information about history.	• Two participants included negative comments/tone in their definition. • Only one participant was confident about their knowledge of autism and related things. This was facilitated by a family member.
Cultural identification	• Three listed benefits of having autism. • Participants did not appear to spend much time comparing themselves to others. • Three listed benefits of spending time with autistic peers. • Three have disclosed their diagnosis.	• Only two reported autism was an important part of their life. • One reported changes in their feelings towards their autism. • Only one reported difficulties fitting in. • One would not disclose and two appeared reluctant.

Cultural involvement	• All had sought or expressed an interest in seeking information about autism, including through books. • Three were not involved in autism events and clubs. • Three chat online, although not necessarily to people with autism.	• One was involved in autism events due to family involvement. • One had not read any books related to autism. • Only two reported having friends with autism.
Relationship preferences	• None reported.	
Negative treatment	• Negative treatment was attributed to autism.	• Two did not report any negative treatment.

Table 7: Summary of key similarities and differences between the acculturation types

Themes	Similarities	Differences
Definitions and knowledge	• All participants reported having limited knowledge of autism and related things, apart from one bicultural participant. • Bicultural and separated participants shared some knowledge they had, particularly of famous people.	• Only the separated participant discussed their own autism in any detail when defining the condition. • The marginalised participant reported no knowledge about things related to autism.
Cultural identification	• All made neutral to positive comments about having autism.	• Fitting in has been an issue for the separated

	• Most bicultural and the separated participant listed benefits of having autism. • Bicultural and marginalised participants did not appear to spend much time comparing themselves to others. • Most bicultural and the separated participant would or have disclosed diagnoses, although most appeared to have some reluctance. • Most bicultural and the separated participant listed benefits of spending time with autistic peers.	participant and one of the bicultural participants. • The separated participant made negative comparisons to others. • The marginalised and one bicultural participant would not disclose their diagnosis. • The marginalised participant does not spend time with autistic peers
Cultural involvement	• Bicultural and separated participants know autistic peers. • Bicultural and separated participants had sought or expressed an interest in seeking information about autism. • None specifically chat online to people with autism.	• The marginalised participant does not know autistic peers. They reported enjoyed spending time with people, not identifying whether they have autism or not. • The marginalised participant had not sought information about autism and did not feel involved with things related to the condition.
Relationship preferences	• No relationship preferences.	

Negative treatment	- Negative treatment had been experienced by at least one member of each group.	

4. Discussion

4.1 Findings related to the literature

4.1.1 RQ1 findings

What are the relationships between a 'bicultural identity' and psychological wellbeing in autistic adolescents in mainstream settings?

Psychological wellbeing

Correlational analysis revealed a moderate, statistically significant negative relationship between anxiety and self-esteem. This implies that participants who have high self-esteem are likely to have lower anxiety and vice versa. Descriptive statistics revealed mean self-esteem and anxiety scores fell within the 'normal' range, the latter similar to those reported by Williamson, Craig, and Slinger (2008). Nonetheless, opt-in consent may have resulted in sampling bias as participants with lower psychological wellbeing may have been less likely to participate.

Psychological wellbeing and identity

As there is little research on biculturalism and psychological wellbeing in people with autism, findings are related to literature on minority groups.

The findings did not reveal any statistically significant relationships between biculturalism and psychological wellbeing. This conflicts with research with other minority groups that have demonstrated a positive relationship between biculturalism and self-esteem (Cornell & Lyness, 2004; Hintermair, 2008; Smokowski & Bacallao, 2007) and anxiety (Rivera-Sinclair, 1997). Nevertheless, the descriptive statistics revealed bicultural participants had the highest mean self-esteem score and lowest mean anxiety score. This provides tentative support for claims that finding ways for adolescents to explore and feel at ease with their autism identity whilst fitting in could be effective for fostering psychological wellbeing (Myers et al., 2011).

The descriptive statistics revealed the separated group had the highest mean anxiety and second lowest mean self-esteem scores, echoed in past research (Cornell & Lyness, 2004; Hintermair, 2008). Rosenthal (1987) suggests membership of a minority group is often associated with feelings of inferiority due to discrimination and having a lower status and therefore this may account for such findings. Nevertheless, it is important to acknowledge the small sample within this acculturation type and lack of statistical significance.

Descriptive statistics revealed marginalised participants had the second highest self-esteem, which is in opposition to participants with hearing impairments (Cornell & Lyness, 2004; Hintermair, 2008). Nonetheless, Hintermair (2008) found a number of marginalised participants had high self-esteem and suggests this acculturation type is not always linked to poor psychological wellbeing and instead can be actively chosen. Additionally, Leigh (2009) argues marginality can be positive as the person is not restrained by constraints in the culture. This is supported by analysis generated for RQ2 in which the marginalised participant appears satisfied with their experiences where the existence of two ‘cultures’ is not a part of who they are.

4.1.2 RQ2 findings

What are the perspectives of autistic adolescents in mainstream settings regarding their identity in relation to their acculturation type?

Cultural competence

Bicultural and marginalised participants' definitions of autism lacked detailed personal references, whereas the separated participant described their experiences. Half of the bicultural and the separated participant highlighted difficulties or took a negative tone when describing the condition. It is possible this is because children are said to regularly face negative viewpoints about their impairments (Kelly, 2005; Pukki, 2006). Research on autism within the media supports this claim (Farnall & Smith, 1999; Jones & Harwood, 2009). Nonetheless, two bicultural participants named benefits, including increased focus and good career prospects.

Participants across the acculturation types perceived themselves to have minimal knowledge about autism. This is despite calls for young people to have information about their diagnosis (Wheeler, 2003; Whitaker, 2006). There is little research exploring young people's understanding of their autism; however, this confirms findings that they can lack information (Kelly, 2005). In contrast, one bicultural participant appeared confident in their knowledge and attributed this to a family member. This supports research that shows parents play an important role in providing such information (Connors & Stalkers, 2007). Bicultural and separated participants had some knowledge about things related to autism, particularly famous people and peers, whereas the marginalised participant did not.

Cultural identification

All participants made neutral to positive comments with regard to their feelings about autism, although bicultural and separated participants were generally more positive. This conflicts with research where opinions appear more mixed (Humphrey & Lewis, 2008; Huws & Jones, 2008). Nonetheless, two participants reported changes to their feelings. The separated participant described the effect previously rejecting their autism in attempts to fit in had on their psychological wellbeing. The detrimental impact of this confirms previous findings (Baines, 2012; Carrington & Graham, 2001). The change in feelings towards their diagnosis overtime supports the claims of Huws and Jones (2008) and that identities are not static (Holland et al., 1998).

Participants' views on the importance of having autism varied. For half of the bicultural and the separate participant it appeared important; however for others it is just one of many aspects of their life, echoed in the literature (Connors & Stalker, 2007; Kelly, 2005).

All but one bicultural and the separated participant identified benefits of spending time with autistic peers supporting calls for such opportunities to be available (Israelite, Ower, & Goldstein, 2002; Leigh, 1999). In contrast, the marginalised participant did not know autistic peers and indicated that relationships were not based on labels.

Making comparisons to others did not appear important for bicultural and marginalised participants, whereas the separated participant regularly made negative comparisons. This participant's concerns supports Kent's (2003) suggestion that modern expectations in western cultures where acceptable individuals are popular and conform to standards expected of them, may make adolescents with SEN feel inadequate.

Three bicultural and the separated participant would or have disclosed their diagnosis; however, two bicultural participants appeared reluctant to do so again. Two participants presented themselves in order to be seen positively, one deliberately trying to prevent others knowing about their diagnosis, as found by Baines (2012). Participants' reluctance to disclose may relate to fears of discrimination or differentiated treatment found previously (Humphrey & Lewis, 2008; Israelite et al., 2002). These mixed findings confirm those found by Huws and Jones (2008).

Cultural involvement

Exploration of adolescents' involvement within an 'autism culture' is an original feature of this research.

Bicultural and separated participants had sought or expressed an interest in seeking information about autism, most commonly through books. This conflicts with Huws and Jones (2008) who found that a number of participants actively avoided information. The marginalised participant had not sought such information, although this appeared to relate to the importance they placed upon it rather than active avoidance.

Involvement in other activities related to autism appeared to be low. Only one bicultural and the separated participant had participated in clubs or events, with facilitation from family or organisations. Comments from participants across the groups indicate that participation is not always viewed as being related to autism or not, particularly reading and talking to others online.

Cultural preferences

Exploration of participants' relationship preferences is also an original feature. Participants expressed no preferences and the separated and marginalised participants indicated this was because relationships were not based on labels. This appears to provide support for Iantaffi, Jarvis, and Sinkas's (2003) finding that minority participants like the opportunity to study in a mainstream environment with a range of peers.

Negative treatment

Four participants from across the groups discussed negative treatment and all but one attributed it to their autism. These findings add to the plethora of research on the issue (Humphrey & Lewis, 2008; Kloosterman, Kelley, Craig, Parker, & Javier, 2013; Punshon, Skirrow, & Murphy, 2009). However unlike this, only one referred to their experiences as bullying. Two participants' discussions were in the past tense possibly indicating a push for schools to further reduce bullying has been effective (Office for Standards in Education, Children's Services, and Skills (Ofsted), 2012).

4.1.3 What do the findings from RQ2 tell us about RQ1?

Comparing the data generated for both RQs revealed a number of possible explanations of why no statistically significant relationship was found in RQ1.

Negative treatment was reported across the acculturation types and four out of five participants who had experienced this had poor anxiety or self-esteem scores or both (appendix thirteen). This mirrors research that demonstrates a relationship between bullying and psychological wellbeing within autism (Zablotsky, Bradshaw, Anderson, & Law, 2013). This suggests that negative treatment might have a greater impact on psychological wellbeing in autistic adolescents than the acculturation type they fall within. This is supported by claims that discrimination is a predictor of psychological wellbeing (Sam & Berry, 2010; Smokowski & Bacallao, 2007).

Analysis generated for RQ2 indicates participants within the bicultural and separated groups reported difficulties fitting in, whereas the marginalised participant did not. This conflicts with research with other minority groups, which suggests that social interaction is best supported by biculturalism (Cornell & Lyness, 2004; Weinberg & Sterritt, 1986). Hintermair (2008) argues that it is the opportunity for social interaction that the acculturation type allows that is important rather than the specific type. Social interaction is part of the triad of impairments in autism (NAS, 2014b), and therefore it may be that satisfaction with interactions is related to the individual and their strengths and difficulties in this area rather than what membership of an acculturation type can offer, as with other minority groups. Nonetheless, analysis from the separated participant indicates this acculturation type may be problematic. This participant spent time with peers and activities related to autism whilst making negative self comparisons to majority group peers. This supports Rosenthal's (1987) claim that membership of a minority group is often associated with feelings of inferiority. It also confirms Bauminger and Kasari's (2000) findings that undertaking social comparisons against majority group peers can result in relationship difficulties.

An exploration of similarities and differences within and between the acculturation types also contributes to our understanding of the findings for RQ1.

A comparison of bicultural participants (table six) highlighted similarities across the five themes; however, it also revealed differences. Most notably, experiences of negative treatment; feelings towards disclosure; and relationships with peers.

A comparison across the three types (table seven) demonstrated a number of differences, although these often related to the marginalised participant only. For example, most bicultural and separated participants sought information about autism; listed benefits of having it; knew peers with the condition and valued spending time with them. Additionally, similarities exist across the three types. Most participants reported having limited knowledge about autism; all expressed neutral to positive feelings about the condition; and none had relationship preferences.

These findings suggest that biculturalism within autism may not be a distinctive enough category to result in a statistically significant difference in psychological wellbeing scores compared to the other acculturation types.

4.2 Summary of main findings

RQ1:

- Participants' mean anxiety and self-esteem scores fell within the 'normal range'.
- No statistically significant relationship was found between a bicultural identity and self-esteem or anxiety, although average psychological wellbeing scores were better for those with bicultural and marginalised identities.

RQ2:

- Key similarities across the acculturation types: most reported having minimal knowledge about autism; none had relationship preferences; and all expressed neutral to positive feelings about their autism.
- Key differences exist between the acculturation types, although most of these relate to the marginalised participant only.
- The prevalence of similarities suggests the acculturation types within autism may not be as distinct as within other minority groups and this therefore might explain the findings within RQ1.

- Negative treatment and difficulties with social interaction found within autism may impact on the effect the acculturation type has within this population.

4.3 Limitations

4.3.1 Sample

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; however, the time scale and strict inclusion criteria, as well as opt-in consent, restricted this. Additionally, for ethical reasons, participants could omit any question on the scales. This resulted in nine participants' data sets being incomplete, an issue also encountered by Hintermair (2008).

Participants were selected by school staff on the basis that they had a formal diagnosis. As it was considered to be in contradiction to the research aims, I did not check the validity of these and therefore it is possible not all participants had a formal diagnosis. Autism is defined as a heterogeneous condition, due to its many etiologies (Geschwind & Levitt, 2007), and as a result, what is true for one autistic participant may not be for another. The Social Responsiveness Scale, reported to be a valid measure of social impairment in the autistic spectrum (Constantino et al., 2003), could have been used to explore the nature of participants' autism in relation to the findings.

The sample employed is at risk of bias as opt-in consent may have meant those with poorer psychological wellbeing were unlikely to agree to take part. Additionally, participants were selected solely from mainstream secondary schools and therefore the experiences of those in alternative settings, such as special schools, resource bases, or home education are not explored. These participants may have greater contact with autistic peers, as well other young people with SEN, which is likely to impact on their acculturation type and experiences. Future research could explore this further.

4.3.2 Methodology

The SCAS has been used successfully with autistic participants (Gillott et al., 2001; Hannah & Topping, 2012), although it is not standardised on an autistic population. Wigham and McConachie (2014) suggest anxiety in autism is different from that within the non-autistic population because it interacts with symptoms, such as repetitive thoughts and difficulties with social skills. Therefore a measure developed and standardised on autistic adolescents would have been the most appropriate. Nonetheless, Wigham and McConachie suggest the measurement properties of the SCAS are robust, and triangulation, in the form of interviews, was used to overcome this limitation.

Rosenberg's SES has recently been used with autistic adolescents (Shipman, Sheldrick, & Perrin, 2011) although Frith and Happé (1999) argue reflecting on thoughts and feelings can be problematic for autistic individuals because of impairments in their theory of mind. Pictorial methods may have been used (Frith & Happé, 1999), although no well-established schedule has been developed. Rosenberg's SES is a one dimensional measure of overall self-worth, whereas a number of other scales are based on a theoretical notion that self-esteem is multi-dimensional (Butler & Gasson, 2005). Debates regarding definitions and theoretical stances of self-esteem are ongoing, although Rosenberg's SES continues to be widely employed (Butler & Gasson, 2005).

Exploring the views of autistic adolescents regarding their identity raised a number of challenges. Research has shown parents and schools can find it hard to discuss diagnoses (Connors & Stalker, 2007; Kelly, 2005) and therefore this may have been the first opportunity participants have had to discuss their identity. In light of this, multiple interview sessions for shorter periods could have been utilised, as proven effective (Frith & Happé, 1999; Hill, 2014).

Difficulties of eliciting autobiographical accounts from people with autism also exist. Hill (2014) and Happé (1991) suggest challenges relating to theory of mind, can result in missing information because the individual does not realise that others do not share their knowledge about personal experiences. Additionally, aspects of their experiences that we are often most interested in, such as theirs and others emotions, may be ones they are not or those they find difficult to share their views on (Happé, 1991).

Despite recommended adaptations put in place during the interviews, a couple of participants provided limited responses. Hill (2014) suggests autistic participants can experience difficulties with the interview process, including social communication; planning and structuring answers; and aspects of language and cognitive functioning. Furthermore, the interview schedule was developed by myself, which Hill argues can impact on the findings as questions are based on constructs from a non-autistic researcher. The schedule was developed from themes in the literature, most of which came from findings from young people; however, involving participants during its development would have further ensured it was participant lead.

The AIS was created for the study and although this revealed some test-retest reliability (p. 30), further development is required, including greater input from participants regarding individual items for inclusion. Nonetheless, Stebbins (2001) argues that within exploratory research, methodological limitations are likely to arise and be improved upon over a number of studies within the new area.

4.3.3 Applying the acculturation model to an autistic population

Myers et al. (2011) present a strong argument for applying the model to an autistic population, although a number of difficulties exist. The presentation of autism differs greatly from a hearing impairment, in particular its impact on social interaction skills, which is likely to affect acculturation, explored further below. Autism is also a heterogeneous condition (Geschwind & Levitt, 2007) and therefore applying the model to all on the spectrum may be difficult.

The acculturation model is based on feelings of alignment to majority and minority groups (Berry et al., 1986) and a risk of applying this to autism is that many could be perceived as marginalised as a preference for solitude is a common trait (NAS, 2014b). Nevertheless, findings for RQ1b and 1c indicate this may not be an issue. Additionally, difficulties with social interaction, communication, and restricted interests can impact on autistic individuals' ability to form relationships and therefore a lack of alignment to one or both groups may result from these difficulties rather than the individual's preferences and how they identify themselves.

The model has previously been applied to minority groups with their own distinct cultures and whether this applies to autism is an ongoing discussion. Davidson (2008) suggests an autism culture is beginning to emerge, particularly online, whilst Jaarsma & Welin (2012) advocate caution, as an independent culture might be limited to those who are high-functioning. Findings from RQ2 are similarly mixed. Participants indicated their participation in activities is not always viewed as being related to autism or not; however, a number showed a shared interest in seeking information; reading books about autism; and spending time with autistic peers. Such a debate warrants further exploration in future research.

4.4 Areas for further research

This paper has, for the first time, attempted to measure identity formation in autistic adolescents and to compare this to psychological wellbeing. Given its small scale and exploratory nature, further research is warranted with larger samples to see whether the positive relationship uncovered between biculturalism and psychological wellbeing in other minority groups (Cornell & Lyness, 2004; Smokowski & Bacallao, 2007) is replicated within autism.

Deeper exploration of the possible characteristics of biculturalism within autism and when this may be advantageous is necessary, including the impact of social interactions and whether this is important rather than the acculturation type, as suggested by Hintermair (2008). Finding the best means to look at this within autism is important. Rudmin (2003) argues that despite their prolific use, fourfold measures of identity have difficulty obtaining accurate measures and fail to acknowledge attitudes of the majority group, and thus a qualitative approach seeking multiple-perspectives may be better.

The literature review revealed a paucity of research into young people's understanding of autism and their involvement within an 'autism culture'. The majority of participants perceived their knowledge and involvement to be low and therefore consideration of what an 'autism culture' might look like could increase our understanding of identity formation within this population.

Finally, the recent removal of Asperger syndrome from the Diagnostic and Statistical Manual (DSM-5) could have implications for adolescents for whom the label is part of their identity (NAS, 2014a). A number of participants used this term to describe themselves and therefore this is an important area for future research.

4.5 Link to paper two

Schwartz and Unger (2010) argue that context is a key factor in understanding the acculturation approach the young person adopts and the school has long been recognised as an important environment in which identity formation takes place (Erikson, 1968; Marcia, 1980). In light of this, paper two aimed to reveal the perceived contextual factors that relate to identity formation for autistic adolescents attending mainstream education provision.

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Paper one appendices

Contents

Word count (excluding Literature Review): approximately 10, 397

Appendix one

University of Exeter
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Literature Review for Thesis

1) Introduction

The aim of the following review is to provide a context in which the proposed study is situated by locating it within previous research and to provide a rationale for its completion (Mertens, 2010). The paper will begin with a justification for the research topic by identifying its original contribution and relevance to the field. This will be followed by an explanation of the search strategy employed and focus topics chosen. Next a narrative style review of current literature will be presented, structured around three key themes: identity formation; psychological wellbeing; and the role of the mainstream education provision, which will move from the general to specific, as expanded upon below. To conclude, gaps and limitations identified in the literature will be drawn together and an outline of how the proposed study will address these will be provided.

2) Rationale for present study

The following section aims to provide a justification for the proposed study through detailing its original contribution and relevance and importance.

Original contribution:

It is important for doctorate level research to make an original contribution and advance knowledge (Hart, 1998), and thus a number of elements of the proposed study are original in nature. One such element is the exploration of identity formation in young people with autism. Bagatell (2007) suggests there is a lack of writing in the area which may be due to deficit based views of the condition as people with autism can struggle with social interaction and therefore identity formation may not seem of great importance. A second element is the role schools play in identity formation. This is said to be under researched despite findings indicating an important relationship between the two and therefore further research is needed to increase our understanding (Lannegrand-Willems & Bosma 2006; Sinai, Kaplan, & Flum, 2012).

Relevance and importance:

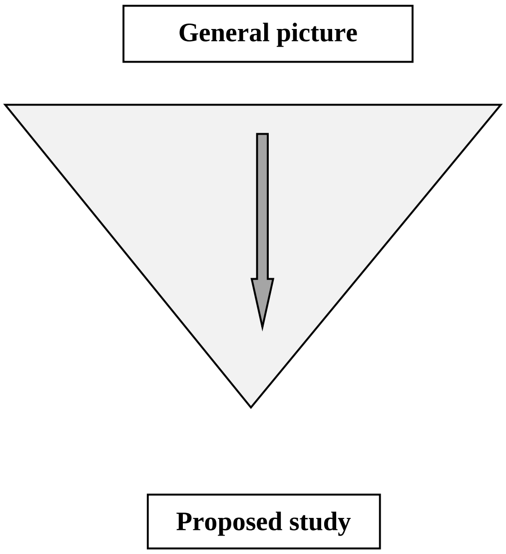
The National Institute for Health and Clinical Excellence (NICE) (2011) report in the past autism was thought to be uncommon; however recent statistics suggest prevalence in at least 1% of children. Unsurprising then, it continues to be a key aspect of work undertaken by Educational Psychologists (EPs) (Gilling, 2012) and therefore the study is not only relevant in terms of the professional development to the researcher on the journey to qualification, but also for those currently working within the field.

Data from the Local Education Authority (LEA) I am working within indicates the number of young people with a statement of special educational needs (SEN) based on a primary need of autism has risen from just over 400 to over 460 in just three years. With these rising numbers, research and means for increasing knowledge are important to help ensure the diverse needs of these young people can be well met. The exploration of mental health issues of adolescents with autism in mainstream settings is also particularly salient as a recent review conducted by the Educational Psychology Service (EPS) in the same LEA found this was an issue that teachers and other professionals were particularly worried about.

3) Review of current literature

Introduction

Research within the field of autism is vast, with a quick, unrestricted search on the database PsycINFO of the term ‘autism’ revealing over 39,000 results. Dominant discourses stem from biological or cognitive perspectives; however, the following review takes a social psychological approach, exploring theory and research relating to the overarching themes: identity formation; psychological wellbeing; and the role of mainstream education provision. The review will take a narrative rather than systematic approach, whereby the range of literature covered will be broad with less restrictions placed upon the studies included (Collins & Fauser, 2004). Additionally, it will be structured using a distance to close approach as proposed by Rudestam and Newton (2001), with the review moving from providing a general picture to exploring directly related pieces, enabling critique and demonstrating where this study is located amongst existing research.



Search strategy

I began with a look at practitioner texts, key websites (including the National Autistic Society (NAS)), and research in the area of identity formation. Results were obtained predominantly from general internet search engines such as Google; however peer-reviewed journal articles were also located through searches using PSYCINFO. From this initial starting point, the searches became more specific, using University texts which focused upon a particular model of identity formation (Phinney, 1990) and online searches using the following:

Search engines:

- EBSCO- E-Journals
- PsycINFO
- ERIC
- British Education Index (BEI)
- Searches within individual journals: ‘Autism’, ‘Contemporary Educational Psychology’

Key terms:

- Autism and identity
- Hard-of-hearing and identity
- Identity
- Biculturalism
- Self-esteem and autism
- Anxiety and autism
- Acculturation

At this point, a key paper on the relationship between identity formation in young people with autism in mainstream schools and their psychological wellbeing was identified (Myers, Ladner, & Koger, 2011).

The final stage explored identity in adolescents with autism using the themes of the identity formation; psychological wellbeing; and the role of mainstream education provision. Papers were sourced from the above search engines as well as a large proportion arising from references within these. Due to the limited research within the field date limits were not set for the literature searches performed.

Definitions

It is important before proceeding any further to define what is meant by autism within this paper. The definition initially selected for use was "**Autism is a lifelong developmental disability that affects how a person communicates with, and relates to, other people" (The National Autistic Society (NAS), 2013, What is autism?, para.1).** However, the term 'disability' used within this does not fit with recently noted movements within the field (Russell & Norwich, 2011), and with the views of the researcher and proposed study. Therefore the following definition has been selected instead: "Autism is a lifelong condition, which affects how a person communicates, interacts socially, and can present difficulties or differences for the person in their thinking, imagination and sensitivity of their senses" (Autism Initiatives, 2013, Autism spectrum condition, para.1). The use of this term is intended to reflect all aspects of the spectrum, including Asperger syndrome. This project involves participants who already have a diagnosis of autism and will not explore the particular definitions on which this was made.

Identity formation is also a term used throughout this paper and therefore requires defining. The definition utilised within this paper is the forming of a person's ideas, attitudes and beliefs and their sense of themselves (Woolfolk, 2010).

Review of literature

Identity formation

Identity formation is most famously associated with the work of Erikson (1968, 1980), who proposed an eight stage model of psychosocial development which emphasized the importance of the interaction with society and the need to search for one's sense of self. Each stage involved a conflict to be resolved, beginning in infancy with Trust vs. Mistrust; reaching adolescence at Identity vs. Identity Diffusion; and finishing in old age with Integrity vs. Disgust, Despair (Erikson, 1980). Searching for one's identity is said to be particularly important during adolescence, where the young person must make decisions regarding their values, career, and beliefs (Erikson, 1980).

Erikson's (1968, 1980) ideas were further built upon by the psychologist, Marcia (1980), who developed four identity statuses in order to empirically study identity theory. The proposed identity statuses are based upon the type of exploration done, including: identity diffusion, having no direction in relation to personal values or a career; identity foreclosure, committing to a career choice and personal values which have been chosen by ones parents; moratorium, struggling with identity in relation to career choices or personal values; and the optimum, identity achievement, reaching a self-initiated decision about which career and personal values to pursue following a period of decision making (Marcia, 1980). Such identity statuses have been widely used in empirical research since their development (Knafo & Schwartz, 2004; Yoon, 2011), although are criticised by some who claim the four statuses do not develop in order as suggested (Côté & Levine, 1983).

More recently there has been growing interest in the elements of identity which people do not have control over, including, gender, ethnicity, and adopted status (Grotevant, 1992). For example, Phinney (1990) explored identity formation in ethnic minorities, something looked at in greater detail below.

Identity formation and minority groups

Ethnic identity is one of the areas of growing research within the field of identity formation (Grotevant, 1992). Key to this research is the concept of acculturation, which is said to be the "... process of cultural and psychological change that results following meeting between cultures" (Sam & Berry, 2010, p.472). For example, in their work on the assessment of acculturation, Berry, Trimble, and Olmedo (1986) describe four possible types of acculturation which relate to the value the person places on maintaining their cultural customs and upholding relationships with people from different groups to their own. These ideas have been further developed and researched by Phinney (1990) and include: assimilation, aligning oneself with the majority culture and rejecting beliefs of own minority culture; separated, associating solely with those from own minority culture; marginality, feeling aligned to neither cultures; and finally, biculturalism, feeling aligned to both cultures.

More recently, the process of acculturation and Phinney's (1990) ideas have been utilised in research involving participants from other minority populations, including those with hearing impairments. A number of scales based on ideas for measuring ethnic identity formation and the process of acculturation have also been utilised (Glickman & Carey, 1993; Maxwell-McCaw & Zea, 2010). For example, Glickman and Carey (1993) developed the 'Deaf Identity Development Scale' (DIDS) using ideas from ethnic identity scales in order to measure four proposed identity outcomes: culturally hearing; culturally marginalised; immersion; and biculturalism. Glickman and Carey indicate the scale has internal consistency; nonetheless, criticisms of it, including its inherent bias towards biculturalism, lead to the development of a measure with a separate subscale for hearing and deaf identities, known as the Deaf Acculturation Scale (DAS) (Maxwell-McCaw & Zea, 2010). This explores acculturation across five areas on each subscale, including cultural involvement, knowledge, language competence, cultural identification, and cultural preferences (Maxwell-McCaw & Zea, 2010). Nonetheless, as with the DIDS, it relies solely on self-report data which is at risk of response bias (Hammond, 1995).

Myers et al. (2011) have explored the notion of bicultural identity formation further, looking at evidence from participants from ethnic minorities and those with hearing impairments, and advocate that positive findings for bicultural identity formation are also relevant to young people with autism. Myers et al. justify this by arguing there are similarities between the experiences of different minority groups and strong links between the historical development of education for students with hearing impairments and those with autism. Nonetheless, the differences that exist between the cultures of different minority groups make any direct comparison difficult. This will be explored further throughout the paper.

Identity formation and autism

Despite the increasing interest in aspects of identity which are assigned (Grotevant, 1992), studies exploring identity formation involving participants with autism remain rare. This is something which is thought to be linked to deficit based views of the condition, including difficulties with social interaction (Bagatell, 2007). For example, Enright and Deist (1979) claim social perspective taking is key to the development of identity and this is a skill which many people with autism can have difficulties with (NAS, 2013). Bagatell (2007) suggests the focus on these difficulties may have led to identity formation in individuals with autism as being seen as less important. However, recent research has begun to question this, providing evidence that individuals with autism are active in this social process (Bagatell, 2007; Baines, 2012). For example, Baines (2012) uncovered findings as part of her two year ethnographic study that demonstrated two adolescents with autism positioned themselves in order to be seen positively by others, using humour; distancing themselves from their label; and joining groups to portray a particular image. Nevertheless, both studies involved only one to two participants and thus further research is needed.

Over the last decade the number of papers exploring the issue of identity formation in autism has slowly begun to rise (Bagatell, 2007; Baines, 2012; Gilling, 2012; Humphrey & Lewis, 2008; Myers et al., 2011), suggesting a possible shift in perspectives in regarding its importance and relevance. A key theme emerging from this research is the difficulty adolescents can have in accepting autism as part of their identity. For some, this appears to be expressed through the desire to fit in and appear normal (Carrington & Graham, 2001; Humphrey & Lewis, 2008), and for others it is through distancing themselves from their autistic identity (Baines, 2012; Huws & Jones, 2008) or searching for a cure (Bagatell, 2007). Such findings fit with Erikson's (1968) claim that adolescence is the period in identity development during which young people can become unhealthily preoccupied with how others see them.

Also evident within the literature are the problems having a difficulty with acceptance can lead to, such as poor psychological wellbeing (Bagatell, 2007; Carrington & Graham, 2001). A suggestion for such a finding is that autism is not viewed as a valid identity by society, demonstrated through the use of therapeutic interventions to correct 'deviant' behaviour (Brownlow, 2010) and pressure from adults to fit in (Bagatell, 2007). In contrast to these difficulties, Humphrey and Lewis (2008) describe a subset of participants who appeared to have accepted their autism as part of their identity; nevertheless, how they came to this acceptance and its impact are not detailed.

The aforementioned research predominantly utilises qualitative methods to obtain in-depth data, enabling us to learn from participants' personal experiences, as advocated by Billington, McNally, and McNally (2000). Nonetheless, this has resulted in limited samples sizes and a paucity of direct measures into identity formation in adolescents with autism and its relationship to psychological wellbeing. Such a relationship is of particular interest due to claims that young people with autism who have achieved a bicultural identity will have increased psychological wellbeing (Myers et al., 2011). This will be explored further in the following section.

Psychological wellbeing

The psychological wellbeing of young people with autism is of particular concern, with reports suggesting that over 70% of this population experience mental health problems, including: anxiety, depression, and self-harm (NAS, 2010). Such concerns are mirrored at a local level, as data from an EPS review in the LEA I am working within revealed that one of the main worries held by teachers and other professionals are the levels of anxiety experienced by young people with autism in mainstream settings.

A large number of studies highlight the issue of anxiety in young people with autism in mainstream settings (Carrington & Graham, 2001; Humphrey & Lewis, 2008; Myers et al., 2011), although this is generally raised as part of the wider findings, with only a limited number focusing upon it (Bagatell, 2007; Gillott, Furniss, & Walter, 2001). An in-depth exploration is possible in Bagatell's (2007) study due to the selection of ethnography as the dominant methodology; however, such an approach also means the findings are presented from the reality of one participant. This raises some difficulties due to the unique presentation of autism in each individual (Autism Initiatives, 2013), and therefore further research is required.

Levels of self-esteem are also a concern for young people with autism (NAS, 2010). Recent research has demonstrated a relationship between feelings of social isolation and low self-esteem (Hall-Lande, Eisenberg, Christenson, & Neumark-Sztainer, 2007) and although conducted on a non-autistic population, the prevalence of such feelings of isolation in those with autism (Nikolaraizi & Hadjikakou, 2006; Ochs, Kremer-Sadlik, Solomon, & Sirota, 2001) suggests these findings are likely to be of relevance. Despite recognition that self-esteem can be an issue for young people with autism (NAS, 2010) and the claim that research has demonstrated links between this and a range of other aspects of psychological wellbeing (Myers et al., 2011), there appears to remain a lack of literature within this area.

Psychological wellbeing and identity in minority groups:

Of particular interest in Bagatell's (2007) research is the apparent link between the young person's mental health issues and his struggle to construct his identity. The notion that such a relationship exists is said to stem back to Erikson's (1980) work, which developed from his interest in understanding positive psychological wellbeing (Waterman, 1992). In his work on identity and development, Erikson discusses his eight stages in terms of the healthy personality, identifying the impact each stage can have on wellbeing.

Since this work, research utilising participants from minority groups, particularly ethnic minorities or those with hearing impairments, has demonstrated such a relationship, predominantly using quantitative data to do so (Cornell & Lyness, 2004; Hintermair, 2007; Phinney, 1992; Zamboanga, Schwartz, Jarvis, & Van Tyne, 2009). In many cases, this data is obtained through the use of scales exploring aspects of psychological wellbeing and those developed to measure identity, such as those the DIDS (Glickman & Carey, 1993) and the DAS (Maxwell-McCaw & Zea, 2010), highlighted previously. For example, Hintermair (2007) performed a correlational analysis on data from an internet survey which utilised a number of scales, including the DAS and the Rosenberg self-esteem scale, to conclude biculturalism is the best outcome for participants who are deaf or hard of hearing. Hintermair utilised a large sample, increasing the reliability of such results and importantly, piloted all of the scales before use to ensure they were suitable for participants with hearing impairments. Furthermore, his findings are supported by Cornell and Lyness (2004) who uncovered a positive correlation between high scores on the bicultural subscale of the DIDS (Glickman & Carey, 1993) and scores for self-concept. However, in both cases, adults rather than adolescents were used even though adolescence is acknowledged as a key period for identity development (Erikson, 1980). Additionally, Hintermair acknowledges that despite finding such a relationship, the results revealed participants who fell into the marginalised category could still develop high self-esteem.

The methodological approach used widely within the literature has a number of benefits, such as the ability to perform correlational analyses which can uncover relationships between data, including the direction and strength (Dancey & Reidy, 2007). Nonetheless, Waterman (1992) importantly reminds us that correlational relationships cannot tell us about causation. This highlights a further limitation of such research and one that is acknowledged by Hintermair (2007), that the lack of qualitative data prevents further exploration of the findings.

Psychological wellbeing and identity in adolescents with autism:

Research directly exploring the relationship between identity and psychological wellbeing with participants with autism remains scarce, although a number of studies which provide personal accounts from individuals with autism indicate such a relationship exists (Bagatell, 2007; Carrington & Graham, 2001; Humphrey & Lewis, 2008). These accounts varying depending on the age and experiences of participants; however, a reoccurring theme is the notion that hiding ones autism to try and fit with the majority group is associated with negative psychological wellbeing, including depression (Bagatell, 2007; Carrington & Graham, 2001). This notion is further reinforced by Humphrey and Lewis (2008), who found participants who celebrated their autism spoke positively about themselves and their friendships. However, poor psychological wellbeing was not raised by Baines (2012) despite also finding her participants tried to hide their autism. Nevertheless, Baines’s aim was to explore identity formation in relation to the context within which the adolescents lived rather than focusing on the individuals and therefore this may be why such a topic is not raised.

Within the limited research on psychological wellbeing and identity in adolescents with autism there is an overwhelming focus on qualitative methods as noted with research looking at identity formation in adolescents with autism. This enables researchers to focus on the previously undervalued participant voice; however, this has resulted in a lack of direct exploration into what identity traits would lead to increased psychological wellbeing, as has been explored with other minority groups (Cornell & Lyness, 2004; Hintermair, 2007). One paper which does explore this issue advocates identity formation in individuals with autism parallels that of individuals with hearing impairments and thus having a bicultural identity will also have a positive relationship with psychological wellbeing in this population (Myers et al., 2011). A thought provoking argument is set out through identification of similarities to the history of deaf education; nonetheless, such claims lack empirical evidence from participants with autism and as different minority groups differ enormously, what may be true for one may not be for another.

The role of mainstream education provision

The number of young people with autism being educated in mainstream state schools has risen from 25,020 (Department for Education and Skills, 2005) to 43,425 in just 6 years (Department for Education, 2011). However, at the same time these young people are said to find the mainstream secondary school environment especially challenging (Humphrey & Lewis, 2008; Myers et al., 2011). Of particular interest within this review are the contextual factors that have been identified in such provision that relate to identity formation in young people from minority groups.

The notion that the school plays an important role stems back to Erikson's (1968) work and continues to gain support (Flum & Kaplan, 2012; Lannegrand-Willems & Bosma 2006; Marcia, 1980). It is based on the premise that the interaction a person has with their environment is central to their identity formation, with the school being a social setting in which adolescents spend a large proportion of their time (Lannegrand-Willems & Bosma, 2006). Searches of literature related to young people with autism and education provision reveal an abundance of findings regarding interventions, such as social stories and circle of friends (Kalyva & Avramidis, 2005; Styles, 2011); however, explorations of the role of the school in identity formation are scarce, something which is not limited to young people with autism (Lannegrand-Willems & Bosma, 2006). This lack of research has been highlighted by a number of authors and the need for further exploration advocated (Flum & Kaplan, 2012; Sinai et al., 2012). For this reason, the following review of literature will outline contextual factors related to identity formation by drawing upon research including participants with hearing impairments, autism, and those from ethnic minorities.

Understanding and awareness and the sharing of diagnoses

The notion of sharing of a young person's autism diagnosis and information about autism with others has been explored over a number of years, with mixed findings (Chambres, Auxiette, Vansingle, & Gil, 2008; Ochs et al., 2001; Swaim & Morgan, 2001). The idea that providing information about autism will lead people to view behaviours presented by that person as out of their control, stems from attribution theory, which explores how a person's perceptions and beliefs about why something occurred affects their attitudes and behaviours (Weiner, 1972). It is of particular interest in relation to identity formation as it has been suggested that whether someone feels marginalised, aligned to both groups, and so on, can be influenced by the attitudes and behaviour those around them have, particularly when discrimination is experienced (Sam & Berry, 2010).

Gilling (2012) notes how this issue was raised during her work as an EP and highlights concerns regarding the possibility of negative consequences of sharing a diagnosis, evidence for which can be found (Humphrey & Lewis, 2008; Huws & Jones, 2008; Swaim & Morgan, 2001). For example, Huws and Jones (2008) obtained mixed findings from college students regarding the sharing of their diagnosis of autism, with participants revealing it can lead to a decrease in negative treatment from some people but an increase in discrimination from others. Similarly, Humphrey and Lewis (2008) report comparable feelings from participants in their study. Nonetheless, Huws and Jones found that some participants' felt people might prejudge them although acknowledged this had not actually happened to them or people they knew. Researching this further through discussions with peers without autism would have enabled deeper exploration of this issue.

A small number of studies have researched this issue with participants without autism, including Swaim and Morgan (2001) who took an experimental approach, using a video of a child displaying autistic type behaviours to measure the impact sharing information about autism beforehand had. Their findings demonstrated participants' attitudes towards the child were less positive, even when they were given information about autism (Swaim & Morgan, 2001). Nonetheless, Chambres et al. (2008) also used this approach and found the opposite, which suggests the contents of the video and its presentation may have impacted upon the results achieved. However, the participants within Chambres et al.'s study were at least five-seven years older and therefore age may have affected the impact of the video.

Despite these mixed findings, such an approach has gained in popularity, with visual media aimed at promoting autism awareness becoming increasingly available online, an example of which can be found on the Newsround website (BBC, 2011). Furthermore, in 2012 the Australian government took the decision to provide a DVD aimed at fostering an understanding of autism to around 10,000 schools (Senator the Hon Jan McLucas, 2012). Promotion of this approach on such a large scale suggests strong support for raising awareness about autism within schools; nevertheless, an evaluation of its impact appears unavailable at this point due to its recent commission.

A criticism of the research carried out by Swaim and Morgan (2001) and Chambres et al. (2008) is the lack of external validity due to the artificial setting of both studies. This was overcome by Gus (2000) who found positive findings for sharing information through the use of a circle of friends approach to initiate a discussion about a young person with autism and increase peer awareness. Reports from school staff indicate the young person with autism appeared happier after the session and findings from the student questionnaires revealed a high proportion self-reported an attitude change (Gus, 2000). Such positive findings are supported by a number of other studies (Chambres et al., 2008; Ochs et al., 2001) and have lead Gus to suggest that EPs should promote information sharing about autism in mainstream classrooms. Recent access to an EP online forum indicates this promotion is currently being undertaken by some, including the use of circle of friends, and the sharing of DVDs and books (EPNET, 2013). Nonetheless, the participants' voice in Gus's study is missing and thus it feels as if psychology is being done to him rather than with him. The reader is left questioning how the young person felt and has to rely on staff reports regarding this. Similar limitations are evident within Myers et al.'s (2011) paper, where the promotion of biculturalism in schools through increasing knowledge about autism is advocated without seeking the views of young people with autism, despite recent literature advocating the importance of such input (Billington et al., 2000; Gilling, 2012).

A number of studies exploring the idea of raising awareness ensure the views of young people are directly sought through qualitative methods, such as interviews and focus groups. A reoccurring finding within such studies was the attributing of negative responses from peers to a lack of understanding, thus providing further support for raising awareness within schools (Huws & Jones, 2009; Iantaffi, Jarvis, & Sinka, 2003; Punshon, Skirrow, & Murphy, 2009). Furthermore, Humphrey and Lewis (2008) and Iantaffi et al. (2003) found similar findings for raising awareness amongst school staff. Nonetheless, in ensuring the views of young people from minority groups have been sought, such papers have predominantly relied on self-report data from participants and overlooked the views of peers and staff, making it difficult to see whether such negative responses are related to a lack of understanding.

Relationships with peers

Relationships with young people from the majority group

A contextual theme repeated throughout the literature on schools is the relationships young people have with their peers and a prevalent finding amongst young people with autism are feelings of rejection and isolation (Bagatell, 2007; Ochs et al., 2001; Punshon et al., 2009). Furthermore, in some cases, rejection from peers was reported to have led to episodes of bullying (Humphrey & Lewis, 2008; Huws & Jones, 2008; Punshon et al., 2009). For example, through the use of underutilised techniques such as diaries and drawings, Humphrey and Lewis (2008) report a number of incidents of bullying, including a deeply troubling example of a participant who drew a picture of peers celebrating his death.

The impact of the above experiences of rejection on identity is an interesting but under researched area. Flum and Kaplan (2012) suggest “The process of identity formation is also anchored in a sense of ‘being part of’- a web of relationships, group solidarity, and common culture” (p.240). Adolescents with autism who are socially isolated are unlikely to feel part of such a web and therefore the impact of this on the development of their identity warrants further exploration.

A large proportion of the studies listed above only briefly comment on the impact of such experiences; nonetheless, Bagatell (2007) looks into this further through the use of ethnography. Bagatell reports the young male with autism in her study experienced social isolation and thus constructed his identity in an environment that made it clear he was marginalised. Such a notion is supported by Holland, Lachicotte Jr, Skinner, and Cain (1998) who argue “Persons look at the world from the positions into which they are persistently cast” (p.44). This position is then likely to impact upon psychological wellbeing as Grotevant (1992) suggests difficulties with identity development can occur when society does not value characteristics which are out of a person’s control and this can result in problems, such a low self-esteem. Leigh (1999) warns that such marginalisation is inherent in inclusion practices and thus further research into the role of mainstream education provision in identity formation in adolescents from minority groups is important.

Despite such warnings and negative experiences, positive relationships within mainstream education provision have been highlighted within a number of studies (Iantaffi et al., 2003; Leigh, 1999; Nikolaraizi & Hadjikakou, 2006; Ochs et al., 2001). For example, Iantaffi et al. (2003) found some participants appreciated the diversity in their friendships, and feeling part of a group, despite differences in their ability to hear. Nonetheless, participants in many cases commented on their strategic positioning or great effort within such relationships (Baines, 2012;

Nikolaraizi & Hadjikakou, 2006) or the impact of increased awareness and understanding (Humphrey & Lewis, 2008; Iantaffi et al., 2003; Ochs et al., 2001), suggesting these were important contributing factors rather than the relationships developing naturally.

The literature on relationships with peers provides an interesting exploration of both the positives and negatives of being a young person from a minority group in mainstream education provision; however, as in previous sections, findings which outline the views of peers from the majority group are rare. It is unclear what opportunities young people have for socialising with other young people with autism and what impact strategies such as adult support in lessons or invitations to lunchtime clubs for people with special educational needs, can have on these relationships. For example, Iantaffi et al. (2003) found some participants with hearing impairments felt adult support in lessons sometimes got in the way of friendships. Therefore an exploration of the views of adolescents without autism in mainstream provision would provide further insight into some of these issues.

Relationships with other minority peers

In addition to the relationships with majority peers, the impact and importance of spending time with other minority peers from the same minority group as themselves has also been raised (Bagatell, 2007; Nikolaraizi & Hadjikakou, 2006; Punshon et al., 2009). Iantaffi et al. (2003) explored this issue with a large number of students with hearing impairments in mainstream schools and found most valued spending time with other minority students, including the ease of communication; feeling less isolated; and having a shared understanding. Similar feelings were reiterated by participants within a number of other studies and have led to the advocacy for such opportunities to be made available (Leigh, 1999; Punshon et al., 2009).

These papers demonstrate the benefits contact with minority peers can have from the perspectives' of participants; however, a number rely on retrospective accounts and thus the passing of time may have impacted upon the accuracy of these (Leigh, 1999; Nikolaraizi & Hadjikakou, 2006; Punshon et al., 2009). Evidence in this area also predominantly stems from participants with hearing impairments and therefore may not reflect the feelings of young people with autism. Furthermore, Bagatell (2007) has demonstrated that the positive impact of these experiences can be short lived. Meeting peers with autism initially appeared to have a positive effect on the participant's identity; acceptance of his autism; and psychological wellbeing; however, once this new identity had been embraced, she found he struggled when around majority peers with different behaviour and values (Bagatell, 2007). Similarly, Leigh (1999) discovered a large proportion of participants acknowledged a struggle in being caught between two worlds, including the challenge of participating fully in either. Nonetheless, the young male in Bagatell's study spent time with others with autism outside of school and therefore it is unknown whether the outcome would have been different if such socialisation was done within his education provision.

Relationships with school staff

Adult support

Research has explored young people's relationships with adults within schools and the influence of these on identity. A number of papers raise the issue of adult support, including Humphrey and Lewis (2008), who found many students with autism viewed adult support in lessons negatively as they felt it highlighted them as different. Similarly, Iantaffi et al. (2003) discovered most students with hearing impairments disliked it when teachers' support strategies resulted in them being singled out. These findings are in line with those from the review of literature on identity which indicated many young people with autism wanted to fit in and appear normal (Baines, 2012; Carrington & Graham, 2001; Humphrey & Lewis, 2008). Nonetheless, Humphrey and Lewis (2008) found a number of participants felt the support was positive as it reduced anxiety and incidences of bullying. Additionally, Hall-Lande et al. (2007) found feeling connected to school staff was a protective factor for adolescent boys experiencing social isolation and therefore if the relationship with the adult fosters such feelings this could help protect against negative psychological outcomes if social isolation is suffered.

Role models

A number of studies have explored the availability and importance of having contact with minority group role models (Iantaffi et al., 2003; Leigh, 1999; Myers et al., 2011; Nikolaraizi and Hadjikakou, 2006). A reoccurring theme within this research is the positive impact such adults can have on the lives of young people from minority groups, despite the lack of them (Iantaffi et al., 2003; Leigh, 1999). Nonetheless, in some cases the promotion of role models appears to come from the researchers, rather than a suggestion from participants (Myers et al., 2011; Nikolaraizi & Hadjikakou, 2006). Furthermore, Leigh (1999) found, of the 13 participants who reported having no contact with other minority adults, only one indicated a desire to have had such a person. However, it could be argued that these participants were unaware of the benefits having not had previous experiences of role models as over half of the participants in the study did speak positively about the impact such adults had had on their lives (Leigh, 1999).

4) Identification of limitations and how these will be addressed

The above review has identified a number of gaps and limitations in the literature which the current study aims to address. These limitations will be outlined below through a continuation of the themes presented previously.

Identity:

A high level of interest in the concept of identity has recently been noted (Flum & Kaplan, 2012; Woolfolk, 2010); however, this does not appear to extend to research exploring identity formation in young people with autism. This issue was initially raised six years ago by Bagatell (2007) and since then the number of papers in the field has slowly risen (Baines, 2012; Gilling, 2012; Humphrey & Lewis, 2008; Myers et al., 2011). Nonetheless, it remains an under-researched area at this time. Furthermore, a review of the limited literature available has revealed two issues. First, a number of studies are based in the US and therefore may not offer a true reflection of the situation in the UK due to cultural differences, as well as a disparity between the education systems. Second, research has predominantly utilised qualitative methods which has resulted in limited samples sizes and a paucity of direct measures of identity in autism, as is available in research into identity within other minority groups (Cornell & Lyness, 2004; Hintermair, 2007; Phinney, 1992).

The current study will address each of these issues, ensuring identity formation in adolescents with autism is explored within the UK, and that a mixed methods approach will be utilised to ensure in-depth data is gathered, alongside quantitative measures which will directly explore identity formation in this population.

Psychological wellbeing:

Following a review of evidence on the relationship between bicultural identity formation and improved psychological wellbeing within other minority groups, Myers et al. (2011) concluded such a relationship would also exist in young people with autism. Nonetheless, a shortage of research exploring this issue means it remains unclear whether such a claim is accurate. A number of personal accounts from people with autism have lead researchers to suggest that such a relationship exists; however, this has not been directly measured (Bagatell, 2007; Carrington & Graham, 2001). The present study will address this by performing a correlational analysis on quantitative data on adolescents' identity formation, levels of anxiety, and self-esteem. However, as studies which have explored this relationship within other minority groups have relied too heavily on such quantitative data (Cornell & Lyness, 2004; Hintermair, 2007; Phinney, 1992), a mixed methods approach will be taken, whereby a proportion of adolescents will also participate in semi-structured interviews to explore the findings further. Mixed methods research designs compromise of both quantitative and qualitative elements and allow methods to be selected which will best answer the questions set (Mertens, 2010).

The role of mainstream education provision:

The review of literature revealed a lack of research into the role of the school in identity formation, despite the notion that such settings play an important part stemming back to work by Erikson (1968). Further consideration of the literature revealed this was particularly true for young people with autism, with a number of studies looking at their experiences of mainstream education provision (Carrington & Graham, 2001; Humphrey & Lewis, 2008) but not directly addressing the impact on identity. A small number look at raising the profile of autism within schools through the sharing of information; however, a concern surrounds the limited use of the participant voice within these (Gus, 2000; Myers et al., 2011). This will be addressed through the use of semi-structured interviews to investigate what adolescents with autism perceive to be the contextual factors that relate to identity formation.

Finally, research exploring the role of the school lacks views from peers from the majority group. This was particularly evident within studies looking at peer relationships and awareness and understanding (Huws & Jones, 2009; Punshon et al., 2009) and prevented clarification as to whether experiences of social isolation were due to a lack of understanding on behalf on their peers. The present study will employ focus groups with adolescents without autism in mainstream schools to obtain such information.

From the review of literature and the gaps and limitations raised above, it should now be clear where the present study fits within the field and a rationale for its completion.

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Appendix two

Recruitment materials

Dear [redacted]

I am writing to invite your school to participate in a research project exploring: (i) how secondary school students with autism see themselves and their emotional experiences in school; and (ii) how they see their school experiences and how others see them. The findings from this study could be of interest and benefit to your school in reviewing and developing your inclusive policies and practices.

As a Trainee Educational Psychologist currently working in [redacted] I am undertaking this project as part of my Doctorate in Educational, Child and Community Psychology at the University of Exeter on behalf of [redacted] Educational Psychology Service.

This particular project has been chosen to serve the needs of [redacted] with the aim being to try to find ways to help provide further support to these young people by eliciting their views, as well as those of their peers.

I understand that all schools are busy places, therefore to show my appreciation for your participation, a summary of the findings and conclusions from the research will be provided to the school once the project is completed.

Additionally, student friendly summary sheets will be produced so the information is accessible to all. Further to this, I aim to be able to generate an information pack for schools which will collate the ideas provided by the students on how best to further support adolescents with autism in mainstream settings.

I have attached an information sheet which outlines key information about the project; however, if you would like further information I would be more than happy to discuss this over the phone or to arrange a meeting at your school. I can be contacted at the above address or preferably via phone or email:

Email: [redacted] **or** [redacted] **Phone:** [redacted] **or** [redacted]

I have sent a copy of this letter to your head teacher and have asked them to contact me to let me know if the school would be interested in taking part. If I haven't heard anything within approximately a week, I will give you a call to find out whether you would be happy to participate or require any further information.

Yours Sincerely,

Miss Hayley Jarrett

Information Sheet for Schools

***Project Title:** An exploration of identity formation in adolescents with autism, its relationship with psychological wellbeing, and the role of mainstream education provision in this process.*

The information outlined below is to help you understand what participation in the project entails. If you have any questions or require further information please contact me using the details provided at the end.

What is the aim of the research?

1) To explore how adolescents with autism see themselves and their emotional experiences in school.
2) To explore how they see their school experiences and how others see them.

What is the location and duration of the research?

The project will run from April 2013 until June 2014, although the questionnaires will be completed during this summer term.

What will the project involve?

I am looking for further participants to take part in stage one. This will involve:

- Students with a known diagnosis of autism will be asked to complete three short questionnaires which look at how they perceive themselves, self-esteem and anxiety. These use a 1-5 scale for answering and should take no more than 25 minutes to complete all three. They will then be asked to complete one of the questionnaires a second time. This should be about 4 weeks later and should take about 10 minutes.

What happens to the data collected?

The data will be analysed by myself for my doctoral thesis. A report will be written based on my analysis of the data which you will be provided with a copy of. Your school and student’s names will **not be** used in the report.

How is confidentiality maintained?

All data provided will be treated as confidential and will be completely anonymous. Every reasonable effort will be made to preserve the anonymity of the school and of all participants. Identifying information will **not be** used and pseudonyms will be given. All identifiable data collected will be stored on a secure [redacted] Council laptop to which only I will have access. All raw data collected as part of the project will only be seen by myself and my two research supervisors at the University.

Will we be paid for taking part?

I am not able to offer any payment or incentive for participating in this study; however, you will be provided with feedback from the project. I am also hoping to produce an information pack which will collate the participants' ideas and help schools further support young people with autism. This would be shared with you, along with the opportunity to discuss any information that arises.

What previous experience does the researcher have?

I have experience of working with children; having previously worked as a Primary School Teacher and more recently as part of my role as a Trainee Educational Psychologist. I also have research experience within schools following the completion of an MEd dissertation in 2010.

Ethics and safeguarding

Considerable thought has been given to ensure the project is an ethical one and approval has been received from both [redacted] Council's and the University of Exeter's ethical committees.

Criminal records check

I have undergone a Criminal Records Bureau check at the Enhanced Disclosure level and am happy to provide you with a copy of this.

Where can I obtain further information if I need it?

[redacted]

Appendix three

Participant details

Table 8: Paper one participant details

Age (upon starting project) (years)	Gender	Age of diagnosis (years	Age told about diagnosis	Measures completed S= Scales I= Interviews
10-12	M	0-4	9-12	S + I
10-12	M	5-8	5-8	S + I
13-16	M	5-8	5-8	S + I
13-16	M	5-8	5-8	S + I
13-16	M	0-4	9-12	S
13-16	F	0-4	5-8	S
10-12	M	0-4	0-4	S + I
10-12	M	5-8	9-12	S + I
13-16	M	5-8	5-8	S + I
13-16	M	5-8	5-8	S
13-16	M	9-12	9-12	S
13-16	M	0-4	0-4	S
10-12	F	0-4	0-4	S
10-12	M	9-12	9-12	S
13-16	M	0-4	9-12	S
13-16	F	0-4	9-12	S + I
13-16	M	9-12	9-12	S + I
10-12	F	9-12	9-12	S
10-12	F	5-8	5-8	S

10-12	M	5-8	5-8	S
13-16	M	13-16	13-16	S
13-16	M	5-8	5-8	S
13-16	M	0-4	9-12	S
17-18	M	5-8	5-8	S
10-12	M	5-8	-	S
13-16	M	5-8	9-12	S
17-18	M	0-4	0-4	S
13-16	M	13-16	13-16	S
13-16	M	13-16	13-16	S
13-16	M	5-8	5-8	S
13-16	F	13-16	13-16	S

Appendix four

Data collection materials

- Student and parent information letters and consent forms
- Parental questionnaires
- Autism identity scale (AIS)
- Rosenberg’s self-esteem scale
- Spence children’s anxiety scale (SCAS)
- Semi-structured interview schedule
- Dictaphone
- Letters to prepare participants with autism for their interview
- Drawing materials and wooden puzzle/game for participants to use during the interviews if they wanted to

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**.

Participants were initially verbally informed of this but it was later added onto the scales following a suggestion from a school.

Scale 1

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 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.					
<u>Cultural competence</u>					
• 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

Statement	Strongly disagree	Disagree	Neutral	Agree	Strongly agree
Cultural Identity					
• I don’t call myself Autistic or a person with 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 I fit in with other people without autism or Asperger syndrome at school.					
• I am comfortable with people without autism or Asperger syndrome.					
Cultural involvement					
• I enjoy reading books /magazine/information written by people without autism or Asperger syndrome.					
• I enjoy going to events/parties/gatherings with people who don’t					

have autism or Asperger syndrome.					
• I enjoy talking to other young people online without autism or Asperger syndrome.					
• I enjoy taking part in school events with people who don't have autism or Asperger syndrome.					
<u>Cultural preference</u> **If you could have your way, how 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 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.					
<u>Cultural competence</u>					

• I know lots about teenagers without autism or Asperger syndrome.					
• I know lots of names of famous 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

Scoring

- **Biculturalism=** High score on both scales- bicultural
- **Aligned to autistic group**= High Autism score, low non-autistic score
- **Aligned to non-autistic peers**= High non-autistic score, low autistic score
- **Marginalised**= low scores on both scales

Rosenberg’s self–esteem scale

Instructions

- Below is a list of statements about your general feelings about yourself. If you strongly agree, tick this box. If you agree with the statement, tick this box. If you disagree, tick this box. If you strongly disagree, tick this box.
- Only tick **one** box for each statement. There are **no right or wrong answers**. If you **do not** want to answer a question, that’s fine, just leave it blank.

Statement	Strongly agree	Agree	Disagree	Strongly disagree
1. I feel that I am a person of worth, at least on an equal plane with others.				
2. I feel that I have a number of good qualities.				
3. All in all, I am inclined to feel that I am a failure.				
4. I am able to do things as well as most other people.				
5. I feel I do not have much to be proud of.				
6. I take a positive attitude toward myself.				
7. On the whole, I am satisfied with myself.				
8. I wish I could have more respect for myself.				
9. I certainly feel useless at times.				
10. At times, I think I am no good at all.				

Created by Rosenberg (1965)

Scoring:

Rosenberg scores are calculated as follows:

For items 1, 2, 4, 6, and *7:*

- Strongly agree = 3
- Agree= 2
- Disagree= 1
- Strongly disagree= 0

For items 3, 5, 8, 9, and *10* (which are reversed in valence):

- Strongly agree = 0
- Agree= 1
- Disagree= 2
- Strongly disagree= 3

The scale ranges from 0-30. Scores between 15 and 25 are within normal range; scores below 15 suggest low self-esteem.

SPENCE CHILDREN’S ANXIETY SCALE (SCAS)

Instructions:
Please highlight the word that shows how often each of these things happen to you. There are no right or wrong answers.
If you don’t want to answer any of the questions below, that’s fine, just leave that question blank.

1. I worry about things……………………………………….. Never Sometimes Often Always

2. I am scared of the dark……………………………………..Never Sometimes Often Always

3. When I have a problem, I get a funny feeling in my stomach…………………………………………………..Never Sometimes Often Always

4. I feel afraid………………………………………………………Never Sometimes Often Always

5. I would feel afraid of being on my own at home....... Never Sometimes Often Always

6. I feel scared when I have to take a test………………….Never Sometimes Often Always

7. I feel afraid if I have to use public toilets or bathrooms……………………………………………………….Never Sometimes Often Always

8. I worry about being away from my parents…………..Never Sometimes Often Always

9. I feel afraid that I will make a fool of myself in front of people……………………………………………………..Never Sometimes Often Always

10. I worry that I will do badly at my school work...........Never Sometimes Often Always

11. I am popular amongst other kids my own age..........Never Sometimes Often Always

12. I worry that something awful will happen to someone in my family……………………………………………………...Never Sometimes Often Always

13. I suddenly feel as if I can’t breathe when there is no reason for this……………………………………………………......Never Sometimes Often Always

14. I have to keep checking that I have done things right (like the switch is off, or the door is locked)....…………………………………….Never Sometimes Often Always

15. I feel scared if I have to sleep on my own…………..Never Sometimes Often Always

16. I have trouble going to school in the mornings because I feel nervous or afraid…………………………………………………..Never Sometimes Often Always

17. I am good at sports………………………………………Never Sometimes Often Always

18. I am scared of dogs……………………………………… Never Sometimes Often Always

19. I can't seem to get bad or silly thoughts out of my head………………………………………………………….. Never Sometimes Often Always

20. When I have a problem, my heart beats really fast....…………………………………………………..……Never Sometimes Often Always

21. I suddenly start to tremble or shake when there is no reason for this...Never Sometimes Often Always

22. I worry that something bad will happen to me...…...Never Sometimes Often Always

23. I am scared of going to the doctors or dentists........ Never Sometimes Often Always

24. When I have a problem, I feel shaky...................... Never Sometimes Often Always

25. I am scared of being in high places or lifts (elevators)…………………………………………….………Never Sometimes Often Always

26. I am a good person..Never Sometimes Often Always

27. I have to think of special thoughts to stop bad things from happening (like numbers or words).....................…………………………………...Never Sometimes Often Always

28 I feel scared if I have to travel in the car, or on a bus or a train...Never Sometimes Often Always

29. I worry what other people think of me..................... Never Sometimes Often Always

30. I am afraid of being in crowded places (like shopping centres, the movies, buses, busy playgrounds).........…………………………....... Never Sometimes Often Always

31. I feel happy...Never Sometimes Often Always

32. All of a sudden I feel really scared for no reason at all…………………………………………………..…. Never Sometimes Often Always

33. I am scared of insects or spiders............................ Never Sometimes Often Always

34. I suddenly become dizzy or faint when there is no reason for this... Never Sometimes Often Always

35. I feel afraid if I have to talk in front of my class........ Never Sometimes Often Always

36. My heart suddenly starts to beat too quickly for no reason……………………………………………………....Never Sometimes Often Always

37. I worry that I will suddenly get a scared feeling when there is nothing to be afraid of.................................………………………….........…. Never Sometimes Often Always

38. I like myself.......................…………………………Never Sometimes Often Always

39. I am afraid of being in small closed places, like tunnels or small rooms……………………………………………….………Never Sometimes Often Always

40. I have to do some things over and over again (like washing my hands, cleaning or putting things in a certain order)................................... Never Sometimes Often Always

41. I get bothered by bad or silly thoughts or pictures in my mind…………..………………………………………………..… Never Sometimes Often Always

42. I have to do some things in just the right way to stop bad things happening..……………... Never Sometimes Often Always

43. I am proud of my school work................................. Never Sometimes Often Always

44. I would feel scared if I had to stay away from home overnight………………………………………………….Never Sometimes Often Always

45. Is there something else that you are really afraid of ?.....……...………… YES NO

Please write down what it is……………………………………………………………….

How often are you afraid of this thing?...................………………………………………

SCAS scoring

The responses are scored:

Never = 0

Sometimes = 1

Often = 2

Always = 3

Maximum possible score: 114.

The positive filler items that are not scored in either the total score or the subscale scores include item numbers 11, 17, 26, 31, 38, and 43.

Interview Schedule 1- Identity, Self-esteem, and Anxiety

Identity

1. **What do you know about autism/Asperger syndrome?** ☐ ☐
    - Other teenagers/peers ☐ ☐
    - Famous people ☐ ☐
    - History/key events ☐ ☐
    - Organisations ☐ ☐ ☐ ☐

2. **Do you prefer to be around other people with autism/Asperger syndrome, those without, or both?** ☐ ☐
    - School peers ☐ ☐
    - Friends ☐ ☐
    - Family members ☐ ☐

3. **How involved do you feel with other people and things related to autism/Asperger syndrome?** ☐ ☐
    - Books ☐ ☐
    - Events ☐ ☐
    - Chatting online ☐ ☐
    - Promoting rights/campaigns ☐ ☐

4. **How do you feel about being autistic/having Asperger syndrome?** ☐ ☐
    - Use of term to describe self? ☐ ☐
    - Fitting in with others? Who? ☐ ☐
    - How important is having autism/Asperger syndrome to you? ☐ ☐
    - Importance of being with other people with autism/Asperger? ☐ ☐

Self-esteem

5. **Do you ever think positively about yourself?** ☐ ☐
    - Things to be proud of? ☐ ☐
    - Do you think you have good qualities? ☐ ☐
    - Happy with yourself as you are? ☐ ☐

6. **Do you ever think negatively about yourself?** ☐ ☐
    - Ever feel like a failure? ☐ ☐
    - Lack of respect for self? ☐ ☐
    - Ever feel useless? ☐ ☐
    - Ever feel no good at all? ☐ ☐

7. **How do you feel about yourself when you compare yourself to others at school?** ☐ ☐
    - Equal to others? ☐ ☐
    - Can do things as well? ☐ ☐

Anxiety

8. Do you ever feel worried or scared? ☐ ☐

- **When you are apart from members of your family?** ☐ ☐
  - At home alone? ☐ ☐
  - Away from parents? ☐ ☐
  - Do you ever worry something will happen to your parents when you're not with them? ☐ ☐
  - Stay overnight somewhere? ☐ ☐
- **In situations?** ☐ ☐
  - Tests? ☐ ☐
  - Using public toilets? ☐ ☐
  - Appearing a fool in front of others? ☐ ☐
  - Doing badly in school work? ☐ ☐
  - Talking in front of class? ☐ ☐
  - Being in a crowded place? ☐ ☐
  - Travel in car, train or bus? ☐ ☐
  - In small, closed spaces? ☐ ☐
- **Of particular things?** ☐ ☐
  - The dark? ☐ ☐
  - Dogs? Insects? Spiders? ☐ ☐
  - Doctors or dentists? ☐ ☐
  - Heights? ☐ ☐

9. Do you ever feel like you have to do things or something bad will happen?	☐	☐
______ Checking things repeatedly?	☐	☐
______ Difficulty getting bad/silly thoughts out of head?	☐	☐
______ Need to think special things to stop bad things happening?	☐	☐
______ Need to do things repeatedly or in special order?	☐	☐

Appendix five

Timetable for project

	D	J	F	M	A	M	J	J	A	S	O	N	D	J	F	M	A	M	J	J
Plan	▨																			
University ethics approval		▨																		
LEA ethics approval			▨																	
Recruitment			▨	▨	▨	▨														
Data collection				▨	▨	▨	▨			▨	▨	▨	▨							
Literature review	▨	▨	▨	▨																
Analysis					▨	▨	▨	▨	▨	▨	▨	▨	▨	▨						
Write-up							▨	▨	▨	▨	▨	▨	▨	▨	▨	▨	▨			
Submission																		▨		
Viva																				▨

Figure 4: Original, planned timetable

	D	J	F	M	A	M	J	J	A	S	O	N	D	J	F	M	A	M	J	J
Plan	▨																			
University ethics approval				▨																
LEA ethics approval			▨																	
Recruitment				▨	▨	▨	▨			▨	▨	▨	▨	▨	▨					
Data collection				▨	▨	▨	▨	▨		▨	▨	▨	▨	▨	▨	▨				
Literature review	▨	▨	▨	▨																
Analysis										▨	▨	▨	▨	▨	▨	▨				
Write-up								▨	▨	▨	▨	▨	▨	▨	▨	▨	▨	▨		
Submission																		▨		
Viva																				▨

Figure 5: Actual timetable

Appendix six

Pilot materials

Feedback on Autism Identity Scale (AIS)

The scales look good. My experience of people with AS particularly is that they don't always see that they fit in the term Autistic, as they have been told they have Asperger's (people on the spectrum being very particular about exact terms!). I think it would probably be an idea to outline to them all to start with that in this study Autism includes Asperger's. Or I guess you could add to the statements autism/Asperger Syndrome to make it clear.

I was a little unsure of the meaning of the question on the mainstream questions, under cultural identity, "I feel I am part of same group as people without autism."?

Possibly being a bit picky on grammar (but so may people with AS), the cultural preference opening statement I think either needs to be

If you could have your way, how would you prefer the following situations in your life to be?

or

If you could have your way, what would you prefer the following situations in your life to be like?

PILOT- The Autism Identity Scale

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

Autism acculturation scale

Item	1	2	3	4	5
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 **How much do you enjoy....**					
• 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 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 **How well do you know about....**					
• 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.					

Non-autistic Mainstream peers' acculturation scale

Item	**1**	**2**	**3**	**4**	**5**
Cultural Identity					
• I don't call myself Autistic or a person with 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 I fit in with other people without autism or Asperger syndrome at school.					
• I am comfortable with people without autism or Asperger syndrome.					
Cultural involvement					

How much do you enjoy....					
• I enjoy reading books /magazine/information written by people without autism or Asperger syndrome.					
• I enjoy going to events/parties/gatherings with 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 syndrome.					
Cultural preference **If you could have your way, how would you prefer the following situations in your life to be like?**					
• I would prefer my education to be at a mainstream school like I am 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 about teenagers without autism or Asperger syndrome.					
• I know lots of names of famous 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.					

PILOT- Interview Schedule 1- Identity, Self-esteem, and Anxiety

Identity

1. **What do you know about autism/Asperger syndrome?** ☐
    - Other teenagers/peers ☐
    - Famous people ☐
    - History/key events ☐
    - Organisations ☐

2. **Do you prefer to be around other people with autism/Asperger syndrome, those without, or both?** ☐
    - School peers ☐
    - Friends ☐
    - Family members ☐

3. **How involved do you feel with other people and things related to autism/Asperger syndrome?** ☐
    - Books ☐
    - Events ☐
    - Chatting online ☐
    - Promoting rights/campaigns ☐

4. **How do you feel about being autistic/having Asperger syndrome?** ☐
    - Use of term to describe self? ☐
    - Fitting in with others? Who? ☐
    - How important is having autism/Asperger syndrome to you? ☐
    - Importance of being with other people with autism/Asperger? ☐

Self-esteem

5. **Do you ever think positively about yourself?** ☐
    - Things to be proud of? ☐
    - Do you think you have good qualities? ☐
    - Happy with yourself as you are? ☐

6. **Do you ever think negatively about yourself?** ☐
    - Ever feel like a failure? ☐
    - Lack of respect for self? ☐
    - Ever feel useless? ☐
    - Ever feel no good at all? ☐

7. **How do you feel about yourself when you compare yourself to others at school?** ☐
    - Equal to others? ☐
    - Can do things as well? ☐

Anxiety

8. Do you ever feel worried or scared? ☐

- **When you are apart from members of your family?** ☐
  - At home alone? ☐
  - Away from parents? ☐
  - Do you ever worry something will happen to your parents when you're not with them? ☐
  - Stay overnight somewhere? ☐
- **In situations?** ☐
  - Tests? ☐
  - Using public toilets? ☐
  - Appearing a fool in front of others? ☐
  - Doing badly in school work? ☐
  - Talking in front of class? ☐
  - Being in a crowded place? ☐
  - Travel in car, train or bus? ☐
  - In small, closed spaces? ☐
- **Of particular things?** ☐
  - The dark? ☐
  - Dogs? Insects? Spiders? ☐
  - Doctors or dentists? ☐
  - Heights? ☐

9. Do you ever feel like you have to do things or something bad will happen? ☐

________ Checking things repeatedly? ☐

________ Difficulty getting bad/silly thoughts out of head? ☐

________ Need to think special things to stop bad things happening? ☐

________ Need to do things repeatedly or in special order? ☐

Appendix seven

Interview preparation letter

Hello

Thank you for agreeing to participate in the project about young people with autism and Asperger syndrome.

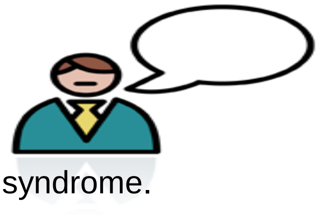
The information below is to let you know the things we will talk about when we meet next time. If you have any questions after you have read the information please ask ……………………………….at school.

We will be meeting on [redacted]

Location: [redacted]

If you are not happy with the date, time or location please let [redacted] know.

What things will we talk about next time?



- What you think about having autism/Asperger syndrome.
- If you ever read books by other people with autism/Asperger syndrome.
- If you ever chat online or go to groups with other people with autism/Asperger syndrome.
- How much you think you know about autism/Asperger syndrome (including: other teenagers, famous people, and groups).
- How you feel about yourself and your confidence.
- If anything makes you feel worried (for example: spiders, crowded places, tests, the dentists, or getting something wrong).

What if you do not want to answer a question?

There are **no right or wrong answers** for the things we talk about, just your opinions. Your opinions are interesting to hear.

You do not have to answer any question that you do not want to, I will not mind at all.

Recording your answers

When we meet I will ask you if I can use my tape recorder to record your answers so I don't have to write them all down.

I look forward to meeting you.

Hayley Jarrett (Trainee Educational Psychologist)

Appendix eight

Stages of thematic analysis

Stage one:

During stage one each interview was transcribed from the recording and continually read to ensure familiarity.

Transcript extract example

A5 Transcription

1. I: Ok…question 1 what do you know about autism or Asperger syndrome?
2. A5: Um I know it is a disorder that some people have when they are born
3. I: Can you tell me anymore?
4. A5: Um I know for everyone 1 girl that has autism 4 men have it
5. I: Do you know any other teenagers in the school that have
6. A5: Um I know a friend of mine called X has Asperger I know that….that's about it
7. I: How about outside of school do you know anybody outside of school?
8. A5: I don't think so
9. I: Do you know any famous people?
10. A5: I can't really I think the guy who created Pokémon had autism I think
11. I: How about any different organisations or clubs about autism?
12. A5: Umm not really no
13. I: Anything in the history or any key events related to autism?
14. A5: Um I think it was first recognised in 1940s by someone I think in the 1940s
15. I: Anything else you want to share about what you know about autism?
16. A5: Well I know that most autistics are normally normally grow up and become excellent engineers great artists or great musicians
17. I: Do you prefer to be around other people with autism or Asperger syndrome those without or it doesn't matter?
18. A5: It doesn't really matter
19. I: You said you've got a friend called X does X go to this school?
20. A5: Yeh he goes to this school

Stage two:

Each participants’ transcript was individually coded and an initial matrix of codes was created for each using an inductive approach. These codes were then revised.

Initial set of codes

A5 codes

Names		Sources	References
Factual description of ASC		1	2
Doesn't know many with ASC		1	1
Limited knowledge of famous people with ASC		1	1
No knowledge of clubs or organisations for ASC		1	1
Historical knowledge		1	1
Has friend at school with ASC		1	2
Has friends without autism		1	1
Doesn't matter if people have ASC or not to them		1	2
Unsure about their involvement in things related to ASC		1	1
Read school book about ASC		1	1
Sought information about ASC themselves		1	1
Some people chat to online have ASC		1	1
Unsure about attendance at ASC events		1	1
Positive outlook of autism		1	3
Thinks ASC has disadvantages when asked		1	1
Other children make jokes about ASC		1	1
Others knew about diagnosis before they did		1	1
Told about diagnosis at competition		1	1
Feelings when told about diagnosis		1	1
Share diagnosis to defend off things		1	2
Probably wouldn't share diagnosis with school staff		1	1
Having ASC important due to its benefits		1	2
Not important to be with others with ASC		1	2
Positive relationships with others with ASC		1	4
Can only compare self to some in school		1	1

Second revision

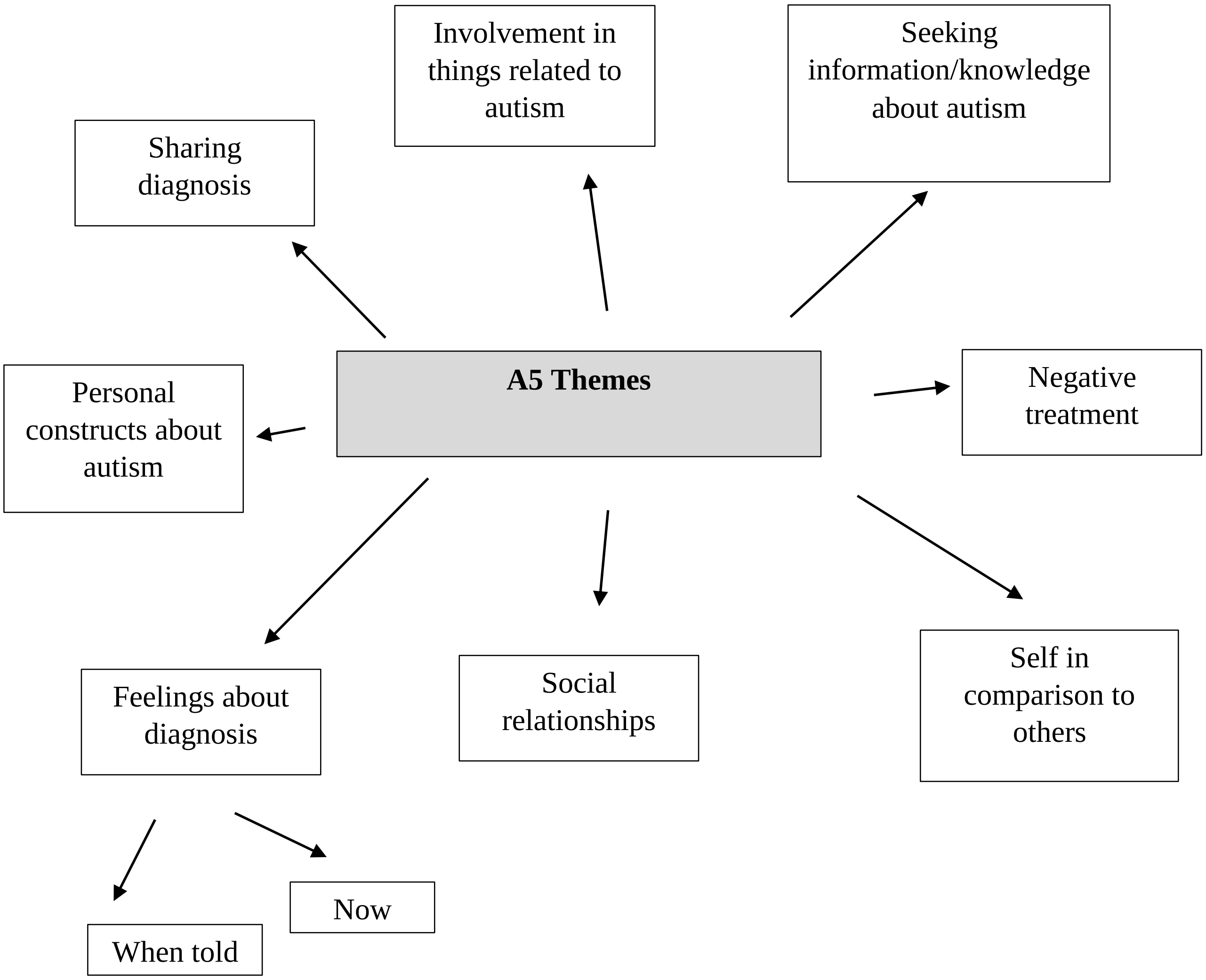
Similar codes were merged with each other. For example, ‘Others knew about their diagnosis before they did’ and ‘Told about diagnosis at competition’ became ‘Others’ knew about their ASC before them’. This process was repeated for each participant.

A5 codes

Names		Sources	References
Chats online to people with and without ASC		1	1
Doesn't know many students with ASC		1	1
Doesn't matter if people have ASC or not		1	3
Factual description of ASC		1	2
Feelings when told about diagnosis		1	1
Feels can only compare self to some in school		1	1
Having ASC important due to its benefits		1	2
Historical knowledge		1	1
Jokes made about their ASC by other children in past		1	1
Limited knowledge of famous people with ASC, clubs or organisations		1	1
Not important to be with others with ASC		1	2
Others knew about their ASC before them		1	2
Personally sought information about ASC		1	1
Positive outlook of autism		1	3
Positive relationships with others with ASC		1	4
Probably wouldn't share diagnosis with school staff		1	1
Read school book about ASC		1	1
Share diagnosis to defend off things		1	2
Thinks ASC has disadvantages when asked		1	1
Unsure about their involvement in things related to ASC		1	2

A5 themes:

The codes on the previous page were examined and a set of initial themes emerged.



Stage three:

At this point the themes for each participant were combined to create a set of themes across all participants.

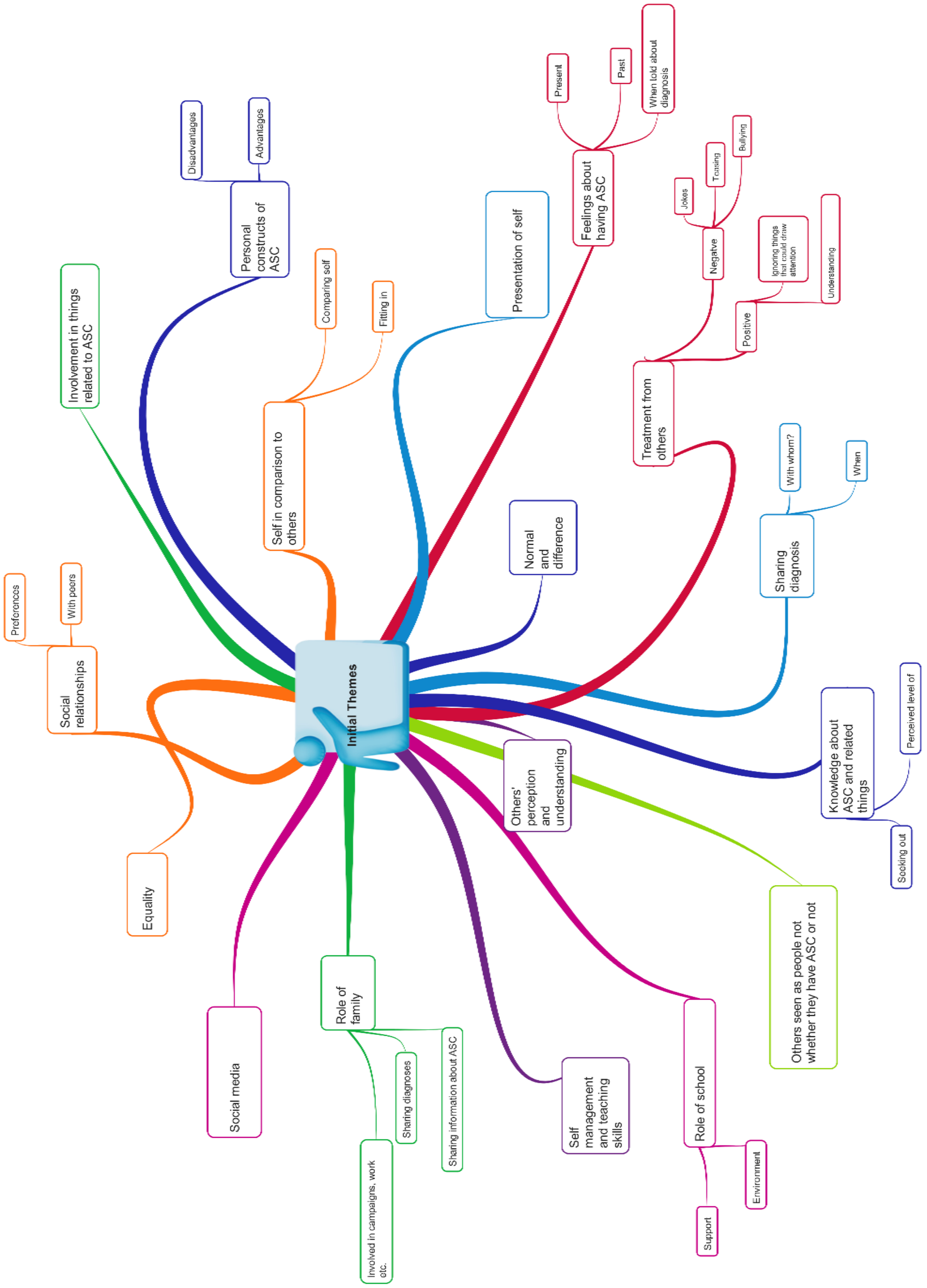


Figure 6: Mind map of inductive themes

Stage four:

All of the transcripts were re-coded in Nvivo 10, applying the group themes from the inductive approach (stage three) and four themes based on a deductive approach which utilised the theory underpinning the interview questions (cultural competence, cultural involvement, cultural preference, and cultural identification).

First structure after combining both sets of themes:

Names		**Sources**	**References**
Cultural competence		7	21
Perceived knowledge about ASC and related things		8	28
Personal constructs of ASC		5	8
Cultural identification		3	11
Feelings about having ASC		8	24
Normal and difference		2	6
Presentation of self		1	1
Self in relation to other		8	24
Sharing diagnosis		9	16
Social relationships with peers		6	17
Cultural involvement		9	47
Role of family		2	7
Role of social media		9	16
Seeking knowledge about ASC		5	5
Cultural preference		9	31
Other		5	10
Equality		2	3
Others' perceptions and understanding		6	16
Others seen as who they are not by labels		5	6
Role of school		4	7
Self-management of ASC		3	4
Treatment from others		0	0
Negative treatment		5	14
Positive treatment		1	1

Stage five:

The data were repeatedly examined and themes were refined and reassessed.

Level one and two sub-themes emerged.

Names		**Sources**	**References**
Cultural identification		0	0
Fitting in		0	0
Difference		3	6
With those with and without autism		5	8
Importance of autism to person		1	1
Having autism important		3	3
Having autism not important		3	3
Involvement with others with autism		0	0
Increases personal understanding		2	3
Not important		4	4
Sharing diagnosis		2	2
Others' perceptions and understanding		4	7
Presentation of self		2	4
Shared vs not shared		9	12
Cultural involvement		0	0
Feelings of involvement with things related to autism		4	4
Involvement in activities and events		0	0
Involved		5	6
Not involved		7	14
Not related to labels		4	4
Role of family and school		5	11
Seeking knowledge about ASC		5	6
Social relationships with peers		3	4
Use of social media		9	16
Knowledge about autism		0	0
Autism		5	9
Famous people and authors		9	10
History		8	9
Organisations, clubs, events		8	9
Peers with autism		8	8
Negative treatment from others		0	0
Difference		1	4
Negative treatment experienced and perceived		5	14
Role of school		2	4
Personal constructs of autism		1	1
Definitions of autism		1	1
Difference		6	8
Factual		2	2
Spectrum		5	6
Feelings about autism		0	0
Change		4	7
Positive		6	11

Personal traits		3	8
Self-management of ASC		3	4
Relationship preferences		0	0
Importance of difference		1	3
Preference not based on labels		3	3
Preference vs no preference		9	23
Self in relation to others		6	8

Revised again:

Cultural identification	
Feelings about ASC	
Change	
Importance of ASC to person	
Positive	
Self in relation to others	
Comparison of self to others	
Fitting in	
Personal traits	
Spending time with others with ASC beneficial vs not important	
Sharing diagnosis	
Others' perceptions and understanding	
Presentation of self	
Shared vs not shared	
Cultural involvement	
Feelings of involvement with things related to ASC	
Involvement in activities and events	
Involved vs not involved	
Involvement not related to labels	
Seeking knowledge about ASC	
Support for involvement from family and school	
Use of social media	
Social relationships with peers with ASC	
Negative treatment from others	
Personal definitions of and perceived knowledge about ASC	
How participants define ASC	
Perceived levels of knowledge about ASC and related things	
ASC	

History, famous people and authors	
Organisations, clubs, events	
Peers with ASC	
Relationship preferences	
Preferences	
Reasons behind preferences	

Stage six:

At stage six the final themes were decided upon (below) and the findings were reported (see chapter 3).

Final themes:

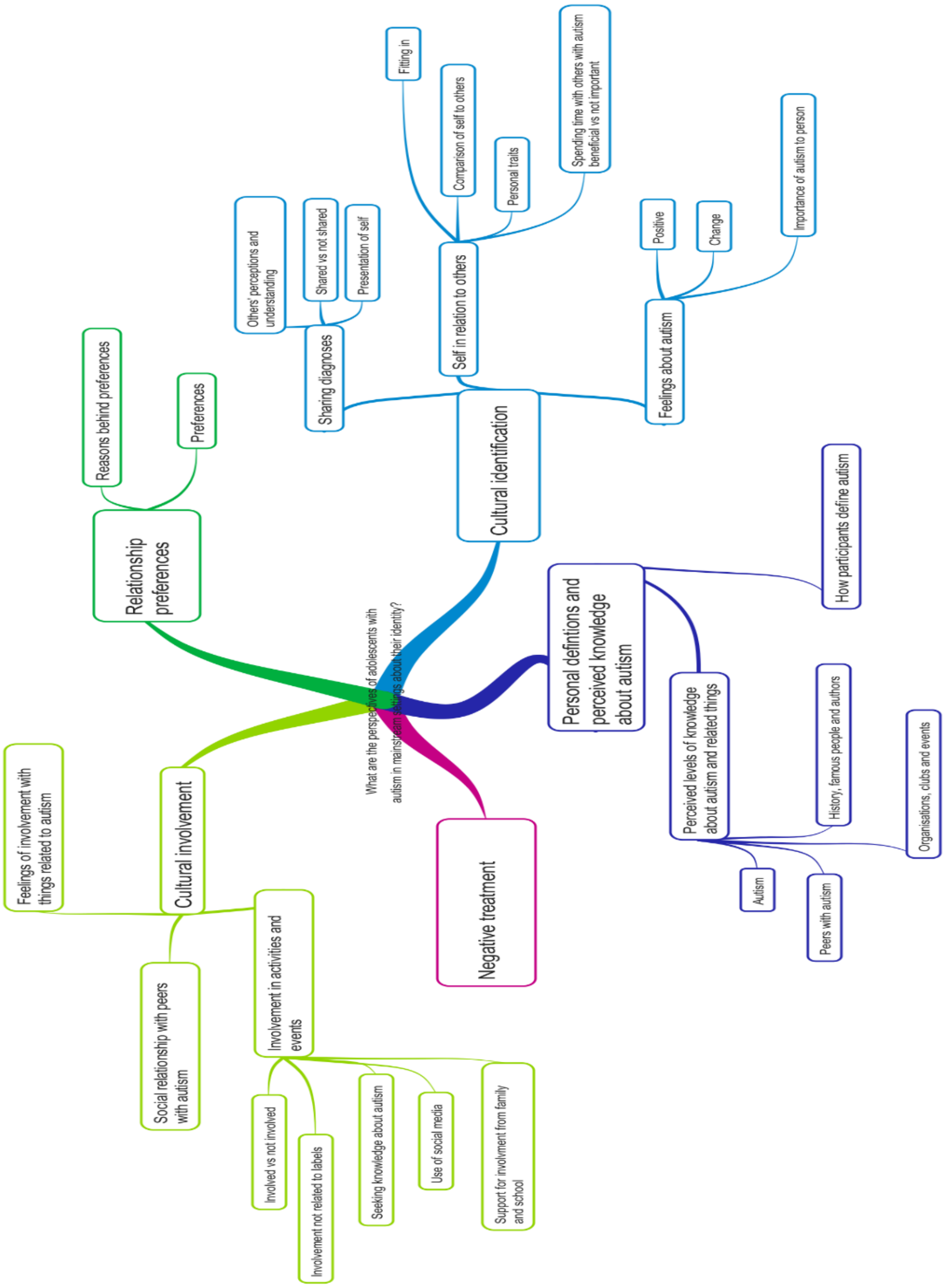


Figure 7: Mind map of final themes

Appendix nine

Inter-rater reliability materials

Table 9: Inter-rater reliability information for participants' anxiety ratings from the interview data

Anxiety Levels	Description	Person 1	Person 2	Person 3
Low anxiety	Lots of comments that indicate not bothered/worried (e.g. - not really…", "wouldn't really bother me….")	A11, A28, A38	A17, A11	A38
Some anxieties	Quite a few comments show some anxiety (**"**Sometimes….", "can do….")	A34, A5, A17, A22		A5, A34
High anxiety	Lots of comments show anxiety (**"**I am scared of….", "that worries me…")	A12, A16,	A12	

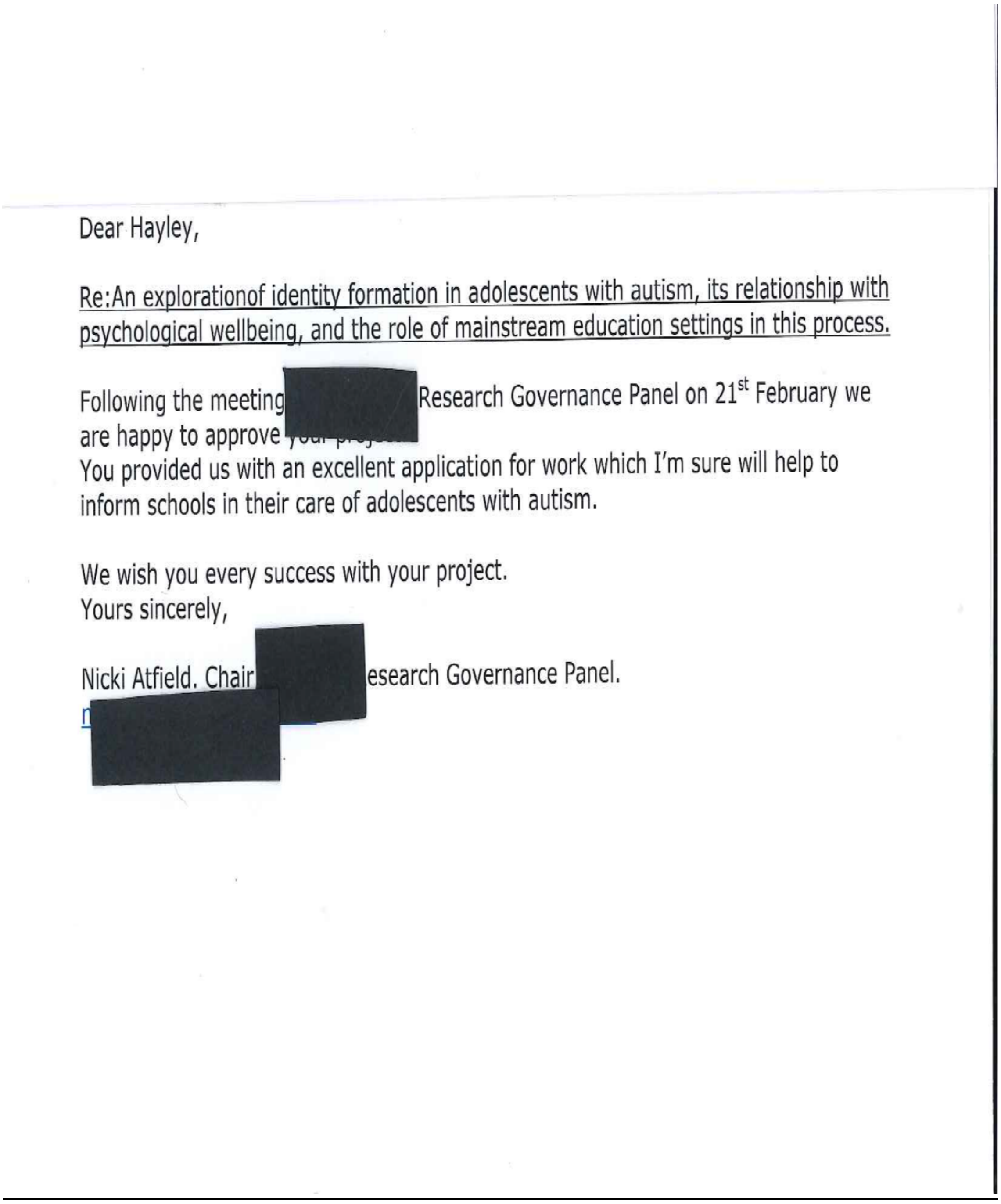
Table 10: Inter-rater reliability information for participants' self-esteem ratings from the interview data

Self-esteem	Description	Person 1	Person 2	Person 3
Low self-esteem	Lots of clear negative comments ("No good at all….")	A16		
Medium self-esteem	Comments show sometimes positive and sometimes negative (**"**Sometimes….")	A34, A17, A12, A22,	A34, A5, A17	A22,
High self-esteem	Lots of clear positive comments (I have…..I am ….)	A38, A5, A11, A28	A38	A11, A12

Appendix ten

Ethical consideration materials

LEA approval



Dear Hayley,

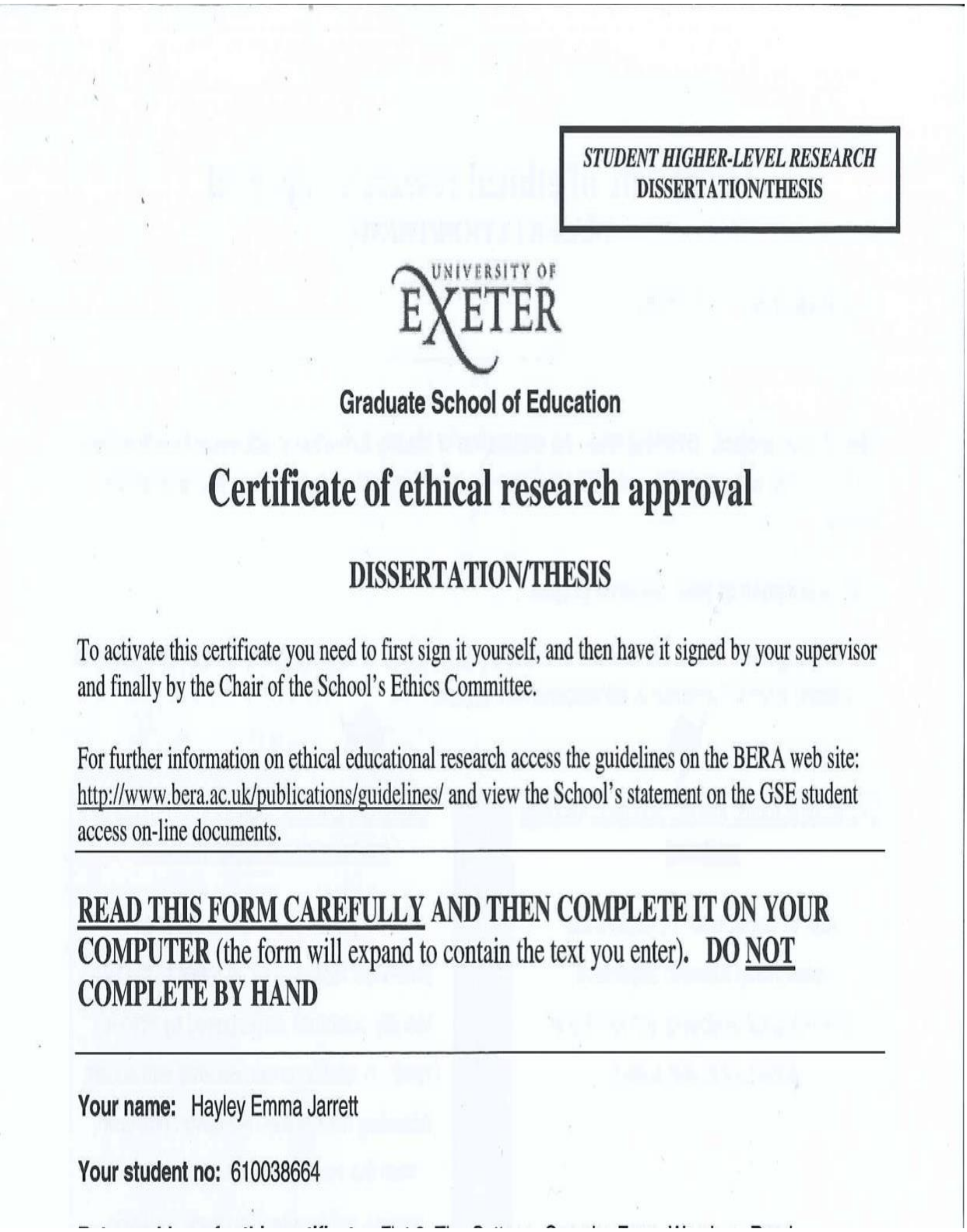
Re:An explorationof identity formation in adolescents with autism, its relationship with psychological wellbeing, and the role of mainstream education settings in this process.

Following the meeting [redacted] Research Governance Panel on 21st February we are happy to approve [redacted]
You provided us with an excellent application for work which I'm sure will help to inform schools in their care of adolescents with autism.

We wish you every success with your project.
Yours sincerely,

Nicki Atfield. Chair [redacted]esearch Governance Panel.
[redacted]

University approval



STUDENT HIGHER-LEVEL RESEARCH
DISSERTATION/THESIS

UNIVERSITY OF EXETER

Graduate School of Education

Certificate of ethical research approval

DISSERTATION/THESIS

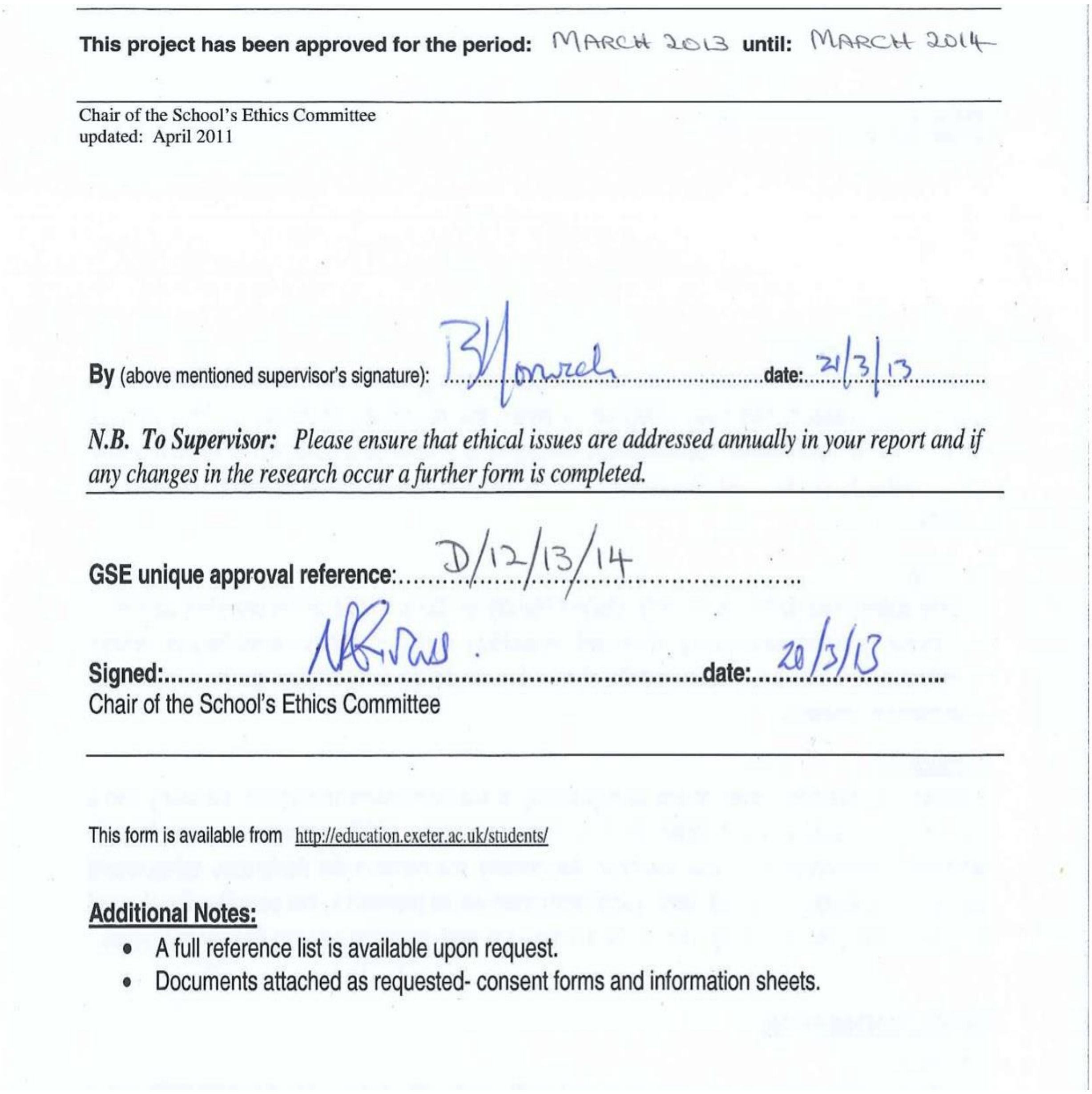
To activate this certificate you need to first sign it yourself, and then have it signed by your supervisor and finally by the Chair of the School's Ethics Committee.

For further information on ethical educational research access the guidelines on the BERA web site: http://www.bera.ac.uk/publications/guidelines/ and view the School's statement on the GSE student access on-line documents.

READ THIS FORM CAREFULLY AND THEN COMPLETE IT ON YOUR COMPUTER (the form will expand to contain the text you enter). **DO NOT COMPLETE BY HAND**

Your name: Hayley Emma Jarrett

Your student no: 610038664



This project has been approved for the period: MARCH 2013 **until:** MARCH 2014

Chair of the School's Ethics Committee
updated: April 2011

By (above mentioned supervisor's signature): ....**date:** 21/3/13

N.B. To Supervisor: *Please ensure that ethical issues are addressed annually in your report and if any changes in the research occur a further form is completed.*

GSE unique approval reference: D/12/13/14

Signed:..**date:** 20/3/13
Chair of the School's Ethics Committee

This form is available from http://education.exeter.ac.uk/students/

Additional Notes:

- A full reference list is available upon request.
- Documents attached as requested- consent forms and information sheets.

Example information and consent pack

Overleaf is an example of the pack sent to participants asked to complete the scales and interviews. Participants who were only asked to complete the scales received a similar pack with the interview information removed.

Parent/Guardian Questionnaire

Please could you complete this short questionnaire and return it to the school with the consent form.

Name of son/daughter: ………………………………………….

School: ………………………………………………… Year group: …………….

1. How old was your son/daughter when they received a diagnosis of autism/Asperger syndrome?

   …………………………………………………………………………………

2. How old was your son/daughter when they were told about this diagnosis?

   ………………………………………………………………………………….

3. (a) Are you a member of the National Autistic Society?

   ………………………………………………………………………………….

   (b) How active are you within this group? (*please circle one*)

   Not very active **Fairly active** **Very active**

4. (a) Are you a member of any other groups related to autism/Asperger syndrome or special educational needs? If yes, please name.

   …………………………………………………………………………………

   …………………………………………………………………………………

   (b) How active are you within this group? (*please circle one*)

   Not very active **Fairly active** **Very active**

Thank you very much for your time!

UNIVERSITY OF EXETER

PARENT/GUARDIAN and YOUNG PERSON'S CONSENT FORM

Project Title: *An exploration of identity formation in adolescents with autism, its relationship with psychological wellbeing, and the role of mainstream education settings in this process.*

Have you read the Information Sheet?	**YES/NO**
Have you received enough information about the study?	**YES/NO**
Do you consent for your/ your son/daughter's interview session(s)/focus group to be audio taped as detailed in the Information Sheet?	**YES/NO**
Do you understand any information which I/they give will be used **anonymously** and solely for the purposes of this research project, which may include publications?	**YES/NO**
Do you understand that you do not need to take part in the study and if you do take part you are free to withdraw:- - at any time - without having to give a reason for withdrawing - have your data destroyed - and without detriment to you?	**YES/NO**

I have read the enclosed information sheet and am happy for my son/daughter to take part.

NAME:…………………………………………………....DATE:..

SIGNATURE (Parent/Guardian):

……………………………………………………………...

I have read the enclosed information sheet and I am happy to take part.

NAME:…………………………………………………..…DATE:...

SIGNATURE (Young person):

……………………………………………………...

Please return this form to ……… by .... (2 weeks time).

Dear parent/guardian,

I am writing to tell you that your son/daughter has been selected to be involved in a project looking at autism in adolescents from both the perspectives of young people on the spectrum and their peers. The project is being carried out by myself (Hayley Jarrett), a student on the DEdPsych in Educational, Child and Community Psychology at the University of Exeter and Trainee Educational Psychologist who currently works for [redacted] Educational Psychology Service.

The information outlined below is to help you understand what participation in the project entails. Please take time to read the following information and decide whether or not you are happy for your son/daughter to participate. If you would like any further information or have any questions about the research project, please contact me via the details provided at the end of these information sheets.

Title: An exploration of identity formation in adolescents with autism, its relationship with psychological wellbeing, and the role of mainstream education provision in this process.

What is the aim of the research?

The main aim is to explore how adolescents with autism perceive themselves and their experiences in a mainstream secondary school, from both the perspectives of young people on the spectrum and their peers.

Where will the research be conducted?

In your son/daughter's school.

What is the duration of the research?

The project itself runs from April 2013 until June 2014, although data collection will only be in term time between May until December 2013.

What will my son/daughter be asked to do if he/she takes part?

During stage one, your son/daughter will be asked to complete 3 short questionnaires which look at how they perceive themselves, their self-esteem and anxiety. These use a 1-5 scale for answering and should take no more than 20-25 minutes to complete all three. One of the questionnaires will be repeated 4 weeks later. They will then be asked to participate in 1 short interview lasting approximately 30 minutes, with questions relating to the information in the questionnaires.

In stage two they will be asked to undertake 1 short interview for approximately 30-45 minutes which will ask about their experiences of having a diagnosis of autism and attending a mainstream secondary school and any improvements they think their school could make.

Both interviews will be recorded on a Dictaphone to help with transcription of the information; however, once transcribed this recording will be deleted. Full consideration has been given to how to make the process as enjoyable and comfortable for each young person as possible and a number of additional measures have been devised in recognition of this. For example, time will be spent prior to data collection finding out the most appropriate methods to aid participation for each individual, including the best location and time of day, and the most appropriate resources to assist them. Furthermore, participants will be informed they may bring someone along to data collection sessions if they wish.

What happens to the data collected?

The data will be analysed by myself for my doctoral thesis. A report will be written based on my analyses of the data which will also be provided to schools. Your son/daughter's name will **NOT be** used in the report.

How is confidentiality maintained?

All data provided will be treated as confidential and will be completely anonymous. Every reasonable effort will be made to preserve the anonymity of the school and of all participants. Identifying information (e.g. your son/daughter's name) will **NOT be** used and pseudonyms will be given. All identifiable data collected will be stored on a secure [redacted] Council laptop to which I only will have access. All raw data collected as part of the project will only be seen by myself and my research supervisors at University.

Does my son/daughter have to take part?

Participation is entirely voluntary and you have two weeks to read all the information and make a decision. If you and your son/daughter are both happy then **please complete the attached consent form and return by the date stated on the form**. If you and your son/daughter decide to take part and then later change your mind, either before or during the study, you can withdraw your consent, without giving your reasons, and, if you wish, your data will be destroyed.

Will he/she be paid for taking part?

I am not able to offer any payment or incentive for participating in this study; however, each student will be provided with feedback from the project and schools will be provided with feedback to help them best meet the needs of young people with autism.

Criminal Records Check

I have undergone a Criminal Records Bureau check at the Enhanced Disclosure level.

Where can I obtain further information if I need it?

[redacted]

Dear ……………………………… (student)

My name is Hayley Jarrett, and I am training to be an Educational Psychologist. This means I go to lots of different schools and work with young people to help them in school. This is me:

I am writing to tell you that you have been selected to be involved in a project about young people with autism and Asperger syndrome. The information below is to help you understand what the project is about and what will happen if you choose to take part. Please take time to read it carefully and decide if you want to take part.

Project Title: *An exploration of identity formation in adolescents with autism, its relationship with psychological wellbeing, and the role of mainstream education provision in this process.*

1. What is this project about?

This is a project about young people with autism and Asperger syndrome in secondary schools. The aim of the project is to find out how young people feel about having autism or Asperger syndrome, how they feel about what their school does about autism or Asperger syndrome and whether they would like their school to share information with other children about autism or Asperger syndrome.

2. What would I need to do?

If you decide to take part in the project this is what you would be asked to do:

- Complete 3 questionnaires. These have a choice of answers which you can choose from. This will take about 20- 25 minutes.
- Take part in 2 short interviews which will take about 30 to 45 minutes. You will be asked about how you feel about having autism/Asperger syndrome; how you feel about what your school does when it comes to autism/Asperger syndrome; and whether you would like your school to share information with other children about autism/Asperger syndrome. Your answers will be recorded as it will be difficult for me to write quickly enough. Once I have typed up all of the answers I will then delete this recording.

3. When will it be?

You would participate in the project in the summer and autumn term. You will receive your own timetable so you will know exactly when you will be taking part in the project.

4. Where will it be?

All the things that will happen for the project will take place in your school in a place you feel comfortable.

5. What if I change my mind?

Don't worry, that is fine! You can change your mind at any time and all you would need to do is tell me.

6. Will people know the information is about me?

No they will not. When we first meet I will ask you to choose a 'code name'. When I write about the project I will use your code name so people reading the information will not know it is about you.

7. Will I get paid?

No, unfortunately you will not get paid for taking part. However, when the project is finished you will get a feedback sheet which will show you what I have found out!

8. Do I have to take part?

No, you can choose whether you want to take part or not.

What Next?

If you are happy to be in the project **please sign your name** on the form called 'PARENT/GUARDIAN and YOUNG PERSON'S CONSENT FORM'.

School consent form

UNIVERSITY OF
EXETER

Researcher

I, the researcher, confirm that I have discussed with school staff the contents of the information sheet.

Signed:………Hayley Emma Jarrett**……..…** **Date:…………..…………..….**

School

I confirm that I have read the protocol and agree for the project to take place in our school, with the following type of consent:

■ Opt –in

(Parents will be given a form to authorise their children to take part. Children without parental authorisation will not take part.)

☐ Opt –out

(Parents will be given a form to allow them to refuse for their child to take part. If the form is not returned, the School assumes the child can take part.)

☐ Loco parentis

(School gives full consent for all pupils to take part in the study.)

I give permission for scales and semi-structured interviews to be completed with the students as explained in the information form. I understand that all raw data collected as part of the project will be kept by the researcher and shown to her researcher supervisors at University.

Name:……………… ……………………………………………………….

Signature:………………………………………………………………...

Letter to family to provide more information

Dear [redacted]

Thank you for agreeing for [redacted] to take part in my thesis project on autism. [redacted] has now completed the questionnaires at school and before proceeding any further I just wanted to check you were happy with the process of data collection and what will happen with the data once analysed.

As outlined in the parent information letter sent out with the consent forms, all data will be kept confidential as students are provided with a 'code name' which will be used instead of their real name. All of the raw data (questionnaires and interviews) will be kept by myself and only shown to my university supervisors for guidance with the project. However, it is important to acknowledge that data collection is done in school and if [redacted] would like support from school staff to complete the questionnaires or attend the interview with him than this will take place. Once the data has been analysed and written up next year, schools, young people, and their parents will be provided with feedback from the project. This will not identify particular students by name and will instead use code names or general comments, such as "A number of students thought…..".

I hope this provides additional information and clarity about the data collection and analysis process and what will happen with the findings afterwards. I have also included another copy of the parent information letter in case you wanted to refer to this again.

If you now feel unhappy about [redacted] participating, that is completely fine. Please just let myself or [redacted] at school know and his questionnaires will be destroyed and no further data collection will take place. If yourselves and [redacted] are still happy to continue then you do not need to do anything, I will visit the school again in September and begin the interviews.

If you have any further questionnaires please do not hesitate to contact me via the details at the top of this letter or to [redacted] at school.

Best wishes

Hayley Jarrett (Trainee Educational Psychologist)

Appendix eleven

Thematic analysis findings for all interview participants

Theme 1: Personal definitions of and perceived knowledge about autism

Sub-themes	Summary	Illustrative data
How participants define autism	Definitions often lacked personal references and could include negative traits or a negative tone.	*"Well I know that some people are not like…"* (A11). *"…problems with learning difficulties and reading language…"* (A17). "…*but now I don't have to worry about my son or daughter getting it"* (A22).
Perceived levels of knowledge about autism and related things	Knowledge of autism, history, organisations and clubs was generally felt to be low. In contrast one reported acquiring good knowing from a family member. Knowledge of famous people and peers with autism was much better, although one reported not distinguishing between who had autism or not.	*"I only know very basic information…"* (A16). *"not much"* (A12, A38). *"well I know a fair bit about it because XXXXX (family member)"* (A17). "…*no I just usually regard the famous people as… just famous people"* (A28).

Theme 2: Cultural identification

Sub-themes	Summary	Illustrative data
Feelings about autism	Feelings towards autism were generally positive although having it was only deemed to be important to a small number. Benefits included: increased focus and intelligence, and better memory. For two, feelings had become more positive over time. In contrast, one moved between feeling positive and negative due to bullying.	*"…I am quite proud of my autism actually…I feel it has made the person that I am…"* (A16) *"…sometimes it feels good because I've got a creative mind and it also feels bad at times cos cos people make fun of me…"* (A22).
Self in relation to others	Fitting in and comparisons to others were generally not worried about, although one frequently made negatively comparisons to peers, including through Facebook, and reported trying to hide their autism in the past to be like their friends. The importance of spending time with peers with autism provoked mixed responses; for some it provided a sense of shared identity but for others it was not important or interactions were not based on labels.	*"I: do you think you fit in with others at school?* *A28: Yeh"* *"…I was so against accepting my autism when I was in year X and X because the new friends I made I just wanted to be like them…"* (A16). *" I think it is actually quite important that you know I do meet other people with Asperger that way I don't feel like I am on my own or you know I am not like the only one"* (A38).
Sharing diagnoses	Diagnoses are shared or would be shared by more participants than not, including to increase understanding or get others to	*"…yeh I have pretty much told people that I do have autism and Asperger's ….you know just so they can like*

	leave them alone. In contrast, two reported presenting themselves in a way it would be difficult for others to know. Not disclosing or caution regarding this came about from fear of negative treatment; not wanting a label to define them; and disclosure not having an impact.	*understand sometimes why I am all like.."* (A11). "…*defend off things*…" (A5). *"…I have Asperger but I don't really I try not to show it as much as I can"* (A38).

Theme 3: Cultural involvement

Sub-themes	Summary	Illustrative data
Feelings of involvement with things related to autism	Participants had not had much thought regarding their involvement in things related to autism and only a small number felt clear whether they were quite involved or not.	*…I don't really know really I think I am alright"* (A5). *"I don't know…"* (A12). *"Fairly well involved…"* (A17).
Involvement in activities/ events	Limited ongoing involvement in activities related to autism, including reading attending clubs and events which for some was related to not defining activities as to whether they were related to autism or not. Five indicated facilitation for involvement in activities from school or family members had occurred. In contrast many have independently sought knowledge about autism at some point,	*…I do read some not books about autism I read normal books"* (A22). *"Um….I don't really know who has and who hasn't (authors)"* (A28). *"…my X takes me show takes me to like introduce me to the other people who have autism..."* (A11). *"Yeh that's where I got most of the facts from a book in the*

	including through books and asking others.	*library that's about autism… I found that by myself"* (A5).
Social relationships with peers with autism	Peers with autism are known by most although good friendships with multiple peers with the condition are only had by a small number, facilitated by special educational needs (SEN) areas.	*"Cos I do hang out with some people who have it but not many…"* (A12). *"…I know a friend of mine called X has Asperger I know that….that's about it"* (A5). *"Yeh I know pretty much everyone in the school with autism….I got to know them because most of us go to X (names SEN area) just to hang out…"* (A38).

Theme 4: Relationship preferences

Sub-themes	Summary	Illustrative data
Preferences	Adolescents with autism do not have preferences for whether friends, family and peers have autism or not; except for one who preferred to be around those without autism.	*"I don't really mind either way…"* (A11). *"…I do prefer to be around people who doesn't have it…"* (A12).
Reasons behind preferences	Relationship preferences or lack of them related to preferences not being based on a label or feeling that people with autism can present with a negative characteristic.	*"…I treat them exactly the same they are still people"* (A17). *"…because they don't wind me up as much"* (A12).

Theme 5: Negative treatment

Summary	Illustrative data
Five participants reported negative treatment of adolescents with autism occurs or is perceived to occur, including teasing, making jokes, and bullying. School staff were both reported to help and do nothing.	*"…might you know tease me about it because they have in the past"* (A16). *"…pushed me shoved me called me names like stupid or ugly…"* (A22). *"…you could meet anyone at an event who could try to pick a fight with you for any reason…"* (A12). *"…I can't be bothered anymore cos I've tried in the past and nothings been done"* (A12).

Appendix twelve

SPSS data

Anxiety vs self-esteem data screening

Data was screened to check if it met the requirements to conduct a parametric test. Screening revealed three of the four conditions were met and therefore the Pearson's product- moment correlation co-efficient was selected.

Table 11: Data screening for anxiety and self-esteem data

Parametric requirement	Result	Met?
Homogeneity of variance	300.2, 21.4	Not met
Scale level data	Yes	Met
Normal distribution	0.108, 0.200	Met
No extreme scores	Only one outlier	Met

Table 12: Test of normality (Kolmogorov-Smirnov) for anxiety and self-esteem data

	Significance
Spence Total	0.108
Rosenberg Total	0.200

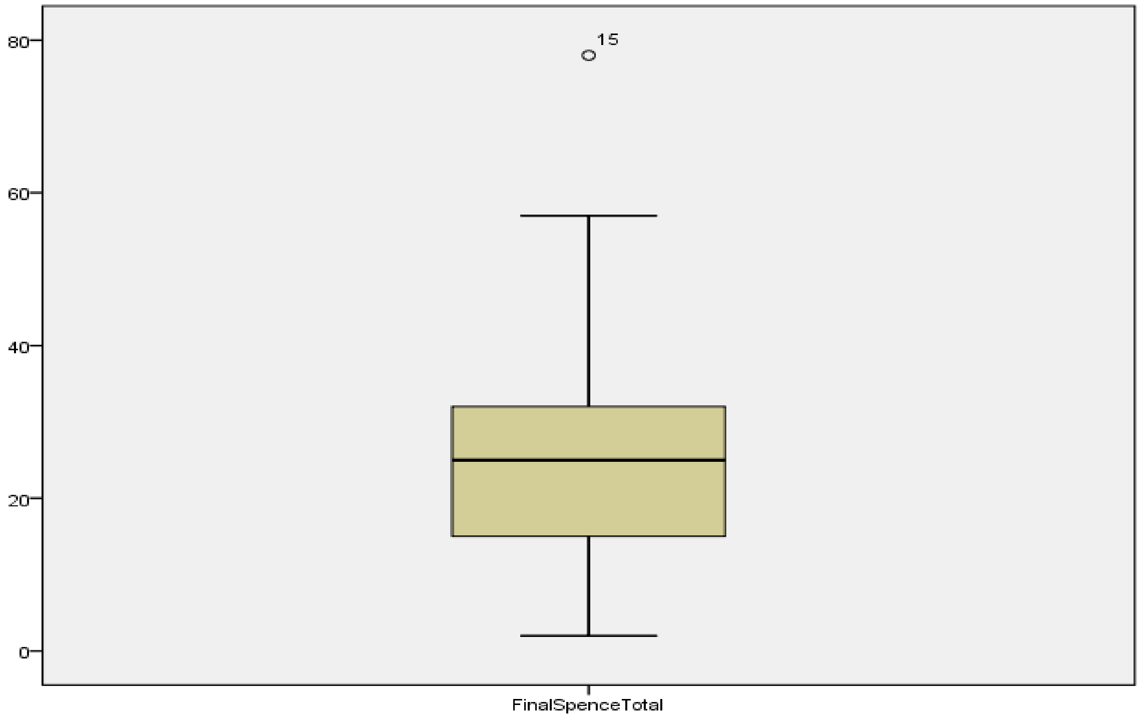


Figure 8: Box plot for anxiety data

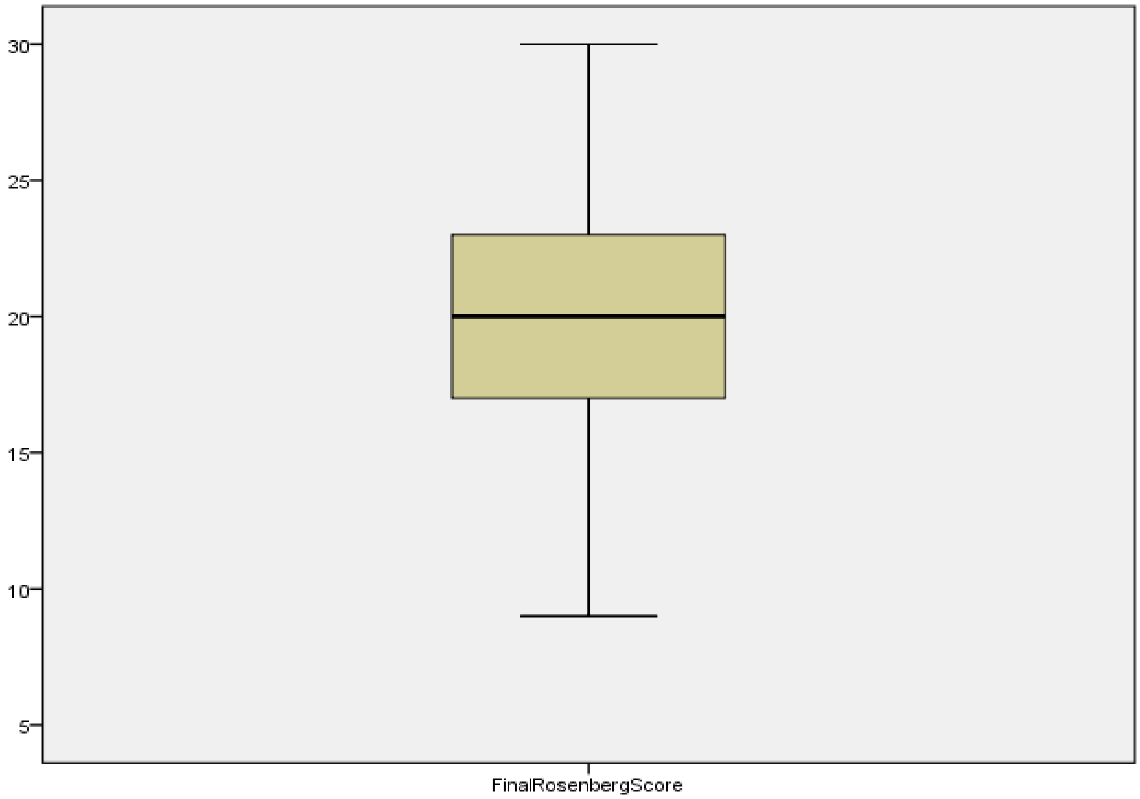


Figure 9: Box plot for self-esteem data

AIS reliability check: Data screening and analysis

Table 13: Data screening for first and second attempts at autistic identity scales

Parametric requirement	Result	Met?
Homogeneity of variance	130.4, 69.7	Yes
Scale level data	Yes	Yes
Normal distribution (Kolmogorov-Smirnov)	0.200, 0.200	Yes
No extreme scores	2 outliers on 1	Yes

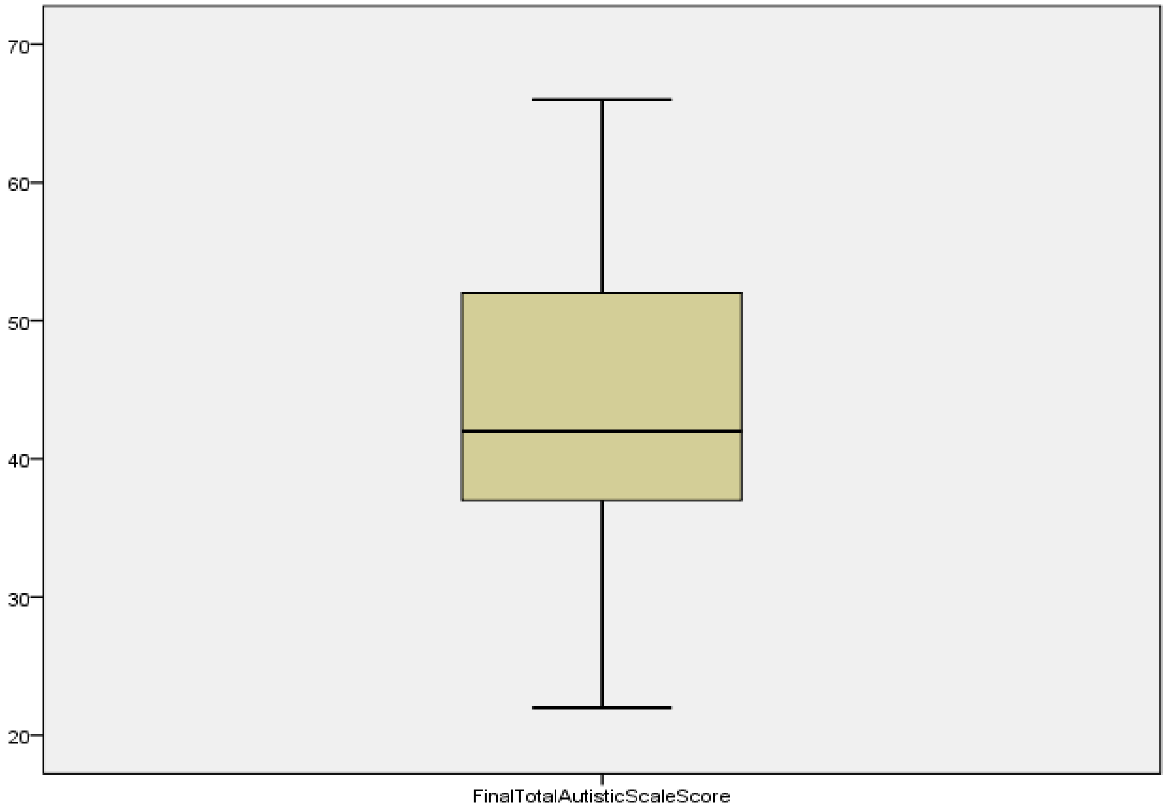


Figure 10: Box plot for first attempt at autistic identity scale

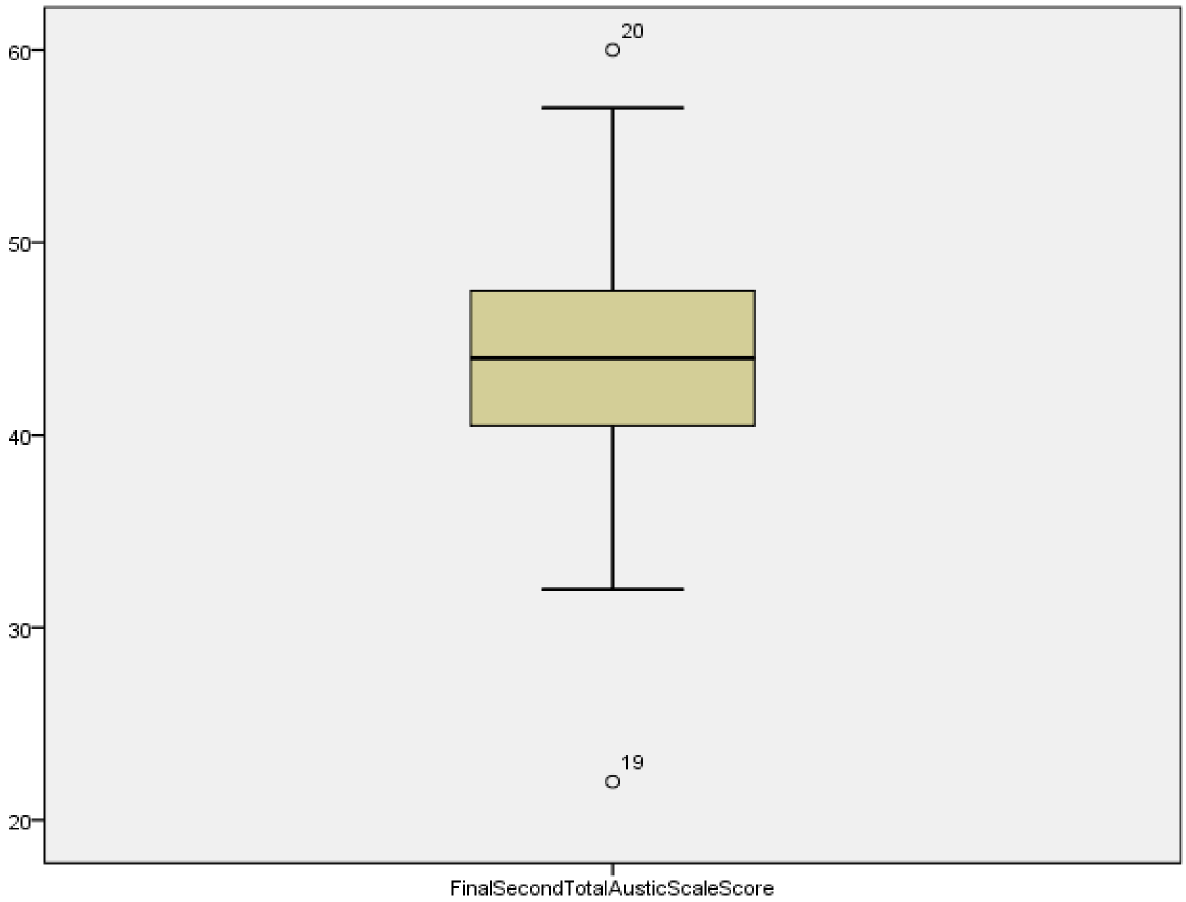


Figure 11: Box plot for second attempt at autistic identity scale

Table 14: Data screening for first and second attempts at non-autistic identity scales

Parametric requirement	**Result**	**Met?**
Homogeneity of variance	71.4, 57.5	Yes
Scale level data	Yes	Yes
Normal distribution (Kolmogorov-Smirnov)	0.200, 0.057	Yes
No extreme scores	Only 2 outliers on 1	Yes

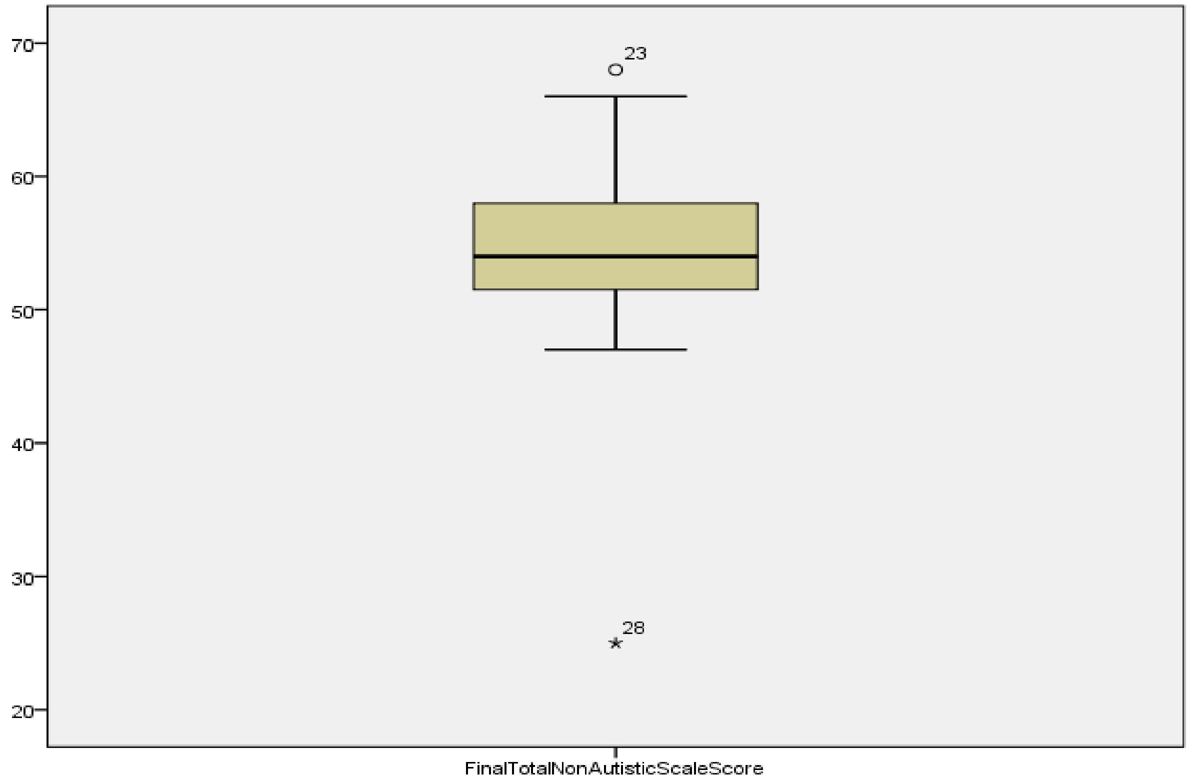


Figure 12: Box plot for first attempt at non-autistic identity scale

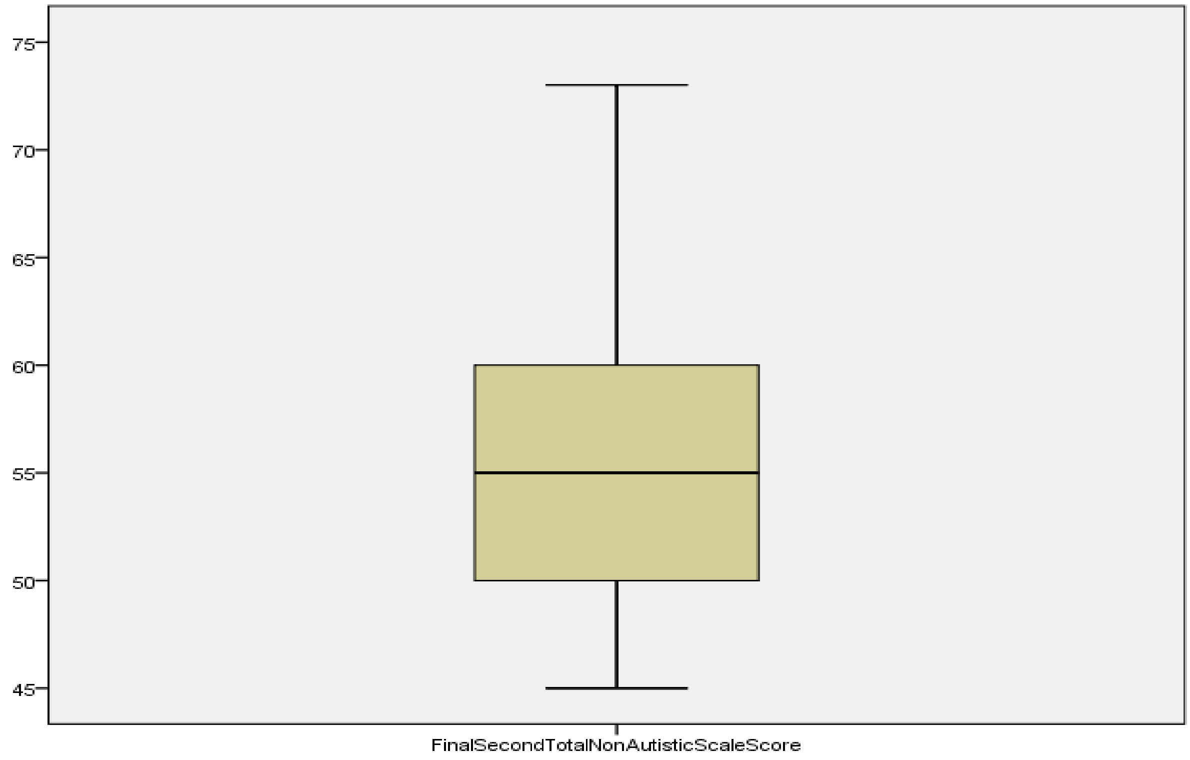


Figure 13: Box plot for second attempt at non-autistic identity scale

Table 15: Descriptive statistics for autistic identity scales

Scale	N	Mean	Standard Deviation (SD)
Total Autistic Scale Score	29	44.44	10.6
Total Second Autistic Scale Score	26	44.11	8.1

The scatter graph showed a positive relationship between participants' first and second autistic scale scores.

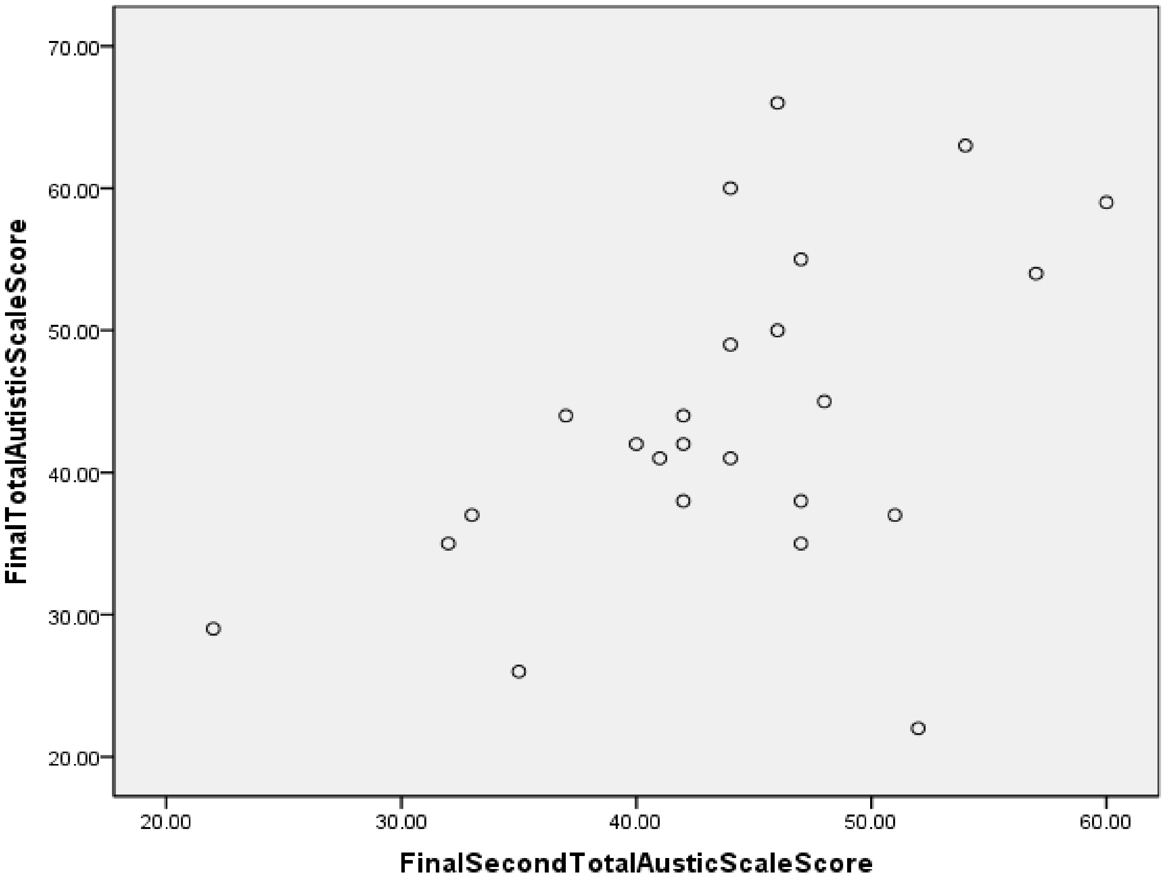


Figure 14: Scatter graph for first and second attempt at autistic identity scales

Table 16: Descriptive statistics for non-autistic identity scales

Scale	N	Mean	Standard Deviation (SD)
Total Non-Autistic Scale Score	28	54.60	8.3
Total Second Non-Autistic Scale Score	24	55.91	7.4

The scatter graph showed a weak, positive relationship between participants' first and second non-autistic scale scores.

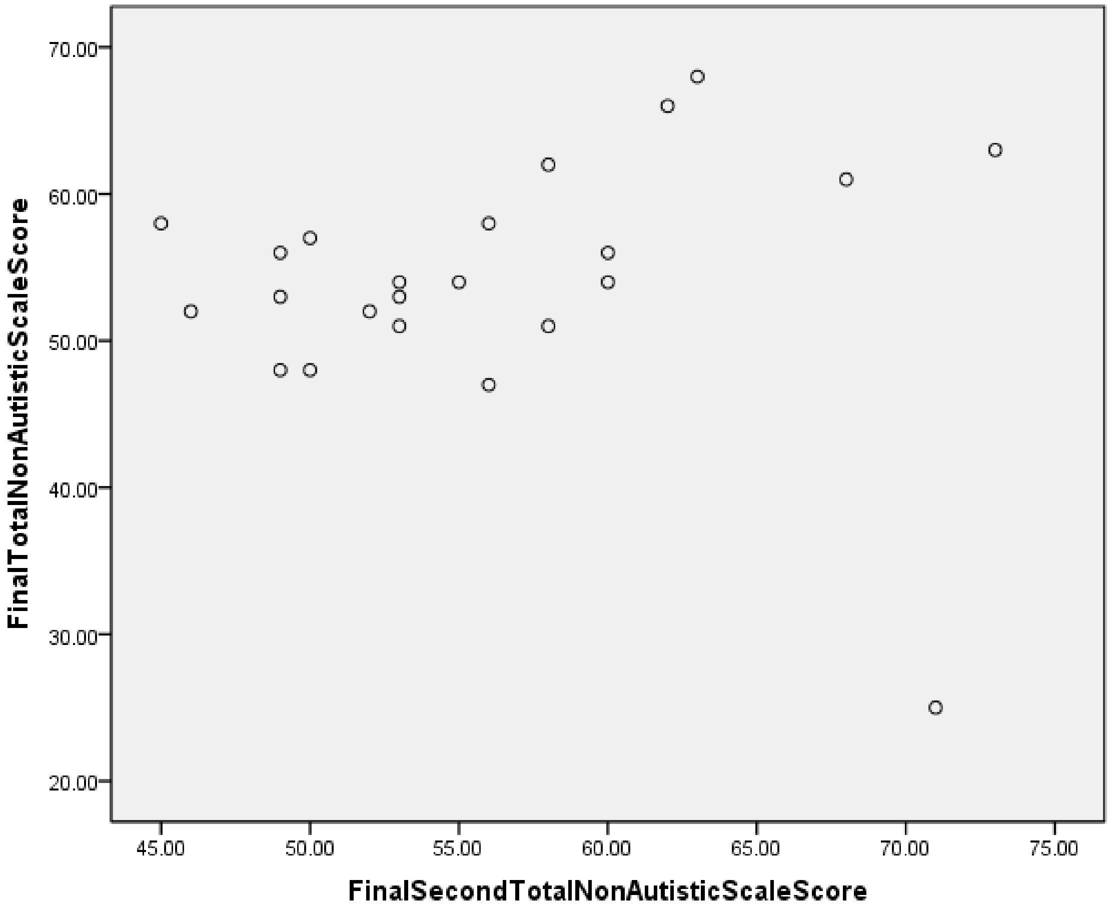


Figure 15: Scatter graph for first and second attempt at non-autistic identity scales

Inferential statistics

Table 17: Pearson's product moment correlation co-efficient inferential statistics

Scale	Significance (1-tailed)	Pearson Correlation
Autistic Scales	0.007	0.498
Non- Autistic Scale	0.450	0.027

Table 18: Related T-test inferential statistics

Scales	Mean	Std. Deviation	t	Sig. (2-tailed)
Autistic Scales	0.041	10.25	-0.020	0.984
Non-Autistic Scale	-1.82	11.20	-0.782	0.443

ANOVA: Data screening and descriptive statistics

Table 19: Separation of AIS data into seven deciles

Statistics

		FinalTotalAutisticScaleScore	FinalTotalNonAutisticScale Score
N	Valid	29	28
	Missing	2	3
Percentiles	14.28571429	35.0000	48.0000
	28.57142857	38.0000	51.2857
	42.85714286	41.8571	53.4286
	57.14285714	44.1429	56.0000
	71.42857143	50.4286	58.0000
	85.71428571	57.8571	62.8571

Marginalised type (1): Autistic scale: score of 42 or less Non-autistic scale: score of 53 or less	**Bicultural type (4):** Autistic scale: score of 45 or greater Non-autistic scale: score of 56 or greater
Assimilated type (2): Autistic scale: score of 42 or less Non-autistic scale: score of 56 or greater	**Separated type (3):** Autistic scale: score of 45 or greater Non-autistic scale: score of 53 or less

Table 20: Data screening for ANOVA

Parametric requirement	Result	Met?
Homogeneity of variance	135.3, 83.7, 289.4, 19.9	No
Scale level data	Yes	Yes
Normal distribution (Kolmogorov-Smirnov)	0.200, 0.192, 0.142, 0.200	Yes
No extreme scores	0, 1, 1, 2 outliers	Yes

Table 21: Descriptive Statistics for ANOVA

	Mean	Variance	Standard Deviation
Total Autistic Scale Score	44.2	135.3	11.6
Total Non-Autistic Scale Score	54.7	83.7	9.1
Total Spence Score	27.1	289.4	17.0
Total Rosenberg Score	19.5	19.9	4.4

Appendix thirteen

Participants’ AIS acculturation type, anxiety, and self-esteem scores

Table 22: Participants’ identity groups, Spence anxiety, and Rosenberg self-esteem scores

Participant	Identity type (decided upon by AIS score)	Spence anxiety score (…/114)	Anxiety rating from interview	Rosenberg self-esteem score (…/30)	Self-esteem rating from interview
(A5*)	Bicultural	38	Some	17	Medium-high
A34*	X	25	Some	20	Medium
A17*	Bicultural	14	Low-some	17	Medium
A38*	Bicultural	2	Low	30	High
A24	Marginalised	6	-	21	-
A1	Assimilated	-	-	19	-
(A22*)	Bicultural	32	Some	24	Medium
A11*	X	19	Low	24	-
(A28*)	Marginalised	11	Low	20	High
A40	Assimilated	45	-	18	-
A9	Separated	-	-	25	-
A25	Bicultural	31	-	19	-
A3	X	-	-	20	-
A30	X	50	-	14	-
A14	Separated	78	-	16	-
(A16*)	Separated	20	High	16	Low
(A12*)	X	28	High	-	Medium to high
A2	Marginalised	21	-	20	-
A20	Assimilated	28	-	22	-
A10	X	30	-	23	-
A23	Assimilated	25	-	22	-
A4	X	46	-	17	-
A7	Assimilated	10	-	16	-
A26	X	21	-	20	-
A6	X	21	-	9	-
A8	X	14	-	24	-

A13	Bicultural	15	-	26	-
A15	Marginalised	29	-	24	-
A18	X	57	-	12	-
A19	Bicultural	-	-	22	-
A21	X	30	-	-	-

Key:

***=** Interview participant

X = Incomplete AIS

(A16*)= Reported negative treatment

Paper Two

Paper two abstract

The aim of paper two was to explore the perceived contextual factors that relate to identity formation in autistic adolescents attending mainstream education provision. Eight participants (aged 11-16 years) with a diagnosis of autism from four mainstream secondary schools participated in a semi-structured interview. Additionally, twenty participants (aged 12-18 years) with no known diagnoses from the same four mainstream secondary schools participated in one focus group with four members. Thematic analysis was undertaken on the two data sets and then these were compared and contrasted to reveal a number of key similarities. Autistic students can be seen as going against the ‘norm’ and can be treated negatively by peers. Students were generally felt to lack understanding about autism and have limited means to find out about it in school. Participants without autism, and some with, reported a strong desire for students to have increased understanding of the condition. These findings are discussed in relation to literature exploring the role of schools in identity formation, with limitations and suggestions for further research included. The two papers conclude with a discussion regarding implications, in relation to theory, practice, and the role of the EP.

Paper two contents

Chapter 1: Introduction

Chapter 2: Methodology

Chapter 3: Findings

Word count: 9,412

List of tables for paper two

List of figures for paper two

1. Introduction

1.1 Rationale

There has been a call for further qualitative research in the field of autism (Carrington & Graham, 2001), along with the need to gather young people's views about contextual factors related to identity formation (Myers et al., 2011). This paper addresses this need by investigating the role of the school in identity formation, which is said to warrant further exploration generally (Flum & Kaplan, 2012; Sinai, Kaplan, & Flum, 2012) and within autism (Myers et al., 2011).

1.2 Review of literature

The important role of the school in identity formation stems back to Erikson's (1968) work and has continued to gain support (Flum & Kaplan, 2012; Israelite et al. 2002). It is based on the notion that the interaction a person has with their environment is central to their identity formation, with the school being a setting where adolescents spend a large proportion of time (Lannegrand-Willems & Bosma, 2006).

1.2.1 Understanding and awareness and disclosure of diagnoses

Roberts and Smith (1999) suggest students' attitudes about peers with disabilities are partly founded on their understanding of the condition. Research with non-autistic participants has shown understanding can be low (Campbell & Barger, 2011; Swaim & Morgan, 2001). An approach used to overcome this is to share diagnoses and information, motivated by a belief that greater understanding will result in others viewing behavioural traits as out of the person's control. Such a notion stems from attribution theory, which explores how a person's perceptions and beliefs about why something occurred affects their attitudes and behaviours

(Weiner, 1972). This is of particular interest in relation to identity as it has been suggested that whether someone feels marginalised can be influenced by the attitudes and behaviour of those around them (Sam & Berry, 2010). Research has shown that sharing information and diagnoses can lead to increased understanding and more positive responses (Chambres, Auxiette, Vansingle, & Gil, 2008; Ochs, Kremer-Sadlik, Solomon, & Sirota, 2001); however, it has also demonstrated the opposite (Huws & Jones, 2008; Swaim & Morgan, 2001). Despite these mixed findings, approaches that raise awareness of autism have gained popularity, with DVDs currently being used in every Australian school (Autism Awareness, 2014).

A criticism of a number of studies that directly look at the impact of teaching children about autism is their lack of external validity, something which has been overcome by research into the use of a Circle of Friends intervention (Gus, 2000; Whitaker, Barratt, Joy, Potter, & Thomas, 1998). Access to an EP forum indicates this approach is being utilised in the United Kingdom (UK) (EPNET, 2014). However the voice of the adolescent with autism is missing within Gus's (2000) study.

Similarly, Myers et al. (2011) advocated increasing knowledge about autism in schools but their work failed to seek the views of those with the condition. This occurs despite literature (Billington et al., 2000; Gilling, 2012) and legislation (Unicef, 1989) promoting the importance of such input. Studies exploring young people's views support earlier discussions of a possible relationship between negative responses and a lack of understanding (Punshon et al., 2009; Sciutto, Richwine, Mentrikoski, & Niedzwiecki, 2012). Nonetheless, the perspectives of non-autistic peers are absent (Campbell & Barger, 2011).

Research into whether young people with autism disclose their diagnosis remains limited, with further work called for by Huws and Jones (2008). Initial findings have revealed a reluctance due to fear of differentiated treatment or discrimination and that participants can distance themselves from an autistic identity (Baines, 2012; Humphrey & Lewis, 2008; Israelite et al., 2002).

1.2.2 Relationships with peers

Young people with autism can experience feelings of rejection and isolation within school, including bullying (Humphrey & Lewis, 2008; Kloosterman et al. 2013; Punshon et al., 2009). Flum and Kaplan (2012) suggest feeling part of a group is a fundamental aspect of identity formation and therefore those who feel isolated are unlikely to experience such feelings. There is limited research exploring this, although Bagatell (2007) found an autistic male experienced social isolation whilst constructing his identity in an environment that made it clear he was marginalised. Holland et al. (1998) argue “Persons look at the world from the positions into which they are persistently cast” (p.44), and Bagatell demonstrates the negative impact of this upon psychological wellbeing. Grotevant (1992) suggests problems with identity development can occur when society does not value characteristics that are out of a person’s control and this can result in difficulties, such as low self-esteem. Leigh (1999) warns this is in-built in inclusion practices.

In contrast, participants can value relationships with mainstream peers, including the diversity and feeling part of a group despite differences (Iantaffi et al., 2003; Leigh, 1999; Nikolaraizi & Hadjikakou, 2006). Nonetheless, research has shown strategic positioning within relationships and increased understanding can be important contributing factors (Humphrey & Lewis, 2008; Ochs et al., 2001).

Researchers have looked at the importance of spending time with minority peers and a number advocate for such opportunities after finding participants felt less isolated and had a shared understanding (Iantaffi et al., 2003; Leigh, 1999; Punshon et al., 2009). However, this evidence is often from participants with hearing impairments and relies on retrospective accounts (Leigh, 1999; Nikolaraizi & Hadjikakou, 2006). Furthermore, Bagatell (2007) found meeting autistic peers initially had a positive effect on the participant's identity and psychological wellbeing; however, once this new identity had been embraced he struggled around non-autistic peers. Similarly, Leigh (1999) discovered participants felt caught between two worlds, finding it a challenge to participate fully in either. Nevertheless, it is not known what the impact would have been if Bagatell's participant had met peers at school rather than outside.

1.2.3 Adaptations

Autistic participants have identified positive and negative evaluations of their teachers' approaches (Brewin, Renwick, & Schormans, 2008; Sciutto et al., 2012); however, how this affects their identity is rarely explored. Participants from minority groups disliked TA support when it highlighted them as different and some felt it could impinge on friendships (Humphrey & Lewis, 2008; Iantaffi et al., 2003). Nonetheless, TAs were also identified as reducing anxiety and incidences of bullying (Humphrey & Lewis, 2008).

A number of papers advocate benefits of contact with minority group role models, although in some cases this appears to come from the researchers rather than participants (Myers et al., 2011; Nikolaraizi & Hadjikakou, 2006). Furthermore, Leigh (1999) found only one participant who had not had such contact desired it. It could be argued that these participants were unaware of the advantages as over half of the participants in the Leigh's study spoke positively of the impact of role models.

1.2.4 Limitations identified within the literature

A review of the literature revealed three key limitations: a dearth of research into the role of the school in identity formation, particularly within autism; a lack of participant voice in papers that look at raising the profile of autism within schools (Gus, 2000; Myers et al., 2011); and limited perspectives from majority group peers (Huws & Jones, 2010; Punshon et al., 2009). The RQs, as well as the methodological choices outlined within the next chapter, aim to overcome this.

1.3 Research aim and questions

Aim

To explore the perceived contextual factors that relate to identity formation of autistic adolescents attending mainstream education provision.

Research questions (RQ)

RQ1: What are the views of adolescents with and without autism regarding contextual factors in their mainstream provision related to identity formation?

a) What are their views about understanding and raising awareness of autism?
b) What are their views about disclosing diagnoses?
c) What are their views regarding relationships with peers?
d) What are their views about adaptations made for young people with autism?

RQ2: What suggestions do these adolescents with and without autism in mainstream settings make in relation to changing provision as regards to autism identity formation?

2. Methodology

2.1 Research design

Qualitative methodology was selected because my interest was to find out how individuals experience events in relation to identity formation of autistic adolescents by seeking their perspectives (Willig, 2001). Placing importance on participant voice fits with my views and those of others in the field, that knowledge should be sought from the young people who know about it best (Billington et al., 2000).

The individual methods selected for use were of particular importance as an assumption of the constructivist stance is that interactions between the researcher and participants are key to the production of knowledge (Mertens, 2010). Semi-structured interviews and focus groups were deemed an appropriate method for achieving this. The use of two methods with a range of participants allowed for multiple perspectives to be explored.

2.2 Participants

Table 1: Participant information

	Interviews	Focus groups
Sampling and recruitment	• Participants were selected from paper one.	• Participants were selected by school staff.
Inclusion criteria	• Between 11and 18 years old. • Studying within the mainstream setting for 95% of the school day.	• As the interview criteria except for participants had no formal diagnoses.

	• A formal diagnosis of autism that they know about.	
Participant details (appendix one)	Four mainstream secondary schools from paper one were selected.	
	• Eight male students with a diagnosis of autism aged 12 to 16 years with a mean age of 13.75.	• Twenty students (11 males, 9 females) aged 12 to 18 years. • Each group contained four participants and myself.

2.3 Data collection materials

A semi-structured interview schedule was created using hierarchical focusing, as proposed by Tomlinson (1989), mirroring paper one. The schedule was created from themes identified within the literature (see appendix three).

Focus group questions were developed from the interview schedule (see appendix four). Focus groups were selected to capture multiple viewpoints and opinions through discussion (Litosseliti, 2003; Wilkinson, 2008).

2.4 Procedures

Piloting: The semi-structured interview and focus group schedules were piloted once and minor amendments were made (appendix five). Additional piloting was not possible due to the limited participants available.

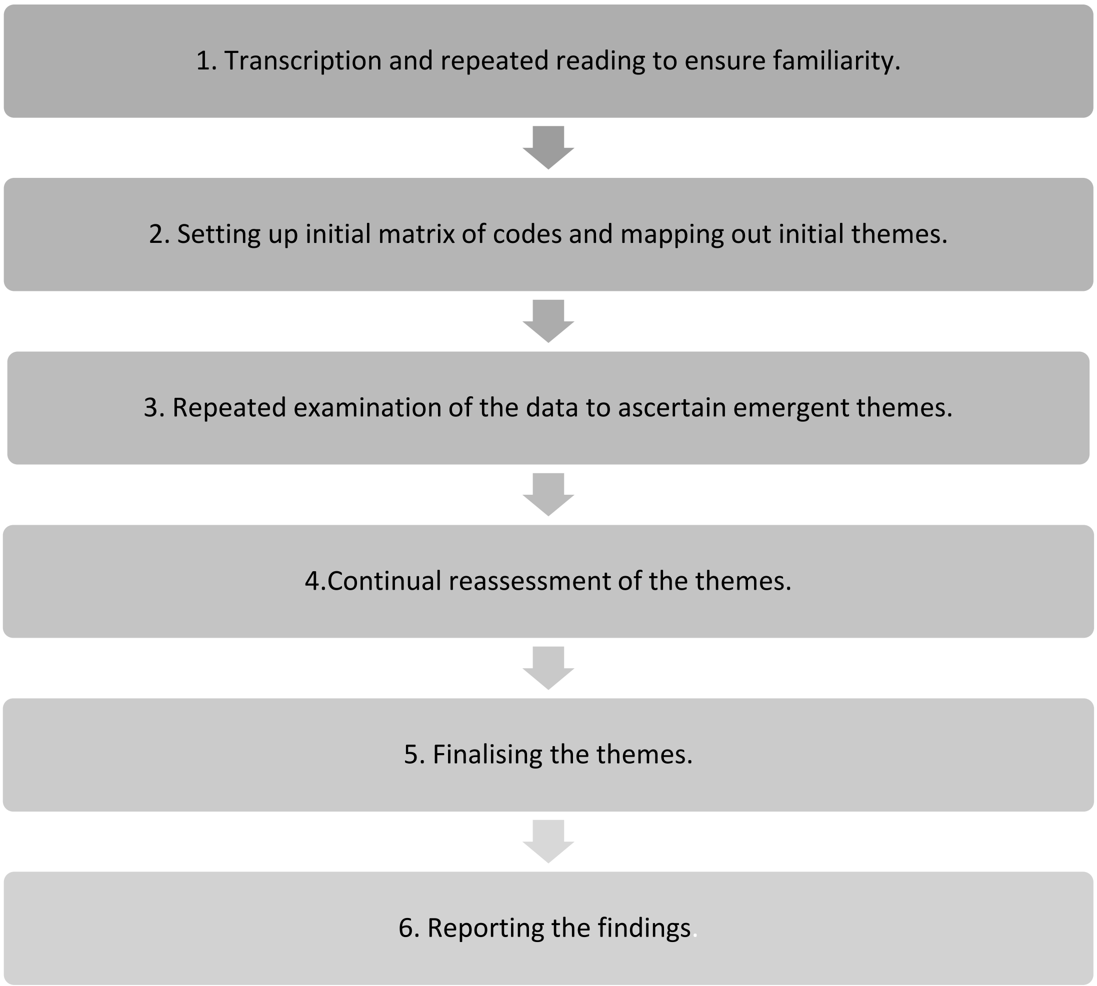
Semi-structured interviews: Each interview was audio recorded and lasted 30-50 minutes. Strategies put in place to support participants in paper one (see p.28) were mirrored here. Resources used to elicit discussion are listed in appendix two.

Focus groups: Each session followed the same structure (see appendix four), was audio recorded, and lasted one hour to fit with school timetables.

2.5 Data analysis

Thematic analysis:

The two data sets were analysed individually using thematic analysis. This followed a series of planned stages as recommended by Braun and Clarke (2006) (appendix seven and eight provide examples of each stage):



1. Transcription and repeated reading to ensure familiarity.
2. Setting up initial matrix of codes and mapping out initial themes.
3. Repeated examination of the data to ascertain emergent themes.
4.Continual reassessment of the themes.
5. Finalising the themes.
6. Reporting the findings.

Figure 1: Stages of thematic analysis

2.6 Credibility

Interview participants were given the opportunity to check their transcript before analysis to ensure it had captured their thoughts accurately, as recommended by Mertens (2010). This was important as some data was removed to protect participants' anonymity. The approach was not replicated with the focus group transcripts as schools had concerns with groups of students being absent from lessons.

2.7 Ethical considerations

All of the ethical considerations from paper one were adhered to. Materials specific to paper two can be located in appendix six.

To reduce the disruption to participants' timetables, two focus groups were chosen from pre-defined groups, such as peer mentors, who already had time available to meet as a group.

3 Findings

3.1RQ1 findings

The data below emerged following thematic analysis of the interview and focus group data. Summaries for each are presented at level one sub-themes with illustrative data. A full hierarchy of the final themes and an outline of the stages of analysis can be found in appendices seven and eight.

RQ1a: What are participants' views about understanding and raising awareness of autism?

The tables below provide a summary of the themes which emerged in relation to participants' views on understanding and raising awareness of autism. Findings are presented for autistic participants followed by non-autistic participants.

Autistic participants

Theme 1: Understanding of autism

Level one sub-themes	
Students' understanding	**Summary:** Limited knowledge about peers' understanding of autism, although one felt this was low. Peers having an understanding was only important to two participants.
	Illustrative data: *"I don't really know"* (A34 and A12). *"Nowhere near enough*" (A17).
Staff understanding	**Summary:** Limited knowledge about staff understanding of autism although staff having such knowledge had some value. One participant thought staff knowledge was too low.

	Illustrative data: *"I'm not really sure really…"* (A11). *"I ..guess so…..then I can ? (inaudible) they understand what autism is"* (A14). *"…no way near enough understanding as they should*" (A17).

Theme 2: Autism resources and information

Level one sub-themes	
Resources and information available in schools	**Summary:** Limited means for finding out about autism in schools; using the internet and asking someone are the most common (see appendix nine for full list).
	Illustrative data: *"They could find out if people...if you tell them…"* (A11). *"I…think they learn that from their mums and dads"* (A14). *"They just can't generally"* (A17).
Discussions about autism in school	**Summary:** Autism is rarely spoken about within school (two participants).
	Illustrative data: *"Nobody really likes to talk about it"* (A5).
Evaluation of autism resources and information	**Summary:** Having autism resources in school was felt to be important by more participants than not, although not highly important. Autism can be presented poorly in the media (two participants) and this can impact on disclosure.
	Illustrative data: *"…it would be useful but I wouldn't say number one important…"* (A28). *"…Wikipedia there is an article about all the lists sort of people they know of that might have had autism and about half the list is sort of serial killers murderers…so that was*

	probably one of the reasons I didn't mention it for ages" (A5).

Non-autistic participants

Theme 1: Understanding of autism

Level one sub-themes	
Students' ideas about autism	**Summary:** Autism is defined in terms of strengths, difficulties, and differences. Definitions can include a negative tone.
	Illustrative data: *"I knew something was wrong with him…"* (S12). *"…makes you take things more literally…"* (S13). *"They might be very clever"* (S17).
Students' level of understanding	**Summary:** Student understanding of autism is felt to be low and can contain stereotypes, believed to be demonstrated by negative treatment of autistic students. Having relatives with autism; age; and time spent with peers with the condition were felt by some to relate to understanding.
	Illustrative data: *"…no not very much"* (S1 & S2). *"Just cos like mostly people just like tease them and stuff…"* (S3). *"I think it's pretty good because I've XXXX autistic people and I know what their experiences are like…"* (S6).

Staff understanding	**Summary:** Staff understanding is generally perceived to be good in comparison to students, although it is thought to differ depending on their role, experience, and training. In contrast, one participant reported an example of poor knowledge being demonstrated.
	Illustrative data: *"I think they know more than us…"* (S5). *"I think it depends who you ask…"* (S10). *"…one of the teachers had a go at him showing that she didn't understand anything to do with it…"* (S6).
Evaluation of the level of understanding in school	**Summary:** Increased understanding will lead to positive outcomes, including better treatment of autistic students.
	Illustrative date: *"…I think if someone knew they had autism they would like stop bullying…"* (S10). *"…it explains to people who normally get quite frustrated with….something you find unordinary happens"* (S14).

Theme 2: Autism resources and information

Level one sub-theme	
Methods for finding out about autism	**Summary:** Discussions and means for findings out about autism in schools are limited or not widely advertised. Information was generally obtained by participants from family, friends, and the media.
	Illustrative data: *"… they don't teach it very often…"* (S5). *"I've heard of it on the tele…"* (S11). *"No one talks about it…"* (S7). *"It is definitely more of a personal thing that is kept quite…"* (S9).

RQ1b: What are participants' views regarding disclosing diagnoses?

The following tables provide a summary of the themes which emerged in relation to participants' views on disclosing diagnoses. Findings are presented for autistic participants followed by non-autistic participants.

Theme 3: Disclosing diagnoses

Autistic participants

Level one sub-themes	
Adults knowledge of their autism	**Summary:** Some staff are reported to have knowledge about participants' diagnoses, including from emails and registers, and when they do this is said to be a positive thing. One felt adults did not pay enough attention to information.
	Illustrative data: *"…I believe it is on their register…"* (A5). *"…one or two teachers that know um one or two basic things…"* (A38). *"…some of the teachers just don't bother reading them (emails)….which I find annoying…"* (A17).
Disclosing their diagnosis	**Summary:** Participants are not always clear who knows about their diagnosis and the control they have over this, although teachers are felt to know more often than peers (see appendix nine). Participants generally do not mind if diagnoses are known about although fear of negative treatment and embarrassment were reasons for not disclosing or being cautious. Some disclose to friends or to stop others bothering them.

	Illustrative data: *"…I'm not really sure…"* (A38). *"…you don't tell them and they just keep on asking and asking again then you might as well just tell them…"* (A11). *"…no it doesn't really matter ……but it matters is it feels more like embarrassment ….a little bit"* (A14).
Knowledge of others' diagnoses	**Summary:** Participants sometimes find out about peers' diagnoses and this is through family members or being disclosed to.
	Illustrative data: *"I heard it from their parents"* (A34). *"…he did just say that he had Asperger's…"* (A11).

Non-autistic participants

Level one sub-themes	
Knowledge of who has autism	**Summary:** Participants do not know whether any staff have autism and some felt it is unlikely this information would be shared. In contrast, most thought they knew at least one peer with autism, although often not well enough to be sure they have a diagnosis.
	Illustrative data: *"I: Does anyone know any adults at school with autism?* *Multiple S: no no"* *"I think there is a couple of people in my year but I am not really friends with them…"* (S8). *"I think I have someone with autism in my form…"* (S9).
Disclosure of peers' diagnoses	**Summary:** Participants generally identify autistic students through traits they perceive to be related to the condition as peers and teachers generally do not disclose and participants would not ask. Diagnoses are often seen as private and something

	that peers may not want to share due to fear of negative treatment and that teachers should only disclose when they have a good reason, e.g.- bullying.
	Illustrative data: *"I don't know if it is autism or…but I think it probably is because there…sometimes they have a short temper…"* (S3). *"I wouldn't want to ask them…"* (S2). *"…they might not want people to know because of like bullying and things"* (S18). *"…if people start to be like nasty to them or something then teachers should tell them not to be nasty and then like sort of try to explain it briefly…"* (S1).

RQ1c: **What are participants' views regarding relationships with peers?**

The following tables provide a summary of the themes that emerged in relation to participants' views on relationships with peers.

Theme 4: Relationships with peers

Autistic participants

Level one sub-themes	
Being normal	**Summary:** Behaviour of autistic students can be seen as abnormal which can relate to a lack of understanding. One participant tried to fit in whereas another questioned others' definitions of normality. One participant felt they got on fine despite their differences.
	Illustrative data: *"…you start like jumping around they're like is this child gone mad…"* (A11). *"…I tried to be like them as possible but…. I just couldn't really"* (A14). *"…they would know why I act so strange but….well strange through their eyes…"* (A5).
Friendships	**Summary:** Participants generally have friends with and without the condition although many do not appear confident making friends with peers without autism is easy. One participant was unsure as they feel labels are not relevant to them. Personalities, rural living, and the role of the school can impact on friendships.

	Illustrative data: *"…it's the person's personality…"* (A12). *"…X (teacher) told me to come into his office and then I came in and I saw X (student with autism) and then um….then X asked me all the stuff that he likes and all the stuff that I like and he basically likes the same stuff as I do"* (A11). *"…the problem is most of my friends live in X and I live sort of 10 odd miles away"* (A5).
Opportunities to meet and spend time with peers with autism	**Summary:** Participants generally know autistic students, with lessons and SEN areas the most common ways to meet. Half valued such opportunities, including spending time with others who could be identified with.
	Illustrative data: *"I: Is it important to you be able to meet other students with autism?* *A34: Not really"* *"…it is like ok to meet somebody that could understand you…"* (A11). *"I go to X (SEN area) where a lot of people with autism or social problems come …."* (A38).
Opportunities to meet and importance of spending time with peers without autism	**Summary:** Opportunities to meet peers without autism comes through lessons, clubs, and social media. Participants generally felt these opportunities are not important or were unsure about this. Reasons included: labels do not matter and not knowing life without such opportunities.
	Illustrative data: *"…no I mean just…the important thing for me is just generally spending time with people…* (A28). *"Well I do it all the time…"* (A38).

Treatment from peers	**Summary:** Participants generally reported they are treated the same whether people know about their autism or not; however, they can be seen as naughty or strange. Negative treatment towards autistic students occurs and participants had mixed feelings as to whether staff know about or stop such treatment.
	Illustrative data: *“Most people treat me exactly the same way”* (A17). *“I think the people who are bullying people with autism just do it for fun…”* (A12). , “*…they sort of think of me as slightly as being slightly strange…”* (A5). *“...they (teachers) would call that person in and start talking to them…”* (A11). *“….teachers don’t really do anything about it…”* (A12).

Non-autistic participants

Level one sub-themes	
Normal vs different	**Summary:** Autistic students are perceived by some participants to behave differently and go against the ‘norm’, although this does not necessarily lead to negative treatment. Lack of understanding was felt to play a role in such perceptions. Autistic students are perceived to try hard to fit in. One participant felt autistic students would want to be the same as mainstream peers to the extent they would not want to have autism anymore.
	Illustrative data: *“…it is odd you know erm…he bought a colander……(words removed) yeh and they wear colanders…”* (S13).

	"*He was quite well liked though…"* (S18). *"…I think it would people would think it is more normal…(if more teaching about autism took place)"* (S18). *"cos they probably all want to be like the same as us instead of having like a autism…"*(S3).
Opportunities to meet and spend time with peers with autism	**Summary:** Participants had mixed feelings regarding the ease of meeting autistic students. Knowledge of diagnoses, friendships, and year groups are perceived to play a role.
	Illustrative data: *"I guess it would be if they were there and you had to be with them like at the start of like? (inaudible) you join a form group…"* (S12). *"yeh I think (it is difficult)…like I said it's just kind of it would be a little bit harsh to…assume…"* (S2). *"Well yeh I'd say so (it is easy)"* (S14).
Treatment of peers	**Summary:** Autistic students are generally perceived to be treated differently when others know about their diagnosis, including negative treatment and notions of help and sympathy. Age; understanding; presence of a TA; and relationships with the student are felt to impact on such treatment. Non-autistic participants can be fearful of doing or saying the wrong thing around autistic students, thought to be related to low levels of understanding.
	Illustrative data: *"…people might look at you a bit differently…"* (S2). *"…like help them and um be nice to them…"* (S1). *"…people in my tutor think they know he's got autism and just try to make him do it because they think it's funny"* (S3). *"…maybe we wouldn't be as conscious when talking to them if we know more about it…"* (S11). *"I can't talk to them as much as I don't want to offend them…"* (S10).

RQ1d: What are participants' views about adaptations made for young people with autism?

The following tables provide a summary of the themes that emerged in relation to participants' views on adaptations made for autistic students.

Autistic participants

Theme 5: Adaptations

Level one sub-theme	
Adaptations made due to autism	**Summary:** TA support and access to SEN areas are the most common adaptations.
	Illustrative data: *"Support"* (A12). *"Go to X (SEN area)"* (A14).

Theme 6: Relationships with staff

Level one sub-themes	
Knowledge and opportunities to meet adults with autism	**Summary:** Participants do not know any staff with autism and this is not important to them, although one thought it might be beneficial.
	Illustrative data: *"No"* (multiple participants). *"… if I was in year X or X and going to try and find a job maybe it would be interesting to see how other adults with Asperger cope…"* (A38).
Treatment from staff	**Summary:** Participants have mixed experiences of whether they are treated differently by staff and whether they like this. Benefits of differentiated treatment include, extra help and increased flexibility in lessons.

	Illustrative data: *"...sometimes give me a little bit more help"* (A28). *"…they all treat me the same"* (A34). *"I don't want to be treated differently…"* (A17).

Non-autistic participants

Theme 5: Adaptations

Level one sub-themes	
Adaptations in place	**Summary:** TA support; SEN areas; and teachers' differentiated approach were the most common adaptations reported. Teachers' differentiation includes: additional help; flexible sanctions; a sympathetic approach; and being careful about what is said. A lack of differentiation is felt to relate to poor understanding or an equal treatment for all ethos.
	Illustrative data: *"…a special area that they can go to at lunchtime…"* (S1). *"They'll be in lessons but they'll have a helper …"* (S15). *"…they kind of treat him better so like if he ran away from a detention they wouldn't like go… ape at him"* (S7). *"…if they were in trouble they would treat them like anyone else…there are some teachers that wouldn't want to understand better…"* (S6).
Evaluation of adaptations	**Summary:** TA support is felt to have advantages and disadvantages for autistic students. Disadvantages include: risk of bullying; pressure to behave; and reduced opportunities for peers to socialise with them in lessons. TA support can result in the separation of autistic students, along with SEN areas.

	Illustrative data: *"…you're not going to socialise as much because… they have got an adult with them"* (S11). *"I think it's good to have support for them…"* (S2). *"…why have they got a person going around with them what's wrong with them"* (S10). *"…they are not with you when you eat lunch and they are always like in their little section…"* (S15).

3.2 RQ2 findings

RQ2: What suggestions do these adolescents with and without autism in mainstream settings make in relation to changing provision as regards to autism identity formation?

The following tables provide a summary of changes suggested by autistic and non-autistic participants in relation to the themes discussed above.

Autistic participants

Theme	
Understanding of autism	**Changes:** • More information about their own autism and peers with it (one participant). • Increase students' understanding of autism to ensure better treatment of students with the condition (two). • Increase staff understanding (two), although one felt unsure this would result in any change.
	Illustrative data: • *"…it would be helpful if I know a bit more"* (A5). • *"…I think they'd stop really if they knew what Asperger's is like…"* (A11). • *"…I would…get them to understand…"* (A17).
Autism resources and information	**Changes:** • Posters; more books, assemblies, and lessons on autism; and access to reliable information (one-two participants each). • Participants reflected on how effective the resources would be and questioned how motivated students would be to access them.
	Illustrative data: • *"…maybe if there was some books there we might have a look…"* (A38).

	- *"…some people just don't really ….notice about the posters and stuff because they don't really ….don't really want to look at it"* (A14).
Disclosing diagnoses	**Changes:** - More control over who knows about their diagnosis due to a fear of negative treatment if the information was used in the wrong way (two).
	Illustrative data: - *"Yeh I would like more control"* (A5). - *"…if some people know they use it as a bullying tool"* (A12).
Relationships with peers	**Changes:** - Increased information about clubs to meet peers with shared interests and more opportunities to meet autistic students face to face (one). - Adaptations to bullying sanctions (one).
	Illustrative data: - *"…the problem is though that most of the people at this school don't really like what I like…."* (A5). - *"… I wish I know a little bit more because the problem is though is the fact is I personally only know three people who have autism one of them I have never met…"* (A5). - *"…the people who just bully with people with disabilities keep them in room X…"* (A12).
Adaptations	None reported.
Relationships with staff	**Changes:** - No direct suggestions for change although comments suggest opportunities to meet adults with autism might be beneficial for some.
	Illustrative data: - *"If there were some then I would talk to them but there aren't so there is not much to change…"* (A17).

Non-autistic participants

Theme	
Understanding of autism	**Changes:** - The majority want to increase student understanding, including: how to treat people with autism; key facts; traits; and causes of the condition. - Participants generally agreed that teachers should know about autism and training was the most frequently suggested method.
	Illustrative data: - *"I don't think it's right that we don't seem to know much about it…"* (S9). - *"…how to recognise if someone who has autism…"* (S8). - *"…I think they should all be trained…"* (S4).
Autism resources and information	**Changes:** - Having ways to find out about in autism in school is important (three groups). - Issues related to raising awareness: limited time to read information; poor behaviour in certain lessons and larger groups which would be difficult for staff to manage; and some sessions are too short or do not provide opportunities to ask questions, such as assemblies. - Varying views between and within groups on the above issues suggests the approach would need to be carefully tailored. Over a quarter felt autistic students should be consulted first. - Popular suggestions to raise awareness: direct teaching in Personal, Social, and Health Education (PSHE) lessons or equivalent; TV/DVD clips; student mentors with knowledge about autism; and guest speakers (see appendix nine for full list).

	• Use of a casual approach to ensure students become comfortable and relaxed in their approach to autism (one group).
	Illustrative data: • *“…if someone wants to find out more about autism then they should be able to”* (S8). • *“I think they (staff) need to understand that we need to know as well”* (S16). • *“Say somebody laughs in assembly the whole assembly will start laughing…”* (S7). • *“…someone with autism who was older came into the school and talked about it and like how they feel about it…”* (S10). • *“being casual about it helps cos if you treat it really seriously then people are going to be uncomfortable…”* (S13).
Disclosing diagnoses	None reported.
Relationships with peers	**Changes:** • An opportunity to find out how autistic students feel (one). • The importance of allowing students to meet each other naturally and create genuine friendships (raised within one group). • Use of peer mentors and a clear system of punishment in conjunction with awareness raising (one).
	Illustrative data: • *“….maybe know a bit about how they actually feel”* (S2). • *“ ...I don’t think they want to be pushed cos then they don’t know how to cope with it I think you need to sort of approach them in their own time”* (S16). • *“…they could help stick up for them if people start to be nasty to them…* (S1).

Adaptations	**Changes:** - A reduction in the separation of autistic students for those that want it through greater mixing at lunch time and reducing TA support and the number of separated lessons. - Changes to adaptations: introducing key adults or students for autistic students to go to if they need help; explaining the TA role to all students; and developing quiet areas for autistic students. In contrast, one group felt decisions regarding adaptations should be made by autistic students. - Suggestion for changes to teachers' approach: support to be provided to all students as and when needed so autistic students are not singled out (one group).
	Illustrative data: - *"…some of them wouldn't want to sit and eat lunch with everyone else but I am sure some people could…"* (S15). - *"…I think it would (help if TA role was explained) because they wouldn't always think oh why have they got a helper…"* (S9). - *"…perhaps ask everyone in the class if they need any extra help then that would give them the opportunity to put their hand up and ask for help"* (S17).

3.3 Summary of findings

The tables below provide a summary of key similarities and differences in the findings from autistic and non-autistic participants to highlight areas of agreement and conflict.

RQ1a and 2: What are participants' views about understanding and raising awareness of autism, including suggestions for change?

Similarities	Differences
• Participants from both groups believe student understanding is low and call for this to be improved (although non-autistic participants to a much greater extent). • Means for finding out about autism in school are limited or poorly advertised; asking staff is one of the main ways. • Autism is often not spoken about in schools (discussed in greater depth by non-autistic participants). • There was some agreement that increasing understanding would lead to better treatment and perceptions of autistic students. • Both felt methods used to teach students about autism need to be carefully considered.	• Non-autistic participants thought staff understanding was generally good, most autistic participants were unsure. • All non-autistic participants felt teachers should have an understanding of autism whereas autistic participants appeared less concerned about this. • Two autistic participants identified autism could be presented poorly in popular media. • Some autistic participants are sceptical increasing understanding would alter behaviour.

RQ1b and 2: What are participants' views about disclosing diagnoses, including suggestions for change?

Similarities	Differences
• Some autistic students do not disclose their diagnosis due to fear of negative treatment. • Few autistic participants thought peers would know about their diagnosis and this was confirmed by non-autistic participants.	• Most non-autistic participants thought students would want to keep diagnoses private but seven/eight reported it did not matter if people knew.

RQ1c and 2: What are participants' views regarding relationships with peers, including suggestions for change?

Similarities	Differences
• Behaviour of autistic students is seen by some students as strange. • Participants do not know any adults in school with autism. • Negative treatment of autistic students occurs.	• Most autistic participants felt they were treated the same if peers knew about their autism but most non-autistic participants disagreed.

RQ1d and 2: What are participants' views about adaptations made for young people with autism, including suggestions for change?

Similarities	Differences
• Both discussed adaptations, such as TAs and SEN areas. • More participants perceive teachers differentiate their approach for autistic students than those who do not. • Separation of autistic students occurs (although non-autistic participants discussed this to a much greater extent).	• Autistic participants appeared satisfied with adaptations made for them whereas non-autistic participants felt these had some disadvantages. • Autistic participants did not suggest any changes whereas non-autistic participants did. These included: reducing separation; explaining the TA role; and ensuring adult support was only given when required.

4. Discussion

4.1 Summary of findings related to the literature

4.1.1 RQ1a and 2: Understanding and raising awareness of autism

Many participants thought students lacked knowledge of autism. This was especially the case for non-autistic participants, who also thought teachers understood autism better than students. Non-autistic participants had some knowledge of autism, although a number held false beliefs and most lacked confidence in what they knew, as found previously (Campbell & Barger, 2011; Gus, 2000; Swaim & Morgan, 2001). Non-autistic participants felt knowledge and treatment would be better in students who had increased contact with autistic peers. This supports contact theory (Allport, 1954) and confirms previous findings (Mavropoulou & Sideridis, 2014).

Both autistic and non-autistic participants called for an improvement in student and staff understanding. This assumed that increased understanding would improve acceptance and responses towards autistic students, consistent with attribution theory (Weiner, 1972). This concurs with past research that calls for better understanding to improve attitudes and responses (Brewin et al., 2008; Connor, 2000; Sciutto et al., 2012). Such a belief is supported and refuted within past research; however, participants' desire to know more was not solely related to trying to reduce negative treatment.

There is little research exploring current school provision for raising awareness. Means for finding out about autism were perceived to be limited, with asking staff the most common. This concurs with findings from research within other conditions (Connors & Stalker, 2007). Autistic participants proposed the use of books and assemblies whereas non-autistic participants reported a preference for discussion based lessons or DVDs, approaches found to be successful

(Barratt, 2006; Chambres et al., 2008; Gus, 2000). Nonetheless, a number indicated implementation needed to be carefully considered and tailored to classes and schools, supporting past research (Barratt, 2006; Gilling, 2012; Pukki, 2006). For staff, increased training was considered appropriate (Brewin et al., 2008; Dybvik, 2004; Sciutto et al., 2012).

Two autistic participants described the poor presentation of autism in popular media, which is supported by evidence (Jones & Harwood, 2009). This affected one participant's willingness to disclose and caused him concerns that peers constructed their definitions of the condition from this poor portrayal, something proven true (Farnall & Smith, 1999; Haller, Dorries, & Rahn, 2006).

4.1.2 RQ1b and 2: Disclosing diagnoses

Most non-autistic participants thought students would want to keep their diagnosis private, many suggesting they would not want to disclose, implying some stigma. In contrast, all but one autistic participant reported it did not matter if people knew. However, this may be because of the need to provide an explanation for their behaviour, as found previously (Punshon et al., 2009). There was also a fear of negative treatment from disclosure and a need for some control over who knew. These findings contradict evidence which reports attempts to hide diagnoses (Baines, 2012), although confirms research which indicates participants can have mixed feelings about disclosure (Humphrey & Lewis, 2008; Huws & Jones, 2008). Non-autistic participants felt adults should only share students' diagnoses with a valid reason. Some identified peers by behavioural traits instead.

4.1.3 RQ1c and 2: Relationships with peers

Autism as a difference from the ‘norm’ and autistic behaviours as strange was discussed by participants from both groups. A number of non-autistic participants felt peers often wanted to appear ‘normal’, including the use of humour to fit in. One even felt they would want to be ‘normal’ to the extent they no longer had autism. In contrast, the desire to be ‘normal’ or fit in was only raised by one autistic participant. Half indicated autistic behaviours were viewed as different or strange, although they did not generally comment on masking this. Non-autistic participants’ views confirm previous findings (Baines, 2012; Humphrey & Lewis, 2008; Punshon et al., 2009), but autistic participants’ views do not.

Only two autistic participants appeared confident about making friends with non-autistic peers, adding to evidence that developing friendships can be difficult for this population (Church, Alisanski, & Amanullah, 2000; Orsmond, Krauss, & Seltzer, 2004). Despite this, participants did not report feelings of isolation. All indicated they had friends, although one wanted to meet more peers who shared interests.

All but one autistic participant knew at least one peer with the condition, most frequently through lessons and SEN areas. Half valued such opportunities, including the shared understanding found previously (Iantaffi et al., 2003; Jones, Huws, & Beck, 2013; Punshon et al., 2009). Three participants identified the facilitating role of the school in friendships, as in Bauminger and Kasari (2000). Participants did not report feeling caught between two identities by spending time with both groups. Instead, opportunities to meet with autistic peers may be a protective factor against isolation, as in Jones et al. (2013). This conflicts findings by Bagatell (2007) and Leigh (1999).

Whilst autistic participants felt they were treated the same whether peers knew about their diagnosis or not, non-autistic participants generally disagreed. Negative treatment and bullying of autistic students was discussed by participants from both groups with some suggesting interventions such as peer mentoring, used successfully in the past (Banerjee, Robinson, & Smalley, 2011; Mentoring & Befriending Foundation, 2010). This concurs with governmental research into bullying of students with SEN (DfE, 2011a; Ofsted, 2012) and research about autism (Cappadocia, Weiss, & Pepler, 2012; Connor, 2000; Jones et al., 2013).

Other differentiated treatment reported by non-autistic participants was the notion of ‘help’, possibly as a result of television programmes, as this is said to be the image of disability often provided by the media (Farnall & Smith, 1999; Priestley, 1999). Non-autistic participants also felt wary of saying or doing the wrong thing around autistic peers, likely to be linked to their perceived lack of understanding about autism.

4.1.4 RQ1d and 2: Adaptations

TA support was one of the most frequently discussed adaptations. Autistic participants were generally satisfied with this and did not report that it highlighted them as different or impinged on their ability to socialise, as others have found (Humphrey & Lewis, 2008; Iantaffi et al., 2003; Shaw, 1998). A number of non-autistic participants disagreed and felt support should be more subtle and the TA role better explained to students. Participants from both groups indicated that teachers’ differentiated their approach, acknowledging positives and negatives, as in Brewin et al. (2008). Four autistic participants valued differentiation, such as a flexible approach (Sciutto et al., 2012).

Three non-autistic groups discussed the separation created by adaptations, including different lunch areas, and generally indicated a desire for this to be reduced. Nonetheless, concurrent with Humphrey and Lewis (2008), participants acknowledged the difficulties of supporting students whilst reducing separation.

4.2 Summary of main findings

RQ1a and 2:

- Many participants think student understanding of autism is low and this can result in wariness of or negative treatment towards autistic students. Participants from both groups called for an improvement, although non-autistic participants much more so.
- Means for finding out about autism in school are limited and both sets of participants suggested ways to improve this. Participants' discussions indicate such work would need to be carefully planned and tailored within individual schools.

RQ1b and 2:

- Autistic participants generally reported disclosing their diagnosis, although fear of negative treatment, embarrassment, and poor representations of autism in the media makes some cautious.

RQ1c and 2:

- Autistic students can be seen as going against the 'norm' or strange and can be treated differently, including bullying and notions of 'help'.
- Autistic participants generally know peers with the condition and half valued this.

RQ1d and 2:

- Autistic participants appeared satisfied with adaptations made for them; however, some non-autistic participants felt these could cause separation and highlight them as different, things they wanted to reduce.

4.3 Findings related to paper one

A number of the findings from paper two appear to relate to, and provide possible explanations for the findings in paper one, as shown below.

Paper one findings	Paper two findings
• Mean anxiety and self-esteem scores that fell within the ‘normal’ range.	• Autistic participants did not report feelings of isolation and all indicated they had friends. • All but one autistic participant knew at least one autistic peer (which over half listed benefits of in paper one).
• Some autistic participants described difficulties or took a negative tone when defining the condition.	• Limited discussions about autism take place in school and one non-autistic participant referred to it as a ‘taboo’. • Two autistic participants described the poor presentation of autism in the media. • Autism can be viewed as different from the ‘norm’ and behaviours related to autism seen as strange.
• Most autistic participants thought they had minimal knowledge of the condition and related things.	• Means for finding out about autism in school, including discussions, were thought to be limited.
• Over half of autistic participants discussed experiences of negative treatment and all but one related this to their autism.	• Non-autistic and some autistic participants think understanding of autism amongst students is low and this can lead to wariness of or negative treatment of autistic students. • Negative treatment and bullying of autistic students takes place.

• Two autistic participants described presenting themselves to be viewed positively, one tried to prevent others knowing about their diagnosis.	• A number of non-autistic participants felt autistic students wanted to appear ‘normal’.
• The separated autistic participant described difficulties fitting in and regularly making negative comparisons to others.	• Autism can be viewed as different from the ‘norm’ and behaviours related to autism seen as strange.

4.4 Limitations

Caution is required when interpreting the findings due to the study’s small sample. However, the aim of the research was to obtain in-depth insights rather than create generalisable findings, which reflect the methodological decisions made.

The term ‘change’ to elicit views for RQ2, although used in past research (Connor, 2000), may have limited suggestions made by autistic participants as a common trait of the condition is a dislike of change (NAS, 2014b). Visual scenarios could be considered as an alternative, although this might impose the researchers’ views.

Interviews have been used effectively with autistic participants previously and recommended adaptations were implemented (Beresford et al., 2004; Humphrey & Lewis, 2008); however, some participants provided limited responses. A number opted to have an adult present which may have reduced their anxiety but restricted what they were willing to share. Using multiple methods or computer-assisted interviewing might have been worthwhile, as shown by Barrow and Hannah (2012).

Risk of sampling bias is present within the focus groups as due to timetabling constraints, a number of schools selected participants from the same year or interest group who are likely to share a number of similar characteristics. Nonetheless, this may have resulted in participants feeling more at ease and increased the information they were willing to share (Robson, 2002).

4.5 Areas for further research

Findings from this paper, along with others, indicate a belief that increased understanding leads to a reduction in bullying, teasing and wariness towards autistic students, although not all evidence supports this (Huws & Jones, 2008; Swaim & Morgan, 2001). Further investigations would be worthwhile, given the finding that understanding of autism is low amongst students; the prevalence of negative treatment; and the reluctance of some to disclose their diagnosis because of this.

Despite literature advocating a need to increase understanding in schools (Brewin et al., 2008; Myers et al., 2011; Nevill & White, 2011), there remains a paucity of work that considers the best means for doing this with adolescents. Participants have made a number of suggestions which could be examined through action research projects.

Implications

The following section explores the implications for both papers, in terms of theory, practice in schools, and the role of the EP. Personal implications are located in appendix ten.

Theoretical

Identity formation

The context in which identity formation occurs has been central to the theory since its conception (Erikson, 1968), with the school identified as salient. Both papers support this view in autistic adolescents by demonstrating the impact of peer and teacher relationships; peers' understanding of autism; and adaptations. Holland et al. (1998) discuss the importance of interactions with others and the process of making judgements about oneself based on the way others are believed to have judged us. Although many autistic participants reported spending little time making social comparisons, they appeared to be actively involved in this process (Bagatell, 2007; Baines, 2012). For example, positioning themselves to be viewed positively or identifying when their behaviour had been regarded as strange. The idea that identity is something which continually alters (Holland et al., 1998), is supported by a number of participants, who referred to their feelings about autism changing over time.

Findings from both papers suggest that theories of identity and stigma remain relevant (Goffman, 1963). For example, paper two revealed that autism can be seen as going against the 'norm'; negative viewpoints and stereotypes remain; and that differentiated treatment, including bullying and notions of 'help', occurs.

Finally, paper two is consistent with findings that support attribution theory (Connor, 2000; Iantaffi et al., 2003; Nevill & White, 2011). Non-autistic participants indicated that most students have limited understanding of the condition and that increasing this would improve responses to peers.

Identity formation in minority groups

Literature on the four acculturation types, first proposed in regards to ethnic minority identity formation (Berry et al., 1986; Phinney, 1990), has long associated biculturalism with better outcomes (Rosenthal, 1987). Research has demonstrated a relationship with increased psychological wellbeing in ethnic minorities and those with hearing impairments (Cornell & Lyness, 2004; Nguyen & Benet-Martinez, 2013). This association has recently been proposed for autism (Myers et al., 2011); however, no statistically significant relationship was uncovered. Findings from paper one appear to indicate that the acculturation types may exist to some extent within autism, although they may not be distinct categories as in other minority groups. Consistent with the theory, paper one revealed differences in participants' competence and comfort within autistic and non-autistic identities; however, a comparison of three of the acculturation types revealed a large number of similarities. The domains of acculturation require further exploration within autism, particularly relationship preferences and cultural involvement, where a number of participants suggested a dichotomy of autistic vs non-autistic in their choices did not exist.

Practice in schools

Many participants felt that student understanding of autism was low and attributed poor treatment, such as teasing and bullying, of peers with the condition to this. In addition, this lack of understanding makes some students wary of talking to autistic students out of fear of doing or saying the wrong thing. Discussions and means for finding out about autism within school were reported to be limited and many appear to obtain information from popular media which research has found to include poor representations (Jones & Harwood, 2009; Punshon et al., 2009). This therefore highlights an area for future work; to create a culture in which difference can be explored, through teaching students about autism, making resources readily available, and ensuring discussions can openly take place. The expectation is to reduce negative treatment and that, as Brownlow (2010) discusses, autistic adolescents are not surrounded by discourses that suggest autism is a deficit and that they need to alter their behaviour to become 'normal'. Though work has recently been undertaken to reduce incidents of bullying (Ofsted, 2012); negative treatment of autistic students, including bullying, was reported by participants. This is an area for continuing development. This is relevant as participants' indicated fear of negative treatment can make them reluctant to disclose and research has demonstrated the negative impact it can have on psychological wellbeing (Cappadocia et al., 2012).

Schools should continue to carefully evaluate the structures in place for autistic students, for example, ensuring they feel in control of who their diagnosis is shared with. Schools should also be aware of the facilitating role they can play in supporting autistic students to spend time with peers with and without the condition. The former being reported to be beneficial here and in past research (Iantaffi et al., 2003; Punshon et al., 2009).

The role of the EP

Attribution theory is a useful psychological model for exploring participants' views regarding a lack of understanding about autism in schools and poor treatment of autistic students attributed to this. It looks at how we use information to help explain events (Fiske & Taylor, 1991), something Weiner (1985) suggests we are continually looking to do. Weiner (1979) argues control is one of the three dimensions of perceived causality and that research has demonstrated that more positive behaviours are displayed towards the person when the event is perceived to be out of their control. EPs are commonly involved in the training of staff (BPS, 2013), but, as advocated by Gus (2000), could support schools to develop student understanding. Non-autistic participants indicated a desire for key facts about autism; traits; causes; and how to behave towards peers with the condition. Such information may help to provide an explanation for events, including behaviour they may perceive to be strange, and then improve responses towards autistic students.

Findings revealed a need for careful exploration into how best to go about this; to tailor the approach within each school; and to seek the views of students. EPs could support schools to plan and undertake action research in their settings to look at the approaches that would work for them. Moreover, they could help seek the views of young people, particularly those with autism where traditional methods for eliciting pupil voice may not be appropriate. This fits existing legislation that highlights the importance of obtaining the views of young people on issues affecting them (Unicef, 1989), along with impending legislation which places this at the heart of SEN practices (DfE, 2013). One approach suggested by autistic and non-autistic participants was the use of lessons, such as PSHE, and EPs could support schools with planning, signposting to appropriate resources, and initial co-delivery of lessons. EPs could also explore lesson based resources further to help develop an evidence base, including a Circle of Friends approach, as advocated by Gus (2000), and materials used to talk about autism as a sixth sense (Gray, 2002) .

Autistic participants perceived their knowledge of the condition to be minimal and research has found parents and schools can find it difficult to discuss diagnoses (Connors & Stalker, 2007; Kelly, 2005). This suggests a second role for EPs arising from the research, to assist schools and parents to have conversations about diagnoses and identity. This is supported by psychological theory on identity formation that emphasises the need to search for one's sense of self, particularly during adolescence (Erikson, 1968, 1980). EPs could hold consultations with school staff, parents, and young people to help them explore the diagnosis, as well running one-to-one sessions with young people. Additionally, EPs could support staff and parents to undertake discussions independently by providing training; access to supervision/consultancy sessions; and signposting to key texts and resources. Whitaker (2006) highlights the lack of evidence regarding how and when autism diagnoses should be discussed with young people and therefore EPs could use research to evaluate approaches, as well as undertaking in-depth case studies to look at young people's experiences.

Finally, as well as developing student understanding, the findings concur with evidence showing an ongoing need for development of staff knowledge (Brewin et al., 2008; Dybvik, 2004; Sciutto et al., 2012). EPs could use their knowledge and skills in delivering staff training, as well as drawing on evidence based practice, to ensure effective professional development around autism in schools. As with student understanding, approaches should be tailored to individual schools and staff groups within these, and a training needs analysis is a recommended approach for achieving this (Salas & Cannon-Bowers, 2001). This should also ensure professional development is not limited to those who teach specific areas of the curriculum or hold a teaching qualification.

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Paper two appendices

Contents

Word count: approximately 10,134

Appendix one

Participant details

Table 2: Interview participant details

Age (upon starting project) (years)	Gender	Age of diagnosis (years)	Age told about diagnosis (years)
10-12	M	0-4	9-12
10-12	M	5-8	5-8
13-16	M	5-8	5-8
13-16	M	5-8	5-8
10-12	M	5-8	9-12
13-16	M	5-8	5-8
13-16	M	0-4	9-12
13-16	M	9-12	9-12

Table 3: Focus group participant details

Age (upon starting project) (years)	Gender
13-16	F
13-16	F
13-16	M
13-16	M
13-16	F
13-16	M
13-16	F

13-16	M
13-16	M
13-16	M
10-12	F
13-16	M
17-18	M
17-18	F
17-18	F
17-18	M
13-16	M
13-16	F
13-16	M
13-16	F

LA and school details

Information here will not go into specific details in order to protect the anonymity of the LA and schools who participated in the research, although general information is provided to set the context in which the research was conducted.

LA

The LA is situated in south west England and has a small number of special schools, as well as approximately ten resource bases within mainstream secondary schools in the authority, one of which is specifically for young people with a diagnosis or needs on the autistic spectrum. Students who access resource bases also spend time within the mainstream provision. A number of young people also access special schools in the neighbouring authorities or are elective home educated. LA data indicates young people with autism access all of these types of provision, as well as mainstream schools.

Parents and young people make a decision as to where they would like their secondary education to take place and if this is a special school or resource base they must submit an application to be considered by a multiagency panel. Criteria vary across the settings although the young person must have a Statement of SEN or an Education, Health, and Care (EHC) plan that demonstrates a need for more specialist teaching, and be considered vulnerable in a mainstream school. The underlying principle is that young people with SEN should be placed in mainstream schools if their needs can be appropriately met there.

Schools

Four mainstream secondary schools, including maintained and academies, with 1150 to 1400 students on roll participated. Two settings have resources bases within them and outreach provided by staff. LA data indicates the number of young people with a statement of SEN (Autism) in each of the schools varies greatly, from less than five in one to more than 15 in another. Nonetheless, not all young people with autism or autistic traits will have a statement of SEN.

Appendix two

Data collection materials

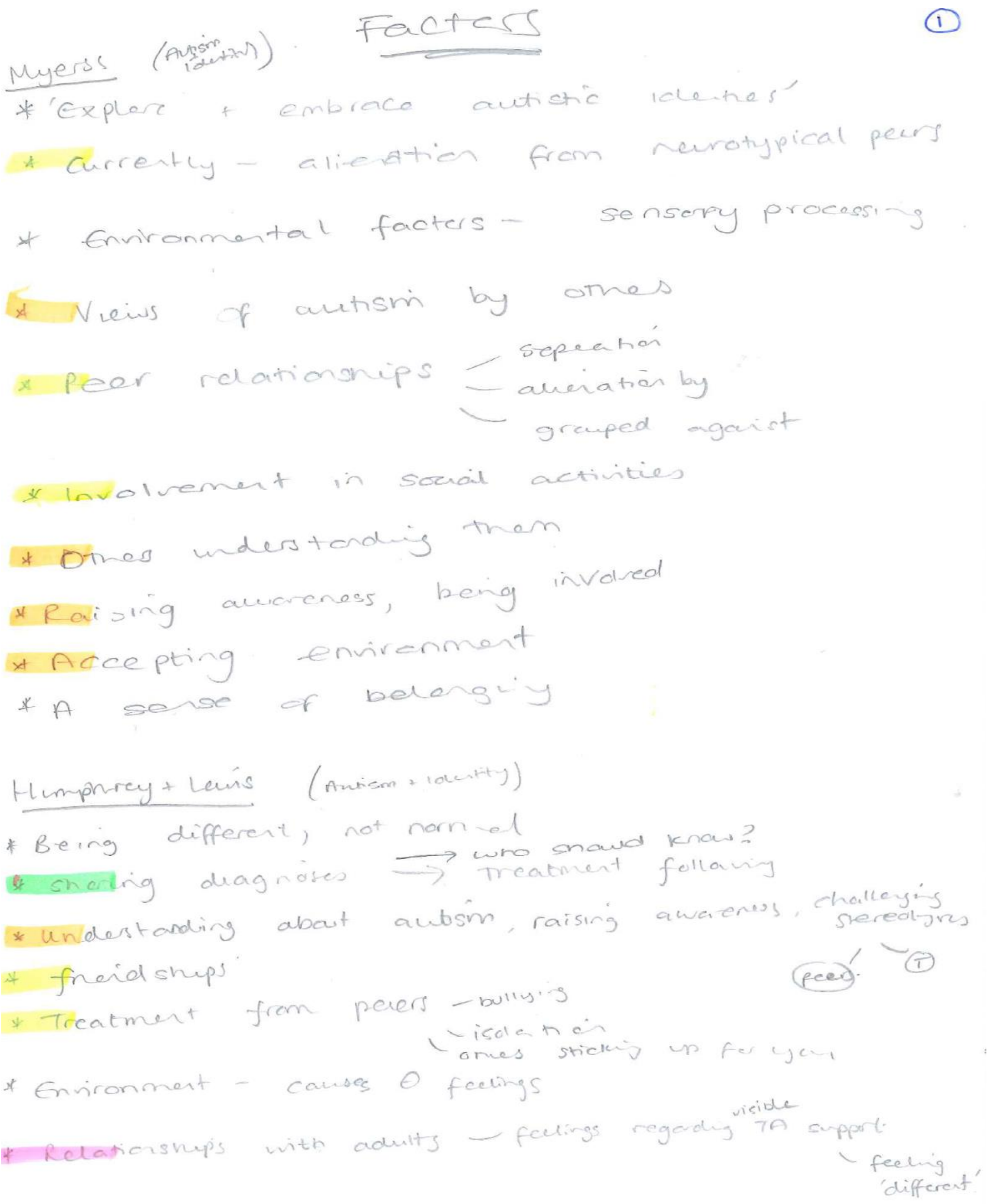
- Student and parent information letters and consent forms
- Parental questionnaires
- Semi-structured interview schedule
- Dictaphone
- Drawing materials for participants to use during the interviews if they wanted to
- Interview preparation letter
- Interview materials shown to participants to prompt discussion:
    - Understanding autism posters (downloaded from the Wiltshire Council website)
    - Books: ‘Autism and Asperger Syndrome’ (Baron-Cohen, S.), ‘Can I tell you about Asperger Syndrome?’ (Welton, J.), and ‘All cats have Asperger Syndrome’ (Hoopmann, K.)
    - DVD: ‘Autism and me’ (Rory Hoy)
- Focus group materials: rules poster, discussion prompt sheet, plan for session, name badges, felt pens, cardboard box with 5 question slips inside, snacks.

Appendix three

Interview materials

Development of schedule

Example of stage 1: Searching the literature for initial themes



Factors

①

Myers (Autism Identity)

* 'Explore + embrace autistic identities'

* Currently – alienation from neurotypical peers

* Environmental factors – sensory processing

* Views of autism by others

* Peer relationships – seperation
– alienation by
– grouped against

* Involvement in social activities

* Others understanding them

* Raising awareness, being involved

* Accepting environment

* A sense of belonging

Humphrey + Lewis (Autism + Identity)

* Being different, not normal

* Sharing diagnoses → who should know?
→ Treatment following

* Understanding about autism, raising awareness, challenging stereotypes

(peer) Ⓣ

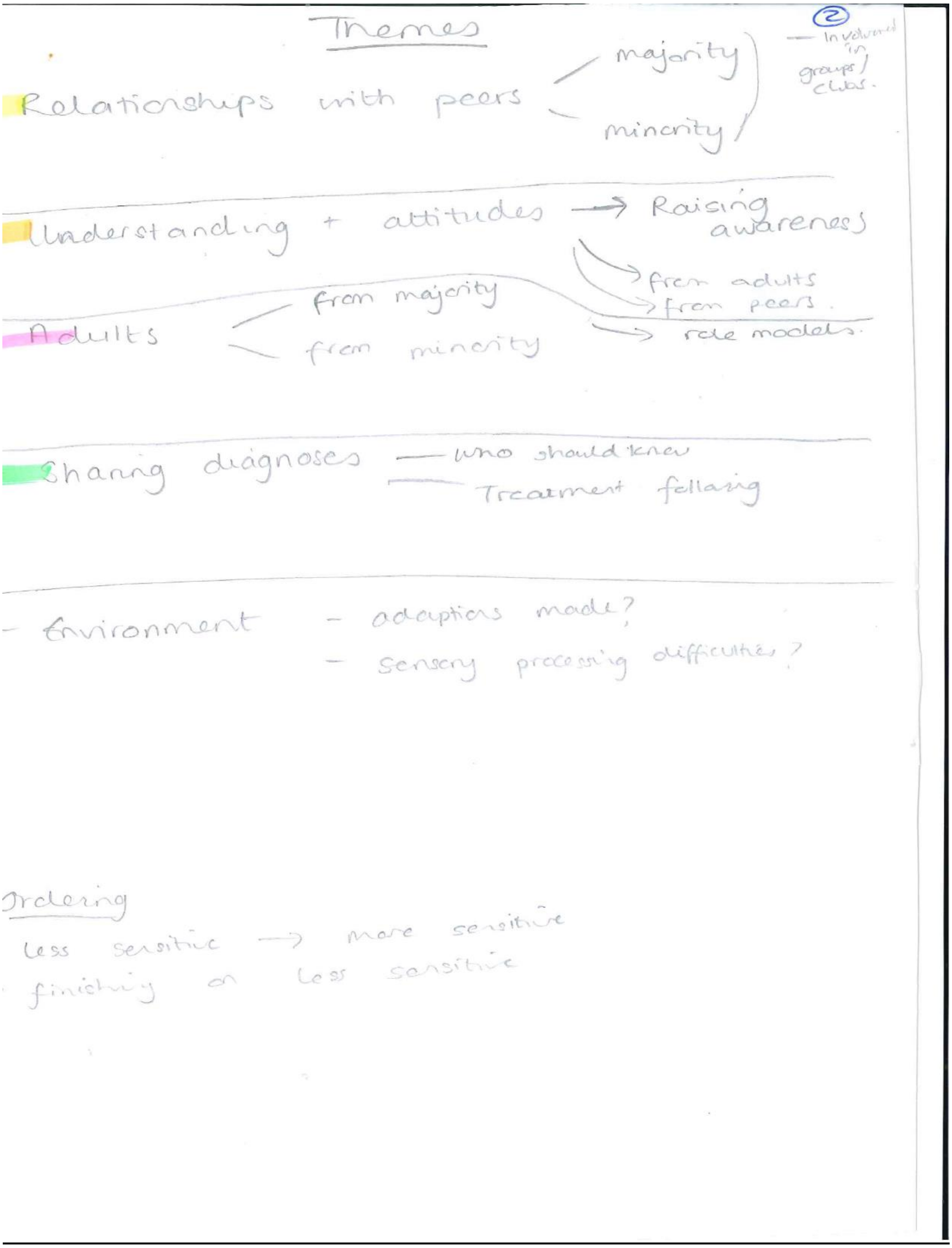
* friendships

* Treatment from peers – bullying
– isolation
– others sticking up for you

* Environment – causes ⊖ feelings

* Relationships with adults – feelings regarding visible TA support
– feeling 'different'

Example of stage 2: Developing initial themes from literature



②

Themes

Relationships with peers — majority / minority — Involved in groups/clubs.

Understanding + attitudes → Raising awareness
→ from adults
→ from peers.
→ role models.

Adults — from majority / from minority

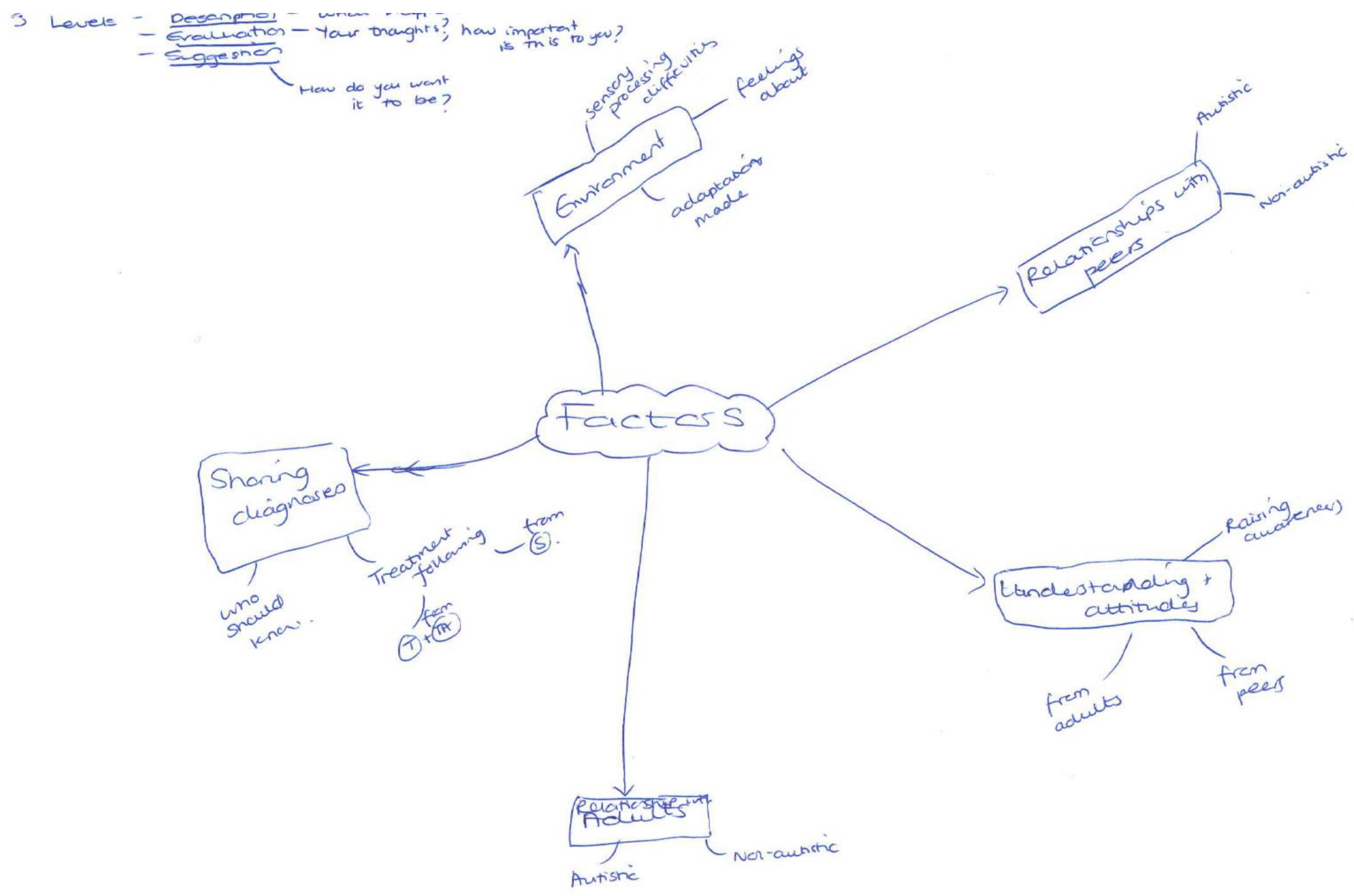
Sharing diagnoses — who should know — Treatment following

- Environment
  - adaptions made?
  - sensory processing difficulties?

Ordering

less sensitive → more sensitive
finishing on less sensitive

Example of stage 3: Refining the themes



3 Levels – Description –
– Evaluation – Your thoughts? how important is this to you?
– Suggestion – How do you want it to be?

Final stage: Final development of themes

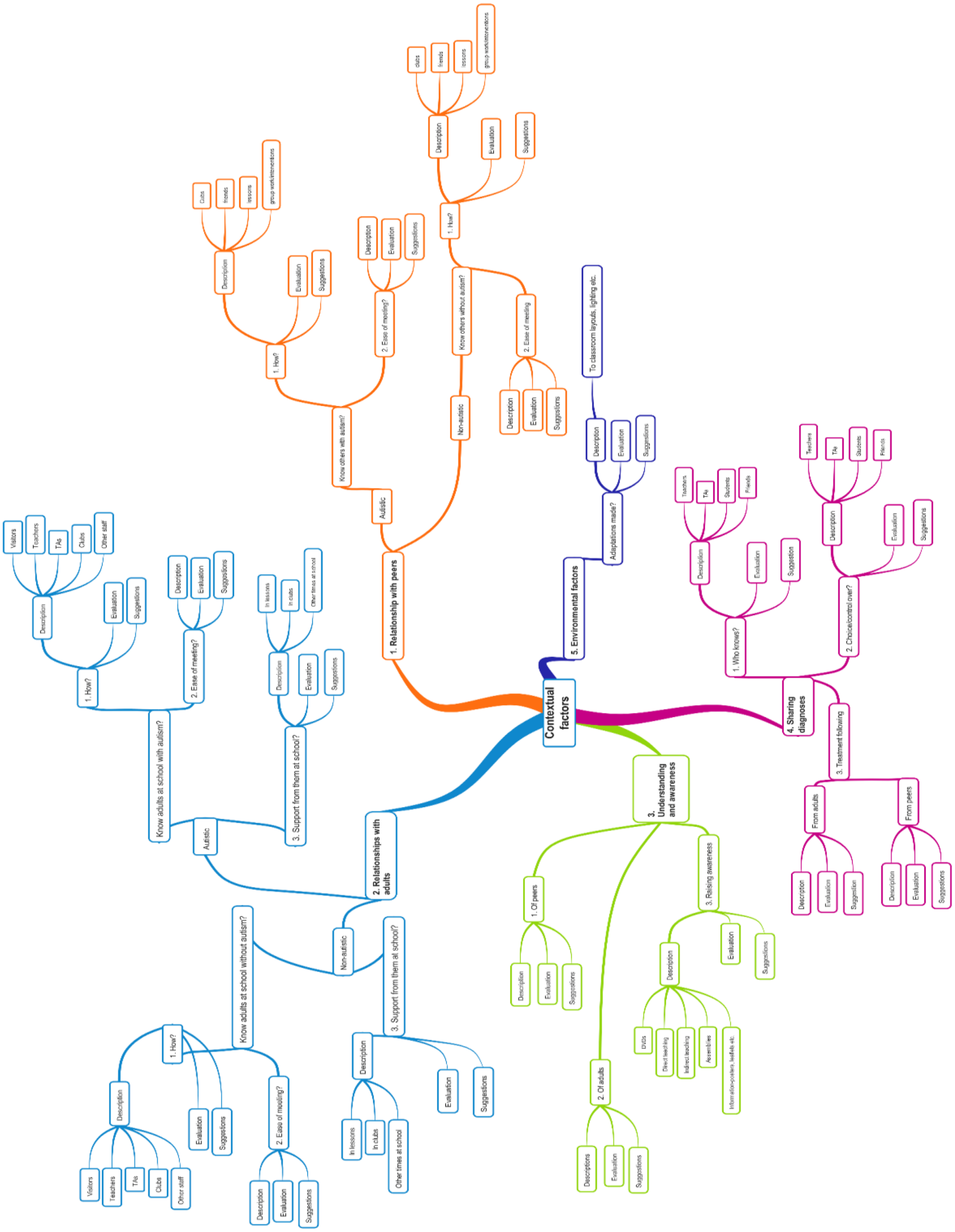


Figure 2: Mind map of final interview themes

Final interview schedule

Relationships with peers

Autistic

1. **Do you know any other students at school with autism/Asperger syndrome?** ☐

   How do you meet other students at this school with autism? ☐

   D- -Clubs? ☐

   -Friends? ☐

   -Lessons? ☐

   -Group work/interventions ☐

   -Through learning support/curriculum support etc. ☐

How easy is it to meet other students with autism/Asperger syndrome at school? ☐

E- What do you think about your opportunities to meet students with autism? Is this important to you? ☐

S- Is there anything that you would change about the opportunities you have to meet other students with autism? ☐

Non-autistic

2. **Are you friends with other students at school without autism/Asperger syndrome?** ☐

   How did you meet these friends? ☐

   D- -Lessons? ☐

   -Break time/Lunchtime? ☐

   -Clubs? ☐

-Group work/interventions ☐

How easy is it to develop friendships with other students at school who don't have autism/Asperger syndrome? ☐

E- What do you think about your opportunities to spend time with students without autism/Asperger syndrome? Is this important to you? ☐

S- Is there anything you would change about developing friendships with students without autism/Asperger syndrome? How? ☐

<u>**Relationships with adults**</u>

<u>Autistic</u>

3. Do you know any adults at school with autism/Asperger syndrome? ☐

How?

D- - Visitors? ☐
-Teachers? ☐
-TAs? ☐
- Clubs? ☐
-Other staff? ☐

D- How easy is it to meet adults at school with autism/Asperger syndrome? ☐

E- What do you think about your opportunities to meet adults at school with autism /Asperger syndrome? Is this important to you? ☐

S- Would you make any changes to the opportunities you have to meet adults at school with autism/Asperger syndrome? ☐

Do you have contact with or support at school by any adults with autism/Asperger syndrome? ☐

D- -In lessons? ☐
-In clubs? ☐
-At other times in school? ☐

E- What do you think about the contact/support that you get from adults with autism/Asperger syndrome? ☐

S- Would you change the contact/support you receive from adults with autism/Asperger syndrome in any way? ☐

<u>Non-autistic</u>

4. Do you have contact/support from adults at school without autism/Asperger syndrome? ☐

How?

D- - In lessons? ☐

-In clubs? ☐

-At other times in school? ☐

E- What do you think about the time you get to spend with adults without autism/Asperger syndrome at school? Is this important to you? ☐

S- Would you change the contact/support you receive from adults without autism/Asperger syndrome in any way? ☐

Understanding and awareness

5. **How much understanding/knowledge do you think the other students at this school have of autism/Asperger syndrome?** ☐

E- What do you think about the other students' level of understanding? Is this important to you? ☐

S- Would you like to change the other students' understanding of autism/Asperger syndrome in any way? ☐

6. **How much understanding do you think the adults at this school have of autism/Asperger syndrome?** ☐

E- What do you think about the adults' level of understanding of autism/Asperger syndrome? Is this important to you? ☐

S- Would you like to change the adults understanding of autism/Asperger syndrome in any way? ☐

7. **How do students at this school find out about autism/Asperger syndrome?** ☐

D- - DVDs ☐
-Information around schools (posters, leaflets etc.) ☐
-Assemblies ☐
-Informal discussions ☐
-Direct teaching ☐
- Indirect teaching ☐

E- What do you think about these methods? Is it important to you that students have ways to find out about autism at school? ☐

S- Would you like to change the way students find out autism in your school? How? ☐

Sharing diagnoses

8. Who knows about your diagnosis of autism/Asperger syndrome in school? ☐

D- - Teachers ☐
-TAs ☐
- Students ☐
-Friends ☐

E- Does it matter to you whether people in school know about your diagnosis of autism/Asperger syndrome? ☐

S- Would you like to change who knows about your diagnosis of autism/Asperger syndrome in school? ☐

9. How much control did you/do you have over sharing your diagnosis of autism/Asperger syndrome in school? ☐

- Teachers ☐
-TAs ☐
- Students ☐
-Friends ☐

E- What do you think about the control you have over who knows about your diagnosis of autism/Asperger syndrome in school? Is this important to you? ☐

S- Would you like to change the control you have over sharing your diagnosis of autism/Asperger syndrome in school? ☐

10. **How do you get treated by students at school who know you have autism/Asperger syndrome?** ☐

E- What do you think about the way other students who know you have autism/ Asperger syndrome treat you? ☐

S- Would you like to change how other students who know you have autism/Asperger syndrome treat you? ☐

11. **How do you get treated by students at school who do not know you have autism/Asperger syndrome?** ☐

E- What do you think about the way other students who do not know you have autism/Asperger syndrome treat you? ☐

S- Would you like to change how other students who do not know you have autism/Asperger syndrome treat you? ☐

12. **How do you get treated by adults at school who know you have autism/Asperger syndrome?** ☐

E- What do you think about the way adults at school who know you have autism/ Asperger syndrome treat you? ☐

S- Would you like to change how adults who know you have autism/Asperger syndrome treat you? ☐

13. How do you get treated by adults at school who do not know you have autism/Asperger syndrome? ☐

E- What do you think about the way adults at school who do not know you have autism/Asperger syndrome treat you? ☐

S- Would you like to change how adults at school who do not know you have autism/Asperger syndrome treat you? ☐

<u>The Environment</u>

14. Have any adaptations been made at school because you have autism/Asperger syndrome? ☐

- Adult support in lessons ☐
- Changes to classroom layout ☐
- Adaptations to timetable ☐
- Adaptations/support during break times and lunchtimes ☐

E- What do you think about the adaptations that have been made in school because you have autism/Asperger syndrome? ☐

S- Would you change anything about the adaptations that have been made? How? ☐

D= Description question

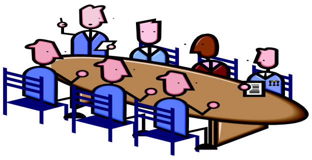
E= Evaluation question

S= Suggestion for change question

Appendix four

Focus group materials

Researcher Prompt Sheet



Starter question- Do you know anything about autism/Asperger syndrome?

Relationships with peers and adults with autism/Asperger syndrome

1. **Does anyone know any students or are friends with any students at school with autism/Asperger syndrome and if so how did you meet them?**

   (a) How?

   (b) Is it easy to meet students with autism/Asperger syndrome?

   (c) If you could, is there anything you would change about this?

2. **Does anyone know any adults at school with autism/Asperger syndrome?**

   (a) How?

   (b) Is it easy to meet adults with autism/Asperger syndrome at school?

   (c) If you could, is there anything you would change about this?

Understanding/knowledge about autism

3. **How good do you think your understanding of autism/Asperger syndrome is?**

   (a) How do you feel about this?

   (b) If you could, is there anything you would change about this?

4. **How much do you think the students in this school know about autism/Asperger syndrome?**
   (a) What makes you think this?
   (b) What do you think about this?
   (c) If you could, would you change anything about this?

5. **How much do you think the adults in this school know about autism/Asperger syndrome?**
   (a) What makes you think this?
   (b) What do you think about this?
   (c) If you could, would you change anything

6. **How can you find out about autism/Asperger syndrome in this school?**
   (a) DVDs, books, information around school, assemblies, informal discussions, direct teaching, indirect teaching?
   (b) What do you think about these methods? Do you think it is important that students have ways to find out about autism at school?
   (c) If you could, would you change anything?

Sharing diagnoses

7. **How would you know if another student had autism or Asperger syndrome?**
   (a) How easy is it to know?
   (b) Do you think you should be told?
   (c) If you could, would you change anything about how things currently are?

8. **If you knew someone had autism/Asperger syndrome do you think it would alter how you interact with them?**

    (a) Why?

    (b) If you could, would you change anything about this?

9. **Do you think it changes how the adults interact with them?**

    (a) Why?

    (b) If you could, would you change anything about this?

<u>Environment</u>

10. **What adaptations are made in your school for people with autism/Asperger syndrome?**

    (a) What do you think about these?

If you could, would you change anything about this?

Session outline:

A. **Introduction** (explain purpose of session, brief description of my research, length…..)

B. **(2min) Gain verbal consent** *(remind students sessions will be recorded and transcribed but anonymous)*

C. **(5min) Create name badges and discuss 'Guidelines' for session-** *(put up on wall)*

D. **(5min) Warm Up- (To create relaxed environment)** Put list of general questions into star box and get each person to pull one out and all answer it (e.g.- do you have any pets? What do you want to be when you grow up?)

E. **(30min) Main Discussion Topics (see sheet)**

F. **(5min) Wrap-up**

- Ask participants if have any questions/want to share anything else.
- Explain I will provide feedback.

Probes/prompts to encourage voice of all:

- Does anyone see it differently?
- What does everyone else think?
- Do you agree with…..?
- What do others think about that?
- That's helpful. Does anyone else have any thoughts?

Appendix five

Pilot materials

PILOT- Researcher Prompt Sheet- Focus Group Discussion Topics

Relationships with peers and adults with autism/Asperger syndrome

1. **What is autism/Asperger syndrome?** (*highlight difference if necessary*)

2. **Do you know any students at school with autism/Asperger syndrome?**
    - How?
    - Is it easy to meet students with autism/Asperger syndrome?
    - If you could, is there anything you would change about this?

3. **Are you friends with any students with autism/Asperger syndrome?**

- How did you become friends?

4. **Do you know any adults at school with autism/Asperger syndrome?**

- How?
- Is it easy to meet adults with autism/Asperger syndrome at school?
- If you could, is there anything you would change about this?

Understanding/knowledge about autism

5. **How good do you think your understanding of autism/Asperger syndrome is?**
    - How do you feel about this?
    - If you could, is there anything you would change about this?

6. **How much do you think the students in this school know about autism/Asperger syndrome?**
    - What makes you think this?
    - What do you think about this?
    - If you could, would you change anything about this?

7. **How much do you think the adults in this school know about autism/Asperger syndrome?**
    - What makes you think this?
    - What do you think about this?
    - If you could, would you change anything

8. **How can you find out about autism/Asperger syndrome in this school?**
    - DVDs, books, information around school, assemblies, informal discussions, direct teaching, indirect teaching?
    - What do you think about these methods? Do you think it is important that students have ways to find out about autism at school?
    - If you could, would you change anything?

<u>Sharing diagnoses</u>

9. **How would you know if another student had autism or Asperger syndrome?**
    - How easy is it to know?
    - Do you think you should be told?

- If you could, would you change anything about how things currently are?

10. **If you knew someone had autism/Asperger syndrome do you think it would alter how you interact with them?**
    - Why?
    - If you could, would you change anything about this?

11. **Do you think it changes how the adults interact with them?**
    - Why?
    - If you could, would you change anything about this?

<u>Environment</u>

12. **What adaptations are made in your school for people with autism/Asperger syndrome?**
    - What do you think about these?
    - If you could, would you change anything about this?

<u>Notes:</u>

- Did not have time to fit in question 12.

PILOT- Interview

Relationships with peers

Autistic

1. **Do you know any other students at school with autism/Asperger syndrome?** ☐

How do you meet other students at this school with autism? ☐

D- -Clubs? ☐

-Friends? ☐

-Lessons? ☐

-Group work/interventions ☐

-Through learning support/curriculum support etc. ☐

How easy is it to meet other students with autism/Asperger syndrome at school? ☐

E- What do you think about your opportunities to meet students with autism? ☐

Is meeting other students with autism important to you? ☐

S- Is there anything that you would change about the opportunities to meet other students with autism? ☐

Non-autistic

2. **Are you friends with other students at school without autism/Asperger syndrome?** ☐

How did you meet these friends? ☐

D- -Clubs? ☐

-Friends? ☐

-Lessons? ☐

-Group work/interventions ☐

How easy is it to develop friendships with other students without autism/Asperger's at school? ☐

E- What do you think about your opportunities to spend time with students without autism/Asperger syndrome? Is this important to you? ☐

S- Is there anything you would change about developing friendships with students without autism/Asperger syndrome? How? ☐

Relationships with adults

Autistic

3. Do you know any adults at school with autism/Asperger syndrome? ☐

How? ☐

D- - Visitors? ☐

-Teachers? ☐

-TAs? ☐

- Clubs? ☐

-Other staff? ☐

E- What do you think about this? ☐

S-How would you like it to be? ☐

How easy is it to meet adults at school with autism/Asperger syndrome? ☐

D- Could you tell me how easy or difficult it is? ☐

E- What do you think about that? Is it important to you? ☐

S- How would you like it to be? ☐

Do you have contact with or have support at school by any adults with autism/asp? ☐

D- -In lessons? ☐

-In clubs? ☐

-At other times in school? ☐

E- What do you think about that? ☐

S- How would you like it to be? ☐

<u>Non-autistic</u>

4. Do you know any adults at school without autism/Asperger syndrome? ☐

How? ☐

D- - Visitors? ☐

-Teachers? ☐

-TAs? ☐

- Clubs? ☐

-Other staff? ☐

E- What do you think about this? ☐

S-How would you like it to be? ☐

How easy is it to meet adults at school without autism/Asperger syndrome? ☐

D- Could you tell me how easy or difficult it is? ☐

E- What do you think about that? Is it important to you? ☐

S- How would you like it to be? ☐

Do you have contact with or have support at school by any adults without autism/asp? ☐

D- -In lessons? ☐

-In clubs? ☐

-At other times in school? ☐

E- What do you think about that? ☐

S- How would you like it to be? ☐

Understanding and awareness

5. How much understanding/knowledge do you think the other students at this school have of autism/Asperger syndrome? ☐

D- As above ☐

E- What do you think about the other students' level of understanding? Is it important to you? ☐

S- How would you like it to be? ☐

6. How much understanding do you think the adults at this school have of autism/Asperger syndrome? ☐

D- As above ☐

E- What do you think about the adults' level of understanding? Is it important to you? ☐

S- How would you like it to be? ☐

7. How do students at this school find out about autism/Asperger syndrome? ☐

D- - DVDs ☐
-Information around schools (posters, leaflets etc.) ☐
-Assemblies ☐
-Informal discussions ☐
-Direct teaching ☐
- Indirect teaching ☐

E- What do you think about ………….. (*each of the above*)? Is it important to you? ☐

S- How would you like it to be? ☐

Sharing diagnoses

8. Who knows about your diagnosis of autism/Asperger syndrome? ☐

D- - Teachers ☐
-TAs ☐
- Students ☐
-Friends ☐
☐

E- What do you think about others knowing about your autism/Asperger syndrome? Is it important to you? ☐

S- How would you like it to be? ☐

9. How much control did you/do you have over sharing your diagnosis? ☐

D- - Teachers ☐

-TAs ☐

- Students ☐

-Friends ☐

E- What do you think about others knowing about your diagnosis? Is it important to you? ☐

S- How would you like it to be? ☐

10. How do you get treated by students at school who know you have autism/Asperger syndrome? ☐

D- As above ☐

E- What do you think about the way they treat you? ☐

S- How would you like it to be? ☐

11. How do you get treated by students at school who do not know about your autism/Asperger syndrome? ☐

D- As above ☐

E- What do you think about the way they treat you? ☐

S- How would you like it to be? ☐

12. How do you get treated by adults at school who know you have autism/Asperger syndrome?

D- As above ☐

E- What do you think about the way they treat you? ☐

S- How would you like it to be? ☐

13. How do you get treated by adults at school who do not know you have autism/Asperger syndrome? ☐

D- As above ☐

E- What do you think about the way they treat you? ☐

S- How would you like it to be? ☐

The Environment

14. Have any adaptations be made at school because of your autism? ☐

D- Do you get any support? ☐

E- What do you think about this? ☐

S- Would you change anything? ☐

Appendix six

Ethical consideration materials

(See appendix ten, paper one for consent form).

Example of focus group information forms

Dear parent/guardian,

I am writing to tell you that your son/daughter has been selected to be involved in a project looking at autism in adolescents from both the perspectives of young people on the spectrum **and** their peers. The project is being carried out by myself (Hayley Jarrett), a student on the DEdPsych in Educational, Child and Community Psychology at the University of Exeter and Trainee Educational Psychologist who currently works for [redacted]

The information outlined below is to help you understand what participation in the project entails. Please take time to read the following information and decide whether or not you are happy for your son/daughter to participate. If you would like any further information or have any questions about the research project, please contact me via the details provided at the end of these information sheets.

Title: An exploration of identity formation in adolescents with autism, its relationship with psychological wellbeing, and the role of mainstream education provision in this process.

What is the aim of the research?

The main aim of the project is to look at the experiences of adolescents with autism within mainstream secondary schools from both the perspectives of young people on the spectrum **and** their peers.

Where will the research be conducted?

In your son/daughter's school.

What is the duration of the research?

The project itself runs from April 2013 until June 2014, although data collection will only be in term time during December 2013 or January 2014.

What will my son/daughter be asked to do if he/she takes part?

Your son/daughter will be asked to participate in one short focus group which will explore how many young people or adults they know at school with autism; what opportunities they have for learning about autism at school; what they would like to know more about; and how they feel this should be approached by their school. The focus group will be with three or four other young people and will last approximately one hour. The discussion will be recorded using a Dictaphone to help with the transcription processes, but once fully transcribed this will be destroyed.

What happens to the data collected?

The data will be analysed by myself for my doctoral thesis. A report will be written based on my analyses of the data which will also be provided to schools. Your son/daughter's name will **not be** used in the report.

How is confidentiality maintained?

All data provided will be treated as confidential and will be completely anonymous. Every reasonable effort will be made to preserve the anonymity of the school and of all participants. Identifying information (e.g. your son/daughter's name) will **not be** used and pseudonyms will be given. All identifiable data collected will be stored on a secure [redacted] Council laptop to which I only will have access. All raw data collected as part of the project will only be seen by myself and my research supervisors at University.

Does my son/daughter have to take part?

Participation is entirely voluntary and you have two weeks to read all the information and make a decision. If you and your son/daughter are both happy then please complete the attached consent form and return it to school**.** If you and your son/daughter decide to take part and then later change your mind, either before or during the study, you can withdraw your consent, without giving your reasons, and, if you wish, your data will be destroyed.

Will he/she be paid for taking part?

I am not able to offer any payment or incentive for participating in this study; however, each student will be provided with feedback from the project.

Criminal Records Check

I have undergone a Criminal Records Bureau check at the Enhanced Disclosure level.

Where can I obtain further information if I need it?

For further information contact:

[redacted]

Dear ………………………………….. (student)

I am writing to tell you that you have been selected to be involved in a research project. The information outlined below is to help you understand what the project is about and what will happen if you choose to take part. Please take time to read it carefully to decide whether or not you are happy to take part.

Project Title: *An exploration of identity formation in adolescents with autism, its relationship with psychological wellbeing, and the role of mainstream education provision in this process.*

1. So what is this project all about?

This is a project about autism and is split into different parts. The part of the project you would be involved in aims to find out how many people you know in school with autism, what opportunities you have for finding out more about autism, what you would like to know more about, and how you feel your school should approach this.

2. What would I need to do?

If you decide to take part in the project you would be asked to participate in one short focus (discussion) group that will last approximately 1 hour.

3. So when and where will it be?

You would participate in the project during December 2013 or January 2014 in your school.

4. What if I change my mind?

Don't worry, that is fine, you can change your mind at any time! All you would need to do is tell me.

5. Will people know the information is about me?

No they will not as I will give you a code and all information you give will be put under this code rather than your name. Only I will know which person has which code and therefore when I write up the results I will use your code so people reading the information will not know it is about you.

6. Will I get paid?

Unfortunately not! However, when the project is finished you will get a feedback sheet which will show you what I have found out!

7. Do I have to take part?

No, you can choose whether you want to take part or not.

What Next?

If you are happy to be in the project please sign your name on the form called 'PARENT/GUARDIAN and YOUNG PERSON'S CONSENT FORM'.

Appendix seven

Stages of thematic analysis: Interviews

Stage one:

Each interview was transcribed by myself and repeatedly read to ensure familiarity.

Transcript extract example:

A38 Transcription	Notes
27. I: So in there you get to meet people with maybe dyslexia as well or ADHD or lots of other not just autism but lots of other…	
28 A38: yeh	
29 I: How about any clubs..at school…any clubs?	
30 A38: Ummm..not so much as clubs usually um on a few days we will go down to the hall to the hall XX and um we'll play we'll have a game of dodge ball for the people who come to X	
31 I: Mmm…so you do things like together as a group	
32 A38: Yeh…like we might do I don't know football together or I don't know badminton if the racquets are left out	
33 I: Is that something that teachers would like organise?	
34 A38: Yeh the TAs would have to organise that and book in advance for it…usually the hall down there is free on 3 or 4 days a week so we go down there for dodge ball or football	
35 I: So if I say how easy is it to meet other students with autism or Asperger syndrome at school?	
36 A38: Ohh essentially quite easy to meet someone cos …most people with Asperger you know or ADHD they come here so you just get to you just get to talk to them and know them even if they don't come here you'll figure out something	
37 I: You could meet them	
38 A38: Yeh and…	
39 I: What do you think about your opportunities to meet students with autism or Asperger syndrome?	
40 A38: I think they are very high and it's perfectly fine	
41 I: Is it important to you or?	
42 A38: It's…..it's good to know that there are other people like me but …..?? I've been with people with autism for two years you know…meeting them on a daily basis is just chatting and having fun…it doesn't seem important to me at the moment….but I guess if…you know I didn't you know cos ?? mainstream school like in the 70s or something I guess it would be quite hard for me	

Stage two:

A list of codes was generated once the first transcript (Participant A5) had been coded.

Names		Sources	References
Access to autism resources		1	10
Adaptations made due to autism		1	2
Adult support in school		1	6
Adults knowledge of their autism		1	2
Adults understanding of autism		1	3
Autism can be presented negatively		1	3
Autism not spoken about		1	2
Autism resources could be used negatively		1	3
Careful consideration when presenting info on autism is important		1	6
Clubs		1	4
Desire for increased knowledge about autism and peers with it		1	1
Disclosing their diagnosis		1	9
Ease of making friends with peers without autism		1	3
Friendships		1	7
Friendships developed through shared interests		1	1
How peer(s) with autism were met		1	3
Increased control over disclosing diagnosis desired		1	2
Increased understanding about autism may alter behaviour		1	1
Knowledge and opportunities to meet adults at school with autism		1	3
Knowledge of peers with autism		1	1
Normal vs weird		1	1
Opportunities to meet peers with autism		1	3
Others' perceptions		1	2
School provides opportunity to spend time with friends		1	1
Sharing of diagnoses between adults		1	2
Sharing others' diagnoses		1	1
Some people dislike those with disabilities		1	1
Students' understanding of autism		1	3
Time spent in SEN area		1	2
Treatment from peers who don't know about their autism		1	5
Treatment from peers who know they have autism		1	2
Treatment from staff		1	5
Unable to explain autism to others as lack knowledge themselves		1	2
Use of social media		1	2

Each transcript was then coded using this list with additional codes added to the list as appropriate. Following this, initial themes were identified

Initial set of themes (All 8 interviews):

Name	Sources	References
Adaptations	0	0
Adaptations made due to autism	8	27
Adult support in school	8	27
Autism resources and information	0	0
Access to autism resources and information	8	49
Autism can be presented poorly	2	4
Autism events and information not accessed by individual	1	2
Autism resources could be used negatively	2	9
Careful consideration when presenting info on autism is important	3	9
Discussions about autism in school	2	4
Sharing autism resources with school	1	1
Thoughts on usefulness of autism resources	7	22
Being normal	0	0
Normal vs weird	1	1
Others' perceptions	3	4
Trying to be like others	1	1
Disclosing diagnoses	0	0
Adults knowledge of their autism	4	5
Control over sharing diagnosis	7	9
Disclosing their diagnosis	8	25
Increased control over disclosing diagnosis desired	2	3
Others guess they have autism	1	3
Sharing of diagnoses between adults	1	2
Sharing others' diagnoses	3	4
Friendships-parent node	0	0
Ease of making friends with peers with and without autism	8	14
Friends without autism met through transition visits	1	1
Friendships	8	23
Friendships developed through shared interests	2	2
Friendships not based on labels	2	4
School provides opportunity to spend time with friends	1	1
Miscellaneous	0	0
Clubs and events	5	5
Others' behaviour	1	1
Some people dislike those with disabilities	1	1
Use of social media	1	2
Opportunities to spend time with others with autism	0	0
Asked by school to be buddy for peer with autism	1	2
Clubs and events for students with autism or SEN	4	4
How peer(s) with autism were met	7	12
Knowledge and opportunities to meet adults at school with autism	8	18
Knowledge of peers with autism	8	9
Opportunities to meet peers with autism	8	23

Role of school's SEN area	0	0
Separation of SEN areas and resources	1	2
Time spent in SEN area	7	12
Time spent with others without autism in school	0	0
Mixed club	1	1
Opportunities to spend time with adults without autism	2	2
Opportunities to spend time with peers without autism	6	8
Relationships with peers without SEN	1	2
Treatment at school	0	0
Bullying	0	0
Desires for bullies to be stopped	1	1

Stage three:

Next the initial themes identified at stage two were repeatedly examined. At this point seven themes emerged (shown in bold below). Level two (underlined) and level three sub-themes began to emerge from these and similar sub-themes were collapsed into each other.

Name		Sources
Adaptations		0
Adaptations made due to autism		0
Adult support in school		8
Other adaptations		7
Evaluation of adaptations		6
Autism resources and information		0
Discussions about autism in school		2
Evaluation of autism resources and information		8
Autism can be presented poorly		2
Careful consideration when presenting info on autism is important		3
Importance of availability of resources and information		5
Thoughts on usefulness of resources		6
Resources and information currently available in schools		8
Disclosing diagnoses		0
Adults knowledge of their autism		4
Control over disclosing their diagnosis		8
Disclosing their diagnosis		0
Evaluation		8
Who knows about their diagnosis in school		8
Knowledge about others' diagnoses		3
Miscellaneous		0
Clubs and events		6
Others' behaviour		1
Time spent in SEN area		5
Relationships with peers		0
Being normal		4
Friendships		0
Do friends have autism		7
Ease of making and sustaining friendships		8
Role of school		3
Opportunities to meet and spend time with peers with autism		0
Evaluation of their opportunities to meet peers with autism		1
Knowledge of peers with autism		8
Opportunities to meet peers with autism or SEN		8
Opportunities to meet and time spent with peers without autism		7
Treatment from peers		0
Bullying		4
Treatment from peers who don't know about their autism		7
Treatment from peers who know they have autism		8
Relationships with staff		0

Knowledge and opportunities to spend time with adults at school with and without autism		8
Treatment from staff		8
Understanding of autism		0
Participants' understanding		1
Staff understanding		0
Evaluation of staff level of understanding		8
How much do staff know		8
Students' understanding		0
Evaluation of students' level of understanding		7
How much do students know		8

Stage four:

At stage four further reassessment of the emergent themes took place. At this point the number of themes was reduced from seven to six.

Name		Sources	References
Adaptations		0	0
Adaptations made due to autism		0	0
Adult support in school		8	27
Other adaptations		7	12
Evaluation of adaptations		6	13
Autism resources and information		0	0
Discussions about autism in school		2	4
Evaluation of autism resources and information		8	30
Autism can be presented poorly		2	6
Importance of availability of resources and information		5	6
Thoughts on autism resources and information		7	19
Resources and information currently available in schools		8	39
Disclosing diagnoses		0	0
Adults knowledge of their autism		4	7
Control over disclosing their diagnosis		8	12
Disclosing their diagnosis		0	0
Incidents of and reasons for sharing diagnosis		8	16
Who knows about their diagnosis in school		8	19
Knowledge about others' diagnoses		4	6
Relationships with peers		0	0
Being normal		4	6
Friendships		0	0
Do friends have autism		7	14
Ease of making and sustaining friendships		8	20
Role of school		3	6
Opportunities to meet and spend time with peers with autism		0	0
Evaluation of their opportunities		1	1
Knowledge of peers with autism		8	9
Opportunities to meet peers with autism or SEN		8	38
Opportunities to meet and time spent with peers without autism		7	13
Treatment from peers		0	0
Bullying		4	14
Treatment from peers who don't know about their autism		7	15
Treatment from peers who know they have autism		8	15
Relationships with staff		0	0
Knowledge and opportunities to meet adults with autism		8	20
Treatment from staff		8	16
Understanding of autism		0	0
Participants' understanding		1	3
Staff understanding		0	0

Evaluation of staff level of understanding		8	10
How much do staff know		8	11
Students' understanding		0	0
Evaluation of students' level of understanding		7	14
How much do students know		8	12

Stage five:

At stage five the final themes were decided upon and given names.

Final themes:

Some example of extracts from:

Relationships with peers: 'Being normal' sub-theme**:**

A11: Yeh and some people and when you're going all hyper like when you've just…like when you've got Asperger or autism and you start like jumping around they're like is this child gone mad or is he is just in a really hyper streak or has he just gone koo koo in the head <changes voice>

<Internals\\A14 Paper 2 Interview> - § 1 reference coded [0.91% Coverage]

1. A14: Yeh…even in my old school I was the only autistic kid in one class and all the others weren't and I tried to be like them as possible but…. I just couldn't really

<Internals\\A38 Paper 2 Interview> - § 2 references coded [2.42% Coverage]

2. A38: That'ssss a good question…..?? an answer but…….I don't think other people are really bothered that people like me have autism they just …it's just…it's just part of everything..it's just… I don't know most people..people at school have figured out that I haven't… that I am not normal like other kids but…….that I've got some difficulties but I am more or less…like other people and I get along I get on fine they get on fine

<Internals\\A5 Paper 2 Interview> - § 4 references coded [2.83% Coverage]

3. A5: Well most people thought my behaviour was strange and it was like why is he acting so…odd…randomly commenting about something that is not even related to the subject

4. Ah well the guy who owns the group sort of asked why I was acting so strangely and I sort of told him and nobody else knew for ages ……until somebody started saying we should remove this guys as an admin so I sort of admitted and sort of owned up

Hierarchy of final themes:

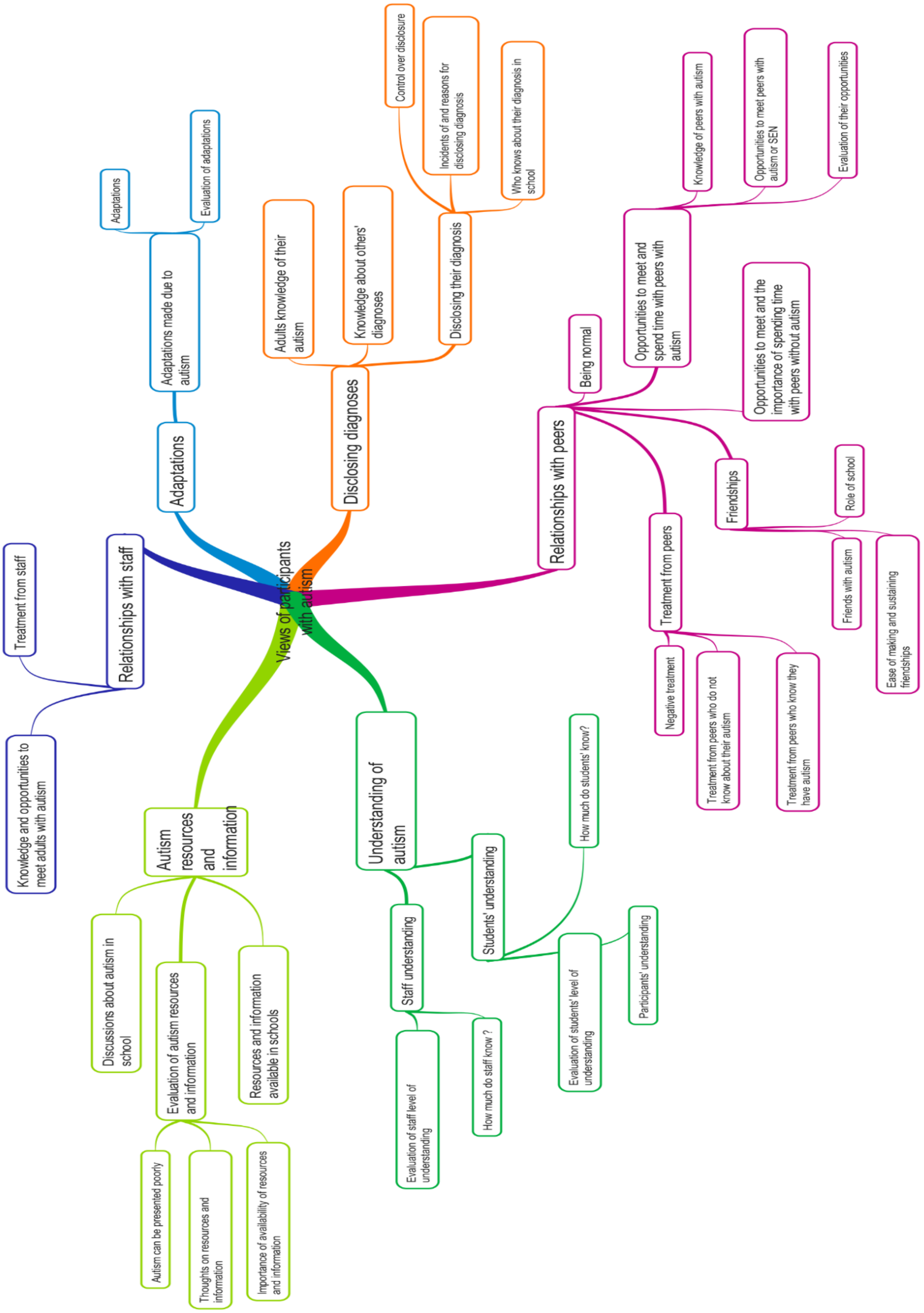


Figure 3: Mind map of final themes for autistic participants

Stage six:

Reporting the findings (see chapter 3).

Appendix eight

Stages of thematic analysis: Focus groups

Stage one:

Each focus group session was transcribed from the recording by myself and repeatedly read to ensure familiarity.

Transcript extract

Group 2 Transcription	Notes
2. S5: Um well I think it kind of ranges from maybe just like not being able to concentrate very much on such a thing at a young age and that’s obviously the far end of spectrum and at the other end you know that’s the more serious end and you could be having? I don’t know 3. I: So it’s like a spectrum? 4. S5: Yeh 5. I: How about anyone else? 6. S6: I heard each ones different so each one has different needs like everyone else and it’s something to do with their brain like their brain functions differently so they see things in a different aspect to everyone else 7. S7: Everyone has it but it’s just at different scales 8. I: It could be like everybody? 9. S7: So everybody has like a tiny bit of it 10. S8: Yeh we talked about it in a science lesson once and it’s about like everyone has a bit of OCD but some people have it a bit more and they can’t like communicate a bit as well as other people 11. I: So S8 you talked about it in perhaps a science lesson… how about everyone else where sort of where have you heard…? 12. S7: My X is like an X and she works with lots of people 13. I: So maybe from family 14. S5: My X used to work with children and there was a little boy with Asperger syndrome and he was like afraid of the lights or something they were too bright for him 15. S6: XXX has autism XXXX (friend) has autism and we think XXXX might be a bit autistic as well	

Stage two:

At stage two each focus group transcript was coded. A list of codes was generated once the first transcript had been coded and then following transcripts were coded using this list, adding new codes as necessary. Below is this initial set of codes for all five focus group transcripts.

Name		**Sources**	**References**
Adaptations have to be ok peers with autism		2	2
Adults' differentiation of their approach		4	19
Adults knowledge of autism		5	26
Adults knowledge of who has autism		2	2
Autism accepted		2	3
Autism hard to explain		1	2
Autism more severe		2	2
Autism not big part of their life		1	3
Autism not seen as a positive thing to have		1	1
Definitions and ideas about autism		4	39
Desire increased understanding		5	23
Disclosure of other needs		1	1
Discussions about autism		4	10
Fitting in		2	2
Group for peers with autism		1	1
Hidden disability		1	1
Important that students have ways to find out about autism		1	2
Increased understanding with age		1	6
Increased understanding would have positive impact		5	24
Interested in whether peers with autism want to learn more about it		1	1
Knowledge of adults with autism		5	8
Knowledge of who has autism		5	27
Lack of confidence about autism knowledge		5	14
Limitations with approaches for teaching about autism		5	27
Negative treatment of peers with autism		4	13
Normal		1	6
Other needs are better known		1	6
Pastoral support available		1	1
Peers believed to have autism identified by behaviour		5	13
Peers disclosure of their autism		5	21
Peers with autism behave differently		2	7
Peers with autism want to be the same as us		1	1
Role of school in preventing negative treatment		2	4
Role of teaching assistants		4	20
School makes adaptations to help students		1	1
SEN areas for peers with autism		4	9
Separation		3	11
Social media		1	1
Sources participants got their autism knowledge from		5	20
Stereotypes or false ideas		1	2

Student shared information about autism with others		1	1
Students have limited understanding of autism		5	27
Students play supporting role to peers with autism		2	4
Suggestions for changing adaptations		1	4
Suggestions for teaching about autism		5	42
Support for peers with autism beneficial		1	1
Teachers' disclosures of peers' autism		5	26
Time spent with peers with autism		5	14
Treat peers with autism with more care		1	1
Treatment of peers when diagnosis is known about		5	43
Understanding of autism due to experiences		4	9
Unsure if peer has autism or not		3	8
Walking on egg shells		3	7
Ways to find out about autism in school		5	37
Would not ask peers if had they autism		2	5
Would not want to disclose diagnosis if they had autism		2	2

Stage three:

The initial set of codes were repeatedly examined to search for themes. From this nine initial themes emerged (shown in bold below), as well as a number of level two (underlined) and level three sub-themes. Similar sub-themes were collapsed into each other.

Initial set of themes:

Name		Sources	References
Adaptations		0	0
Adaptations have to be ok peers with autism		2	2
Evaluation of adaptations		0	0
Suggestions for changing adaptations		1	4
Group for peers with autism		1	1
Pastoral support available		1	1
Role of teaching assistants		4	20
School makes adaptations to help students		1	1
SEN areas for peers with autism		4	9
Separation		3	11
Students play supporting role to peers with autism		2	4
Support for peers with autism beneficial		1	1
Adults' differentiation of their approach		4	19
Autism resources and information		0	0
Autism hard to explain		1	2
Discussions about autism		4	10
Important that students have ways to find out about autism		1	2
Limitations with approaches for teaching about autism		5	27
Sources participants got their autism knowledge from		5	20
Suggestions for teaching about autism		5	42
Ways to find out about autism in school		5	37
Disclosing diagnoses		0	0
Adults knowledge of who has autism		2	2
Disclosure of other needs		1	1
Knowledge of who has autism		0	0
Knowledge of adults with autism		5	8
Knowledge of peers with autism		5	31
Peers believed to have autism identified by behaviour		5	13
Peers disclosure of their autism		5	21
Teachers' disclosures of peers' autism		5	26
Would not ask peers if had they autism		2	5
Fear of doing or saying the wrong thing around peers with autism		3	7
Normal vs different		0	0
Fitting in		2	2

Normal		1	6
Peers with autism behave differently		2	7
Peers with autism want to be the same as us		1	1
Relationship between adults and peers with autism		0	0
Treatment from adults when diagnosis known about		3	5
Relationships with peers with autism		0	0
Time spent with peers with autism		5	13
Treatment of peers		0	0
Negative treatment of peers with autism		4	16
Treatment from peers when diagnosis known about		5	41
Understanding of autism in school		0	0
Adults knowledge of autism		5	26
Definitions and ideas about autism		4	39
Autism accepted		2	3
Autism more severe		2	2
Autism not big part of their life		1	3
Autism not seen as a positive thing to have		3	3
Stereotypes or false ideas		1	2
Desire increased understanding		5	24
Hidden disability		1	1
Increased understanding with age		1	6
Increased understanding would have positive impact		5	24
Other needs are better known		1	6
Participants lack confidence about their autism knowledge		5	14
Students have limited understanding of autism		5	27
Understanding of autism due to experiences		4	9
Student shared information about autism with others		1	1

Stage four:

Further reassessment of the emergent themes took place. Themes were reduced from nine to six.

Name		Sources	References
Adaptations for peers with autism in schools		0	0
Adaptations currently in place		5	23
Evaluation of adaptations		0	0
Suggestions for changing adaptations		4	12
Thoughts on adaptations		5	14
Separation		3	11
Autism resources and information		0	0
Evaluation of autism resources and information		0	0
Important that students have ways to find out about autism		1	2
Limitations with approaches for teaching about autism		5	27
Suggestions for teaching about autism		5	42
How do students currently find out about autism		0	0
Autism found out about by participants from sources other than school		5	20
Autism resources and information available in schools		5	37
Discussions about autism		4	11
Disclosing diagnoses		0	0
Disclosure of other needs		1	1
Disclosure of students' diagnosis of autism		0	0
Peers disclosure of their autism		5	21
Teachers' disclosures of peers' autism		5	26
Knowledge of who has autism		0	0
Adults knowledge of who has autism		2	2
Knowledge of adults with autism		5	8
Knowledge of peers with autism		5	32
Peers believed to have autism identified by behaviour		5	13
Would not ask peers if had they autism		2	5
Relationships with peers with autism		0	0
Normal vs different		0	0
Peers with autism behave differently		2	7
Trying to be normal		3	9
Opportunities to meet and spend time with peers with autism		5	11
Treatment of peers		0	0
Bullying		4	16
Fear of doing or saying the wrong thing around peers with autism		3	6
Treatment from peers when diagnosis known about		5	41
Staff treatment of peers with autism		5	18
Understanding of autism in school		0	0
Definitions and ideas about autism		0	0

Autism not big part of their life		1	3
Autism not seen as a positive thing to have vs accepted		5	6
Students' definitions and ideas about what autism is		4	43
Evaluation of the level of understanding in school		0	0
Desire increased understanding		5	24
Increased understanding would have positive impact		5	24
Staff level of understanding about autism		5	26
Students' level of understanding		0	0
Factors related to understanding		4	16
Other needs are better known		1	6
Participants lack confidence in their autism knowledge		5	14
Students have limited understanding of autism		5	25

Further revision:

Name		**Sources**	**References**
Adaptations for peers with autism in schools		0	0
Adaptations currently in place		0	0
Other adaptations		5	14
Role of TA		4	9
Teachers' treatment of peers with autism		5	17
Evaluation of adaptations		0	0
Suggestions for changing adaptations		4	13
Thoughts on adaptations		5	19
Separation		3	11
Autism resources and information		0	0
Evaluation of autism resources and information		0	0
Limitations with approaches for teaching about autism		5	27
Suggestions for teaching about autism		5	44
How do students currently find out about autism		0	0
Autism found out about by participants from sources other than school		5	20
Autism resources and information available in schools		5	37
Discussions about autism		4	11
Disclosing diagnoses		0	0
Disclosure of students' diagnosis of autism		0	0
Peers disclosure of their autism and reasons behind this		5	20
Teachers' disclosures of peers' autism and reasons behind this		5	26
Knowledge of who has autism		0	0
Autism identified by behavioural traits		5	13
Knowledge of who has autism in the school		5	43
Would generally not ask peers if they had autism		4	9
Miscellaneous		0	0
Autism not big part of their life		1	3

Relationships with peers with autism		0	0
Normal vs different		0	0
Peers with autism behave differently		2	7
Trying to be normal		3	10
Opportunities to meet and spend time with peers with autism		5	11
Treatment of peers		0	0
Autism accepted		2	3
Bullying		4	16
Fear of doing or saying the wrong thing around peers with autism		3	6
Treatment from peers when diagnosis known about		5	40
Understanding of autism in schools		0	0
Evaluation of the level of understanding in school		0	0
Desire increased understanding		5	24
Increased understanding would have positive impact		5	24
Staff level of understanding		5	26
Students' definitions and ideas about what autism is		4	43
Students' level of understanding		0	0
Factors related to understanding		4	16
Other needs are better known		2	7
Participants lack confidence in their autism knowledge		5	14
Students have limited understanding of autism		5	25

Stage five:

The final themes were decided upon and given names.

Example of some extracts from 'Adaptations for peers with autism': 'Adaptations currently in place': 'Adaptations'

The previous level three sub-theme 'Role of TA' was combined with 'Other adaptations' and is now called 'Adaptations'.

Internals\\Group 1 Focus Group Transcript> - § 7 references coded [7.88% Coverage]

5. S3: I think they know quite a lot because they've got like XX (names SEN area) where they are helping like they help the people with autism so..…I think if they've got any problems and that they can go there

6. S1: No it's just like..um I don't think they have a list or anything I just think if like they have a teaching assistant then they might tell them but I don't think they really do know

<Internals\\Group 2 Focus Group Transcript> - § 6 references coded [4.12% Coverage]

7. S7: I've seen a kid in this room (SEN area) before and I think he is in year X or year X or something but he's got I think he might have autism but he hangs out here in break and lunch time

8. they have their personal assistant that goes around with them and if they need any extra help in class they'll get taken out of class…and they'll get taught or caught up to whatever they are going on about in that class …they could also take time out if things are getting too much for them or …..go speak to someone or just have a break basically….if it's getting too much for them

<Internals\\Group 3 Focus Group Transcript> - § 5 references coded [3.67% Coverage]

9. S11: Yeh there is people to go around with them if they want

10. S9: Obviously the XX is somewhere they could go if their getting bullied or they've got problems…. to do with their autism or not

11. I: So it's like support for students can go to get
12. S9: Yeh

<Internals\\Group 4 Focus Group Transcript> - § 5 references coded [1.62% Coverage]

13. But I think we have our XX and… another one I don't know the name of it and um yeh..um a lot of the time they…

14. S15: They'll be in lessons but they'll have a helper …

<Internals\\Group 5 Focus Group Transcript> - § 1 reference coded [0.36% Coverage]

15. S18: Might be..some of them have one-to-one and stuff
16. I: So they would come out of the lesson with the one-to-one?
17. S18: Mmmm

Hierarchy of final themes:

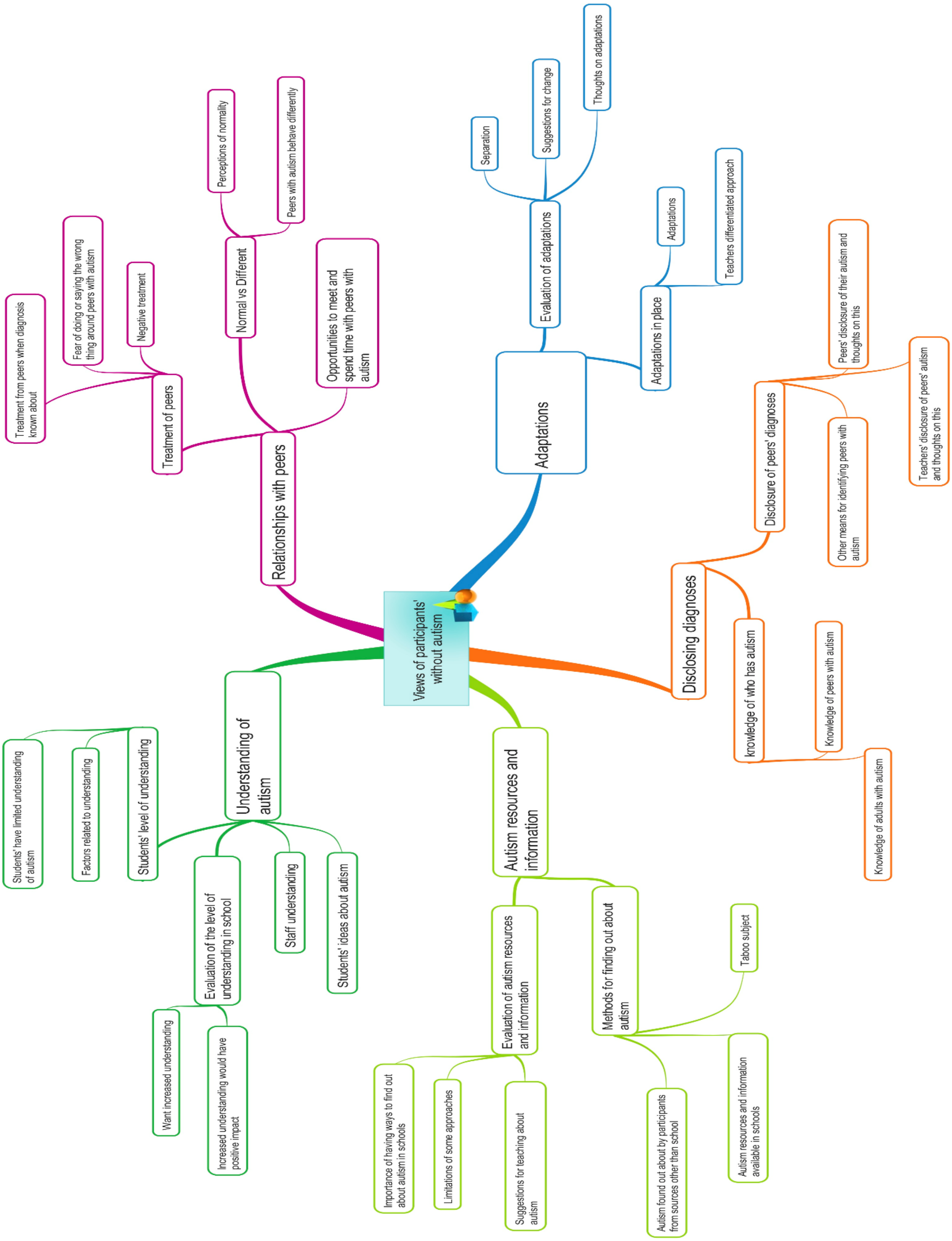


Figure 4: Mind map of final themes for non-autistic participants

Stage six:

Reporting the findings (see chapter 3).

Appendix nine

Quantitative information from analysis write up

Table 4: Means for finding out about autism in school reported by autistic participants

Resource	Participants' comments	Total
Books	A17- books in SEN area only A28- believes would be available in lesson required it A5- only 1 book available A11- bought in own book to school, unsure if books available in school- has not seen any A38- maybe	4
DVDs	A28- believes would be available in lesson required it A38- maybe	2
Lessons	A38- maybe in PSHE A5- maybe once or twice	2
Assemblies	A5- mentioned once	1
Posters and leaflets	A28- 1 or 2 posters promoting awareness and has seen a poster advertising events for people with autism A14- maybe 1	2
Technology, e.g.- Internet	A11 A38- available A5- e.g.- Wikipedia	3
People with knowledge to ask in school	A11 A38- TAs or students with autism	2

Table 5: The people who autistic participants perceive to know about their diagnosis in school

Who knows	No. of participants who think they know	Total (excluding those who are unsure)
Teachers	A11- some A12- some A14- some A17-some A28- a few A34- don't know A38- a good section of	6
Friends	A12- some A14- some A17 A28- cannot remember if told them A34- can't remember A5- told at least 2 but feels can't always trust friends to keep secret	4
Teaching assistants	A11- unsure A12- depends on who they are A14 A28- a few A38- all in SEN area	4
Other students	A11 A12- some A38- some might have figured out, might not know is autism A5- might know, unsure	3
Other students with SEN	A38	1

Table 6: Full list of suggestions for teaching about autism from focus group analysis

Approach	Number of participants who suggested it (or agreed with suggestion)
Lessons in tutor time	4
Assemblies	4
Lessons (typically PSHE type)	10
Use of TV/DVD clips	5
Guest speakers	5
Student mentors with knowledge about autism	4
Books/library resources	3
Small group work	1
Direct input with follow up	3
Autism information in places students look (including computer screen savers)	4
Seeking opinions of autistic students about approach to take	6
A term dedicated to learning about SEN	2

Appendix ten

Reflective account of the research journey and implications for professional practice

Reflecting on my experiences of undertaking research for both papers has lead me to think about the implications it has had on myself and for professional practice.

Recruiting autistic participants for the research was difficult, particularly for the quantitative aspect where larger numbers were required. The literature indicates that understanding of autism from those with it who know about it best remains limited (Kapp et al., 2013) and there are calls for further research employing participant voice (Gilling 2012). Therefore it is important that difficulties with recruitment are overcome to ensure this can happen.

My journey along the recruitment process highlighted a number of important implications for professional practice and future research. Upholding strong ethical standards is important no matter how difficult recruitment is. A number of decisions I made in regards to ethics restricted my sample size, for example using opt-in rather than opt-out consent and providing participants with the option to leave blank any question on a scale they did not feel comfortable answering. This resulted in increased anxiety as well as additional travel as I widened my recruitment zone; nonetheless, this was important to ensure that all of the participants wanted to take part and only involved themselves in aspects they felt comfortable with.

I have also reflected upon the number of data collection sessions and the burden on participants. Keeping the burden placed on participants to a minimum was important to me and highlighted within ethical research standards (BERA, 2011) and therefore I opted to do each interview during one session. However, upon reflection and further reading, multiple sessions of a shorter nature, as recommended by Hill (2014), may have been more appropriate given the nature of the topic. This is something for further exploration within future research with autistic individuals.

Closely linked to this is the importance of the relationship with the participating schools. Research has shown the value schools place in their relationship with their EP and vice versa (Ashton & Roberts, 2006) and my experience is that this relationship is just as important within the research process. Keeping in close contact with staff supported the ethics process, for example by ensuring I became aware that a participant no longer wanted to take part but their need to please others resulted in them only voicing this to a trusted teacher. A close relationship with the schools also enabled me to work with staff, who knew the participants best, to facilitate the completion of the scales.

An important aspect within this relationship, and something which became apparent from my initial recruitment visits/telephone conversations, was that schools needed to ‘buy-in’ to the research. In some cases an interest from the member of staff in the topic or in participating in research was enough; however, others appeared to desire extrinsic incentives. For example a number of schools wanted raw data. This had to be carefully managed to ensure they understood that this was restricted to ensure participants’ confidentiality could be upheld whilst making sure they left feeling happy they would access the general findings. Barrett (2006) refers to this in terms of ‘gatekeepers’ who need to be won over, and as I opted to do, suggests providing information to schools which ensures the research sounds interesting and offering to provide access to the findings upon completion. Although incentives and interest in the research are important, I also feel the relationship skills we utilise in the EP role, particularly the principles of attuned interaction (Kennedy, 2011), are invaluable here in developing a partnership with schools.

Finally, an interesting debate, and one that I have wrestled with myself over the last two years, is whether to use person-first language or not. University modules as part of my first year of training on the doctorate for which this research is submitted, advocated for the use of person-first language and therefore this is something I have adopted since. However, once I started exploring literature for this research I began to question my reasons behind doing so and looking at differing viewpoints, such of that of Autistic Hoya (2011) and Sinclair (2013) who argue for the use of ‘autistic person’ because the condition is an inherent aspect of an autistic person’s identity. One of the key things I have taken from this research is a desire to support autistic adolescents to accept their autism as part of their identity and help schools to create an environment in which autism is part of the norm rather than shying away from it. Therefore upon completion of this research I came to the decision that use of the term ‘autistic person’ most accurately reflected these aims. From my own experience, and through accessing the ongoing debate on the subject (Autistic Hoya; Blaska, 1993; Sinclair, 2013; Snow, 2009), I am aware that not everyone is happy with a move away from person-first language and therefore in our casework with autistic individuals and their families I think it is important that we are led by those we are working with case by case.