THE MENTAL HEALTH OF YOUNG PEOPLE WITH
AUTISM AND ASPERGER SYNDROME IN MAINSTREAM
SECONDARY SCHOOLS: A MULTIPLE CASE STUDY
APPROACH


by

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# ABSTRACT

The increased prevalence and negative impact of mental health difficulties amongst those with autism and Asperger syndrome has been reported by researchers, clinicians and people with autism themselves. Schools are key environments for those with autism, but there is little research regarding how they promote or demote their mental health.

Eleven young people in Key Stage Three from three mainstream schools were part of a multiple case study, which explored and compared the perspectives of young people, their parents and school staff, regarding the mental health of those with autism or Asperger syndrome. Data were gathered using semi-structured interviews and subjected to thematic analysis.

The well-being of many young people was reported to be good, although two showed signs of stress daily. In some cases well-being had varied significantly over recent years. Eight pairs of factors that promoted or demoted mental health were identified. These related to ethos, awareness of needs, friendships, learning support, pastoral care, noise levels, predictability and organisational skills. Further research is needed to clarify these factors, but this study supports the notion of schools as mental health promoting environments for those with autism and Asperger syndrome and highlights potential areas of focus.

# DEDICATION

This thesis is dedicated to all young people and their families who struggle on a daily basis with the impact of mental health difficulties and autism.

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# CHAPTER 1:

# AIMS OF THE RESEARCH

## 1.1 Introduction

Mental health difficulties can have a devastating impact on the lives of those with autism and Asperger syndrome. Despite this, mental health promotion for this group has been generally overlooked by previous research. This study looks at the emotional well-being of young people with autism and Asperger syndrome by considering the perceptions and opinions of the young people themselves, their parents and school staff who know them well. It also considers their views regarding how schools can impact positively and negatively on these young people's mental health.

This chapter introduces the current piece of research and sets it in context. It considers four main areas – the background and inspiration for the research, narrowing the focus for the study, its principal aims and anticipated outcomes. Finally there is a brief description of the structure of the thesis itself.

## 1.2 Background to the Research

Working as the Specialist Senior Educational Psychologist for Autism within a large local authority, I had frequent contact with schools, parents and young people with

autism and Asperger syndrome. The idea for the research arose from a situation which I had observed whilst carrying out my role. During Key Stage Three some academically able young people with autism or Asperger syndrome started to exhibit high levels of behavioural problemsin school. Behaviours included frequent aggression towards staff and students and refusal to follow instructions or complete learning tasks.  In some cases this had led to high levels of support provided by the Local Authority, in others the young person left mainstream and transferred to specialist provision. My experience of supporting schools in meeting the needs of these young people indicated that these behaviour difficulties and subsequent problems with inclusion could be related to (often unrecognised) mental health needs, such as anxiety or depression.

This pattern has been reported elsewhere; in a substantial review of education for children with autism in England, the Autism Educational Trust concluded that one of the two main groups of children with autism in out-of-authority specialist provision are able young people who managed during primary school but found secondary school very difficult and developed significant mental health and behavioural difficulties (Jones et al., 2008). Also supporting this observation are other reports from the literature of an increase in mental health difficulties at adolescence in young people generally (Meltzer et al., 2000) and young people with autism and Asperger syndrome specifically (Wing, 1992; Ghaziuddin, 2005a; Tantam, 2007).

In addition to the identified problem, through my work as an Educational Psychologist and completing an assignment as part of my doctoral studies, I had gained an interest in the application of mental health promotion frameworks to school settings. As part of my EdPsychD course, I had worked with a nursery school to apply MacDonald and O'Hara's (1998) framework. The argument for mental health promotion in settings such as schools, as opposed to a diagnosis and treatment based approach to meeting mental health needs is, in my view, compelling and is discussed further in sections 2.2, 2.3.1 and 2.3.2 of this thesis.

Research in the area of autism and mental health is timely as it has been a key area of study in recent years. Practitioners are becoming increasingly aware of the increased frequency of mental health difficulties in those with autism and Asperger syndrome (Ghaziuddin, 2005a; Madders, 2010). Many have reported the challenges of including academically able young people with autism or Asperger syndrome in mainstream schools (Batten et al., 2006; Jones et al., 2008; Humphrey, 2008; Frederickson et al., 2010) and some have linked this to mental health needs (Jones et al., 2008). However, mental health promotion and demotion for this group of young people in school settings has also received scant attention from researchers.

**1.3 Focus and Boundaries of the Current Study**

I decided that only mainstream schools would be selected for the study because one of the purposes of the research was to work towards promoting inclusion by supporting mainstream schools to meet the needs of these young people and prevent their transfer to special provision. In addition, the environment, both physically, socially and in terms of sensory input, of a mainstream secondary school is so different from a special school that there may be different factors involved in promoting and demoting mental health, which may have affected the cohesion of the study.

The study targeted the 11-14 year old (Key Stage Three) age group for two main reasons. Firstly, as described earlier, it was at Key Stage Three when some young people with autism locally had begun to show increased behaviour problems and in some cases this had led to specialist provision. Secondly, research indicates an increase in the mental health needs of young people with autism (Wing 1992; Tantam and Prestwood, 1999; Ghaziuddin, 2005a) at the start of adolescence, which may be connected to the local observations.

Although some studies in this area consider information about the young person's mental health from only one source, usually a parent, in recent years there has been a move to including two (Gadow et al., 2008; Kanne et al., 2009) or even three informants (Vickerstaff et al., 2007; Hurtig et al., 2009) when investigating the mental

health of children and young people with autism and Asperger syndrome. Many studies describe a lack of agreement between different respondents when discussing the mental health of young people with autism or Asperger syndrome (Gadow et al., 2008; Hurtig et al., 2009; Kanne et al., 2009; Lopata et al., 2010) so I decided that the most reliable insight into the nature of each case would be gained through obtaining data from three sources, parent, a key member of school staff, and the young person themselves.

A further consideration when recruiting people for the study was to decide whether or not to include young people with a diagnosis of autism or Asperger syndrome or both. During my work as the Specialist Educational Psychologist for Autism in the Local Authority, I had observed inconsistencies in diagnosis rates and procedures across the county. The five clinical teams in different areas of the county used different procedures and diagnosed dramatically different numbers of children as having autism and Asperger syndrome, even when variations in population size accessing them were taken into account. Inconsistencies in diagnosis are also noted in the literature (Szatmari, 2004; Jones et al., 2008; Witwer and Lecavalier, 2008; American Psychiatric Association, 2010).

Linked to these diagnosis difficulties there is ongoing debate about whether or not Asperger syndrome and high-functioning autism can be distinguished. Many studies (for example, Ozonoff et al., 2000; Kim et al., 2000; Gilchrist et al., 2001; Macintosh

and Dissanayake, 2006a and b; Witwer and Lecavalier, 2008) have found little difference between the behaviour, social interactions, comorbid mental health difficulties and outcomes of young people diagnosed as having high-functioning autism and those diagnosed as having Asperger syndrome. Indeed, when Ruiz Calzada et al. (2011) interviewed young people aged 9 –16 years with Asperger syndrome or high-functioning autism and their families, they found that many young people and their parents thought that they were either exactly the same thing or very similar. As a result, there is a proposal to remove the term Asperger disorder from the forthcoming DSM V (American Psychiatric Association, 2010).

However, other studies have found differences between high-functioning autism and Asperger syndrome. Both Tonge et al. (1999) and Thede and Coolidge (2007) found higher levels of anxiety in those with Asperger syndrome compared with those with high-functioning autism and in the Tonge et al. study those with Asperger syndrome also showed more disruptive behaviour. Szatmari (2004, 2009) found that language impairment at the age of six years distinguishes the two groups. Ghaziuddin (2010) argues for the preservation of the term Asperger syndrome to define those young people who attempt to interact socially but fail to understand social rules.

In summary, it is not clear whether or not there is sufficient evidence to support the use of the labels high-functioning autism and Asperger syndrome as separate syndromes.  As this question remains unclear, and also as a result of the diagnostic

inconsistencies in the local area, for the purposes of this study, I decided to include young people with both diagnoses and make no distinctions between the two groups in carrying out the research.

Mental health difficulties are sometimes compartmentalised into internalising disorders (in which difficulties are projected inwards leading to anxiety and depression) and externalising disorders (in which difficulties are projected outwards leading to conduct problems and oppositional behaviour). The research focuses on mental health needs generally but has a particular emphasis on internalising disorders as some studies indicate that people with autism or Asperger syndrome are especially likely to suffer from these (Brereton et al., 2006; Tantam 2007; Madders, 2010). Internalising difficulties may also be less evident in school than externalising problems and therefore receive less attention (Cowie et al., 2004).

## 1.4 Aims of the Study

The aim of the research was to examine the emotional well-being of Key Stage Three young people with autism and Asperger syndrome in mainstream secondary schools and whether the young people themselves, their parents or teacher reported any manifestations of mental health difficulties reflected in the young person's cognitions, emotions, behaviours or physiology. The focus was clearly on the young people within their school contexts and how the environment, organisation and

practices of the schools they attend supported their emotional well-being, and also how the school environment could demote their mental health.

This study aimed to discover the reality of the situation as perceived by the young people themselves, their parents and school staff and gain their viewpoints on what they perceived to be mental health promoting and demoting within the school context. It focused on gaining an understanding of the similarities and differences between these different perspectives and opinions. The aims of the study are illustrated in Figure 1, below.

**Figure 1: The Aims and Focus of the Research**

| | |
|---|---|
| | Positive impact of school policies and practices (mental health promoting factors) |
| 3 different perspectives –<br><br>YOUNG PERSON<br>PARENT<br>MEMBER OF<br>SCHOOL STAFF | Young person's well-being – happiness, stress, anxiety, depression and levels of aggression |
| | Negative impact of school policies and practices (mental health demoting factors) |
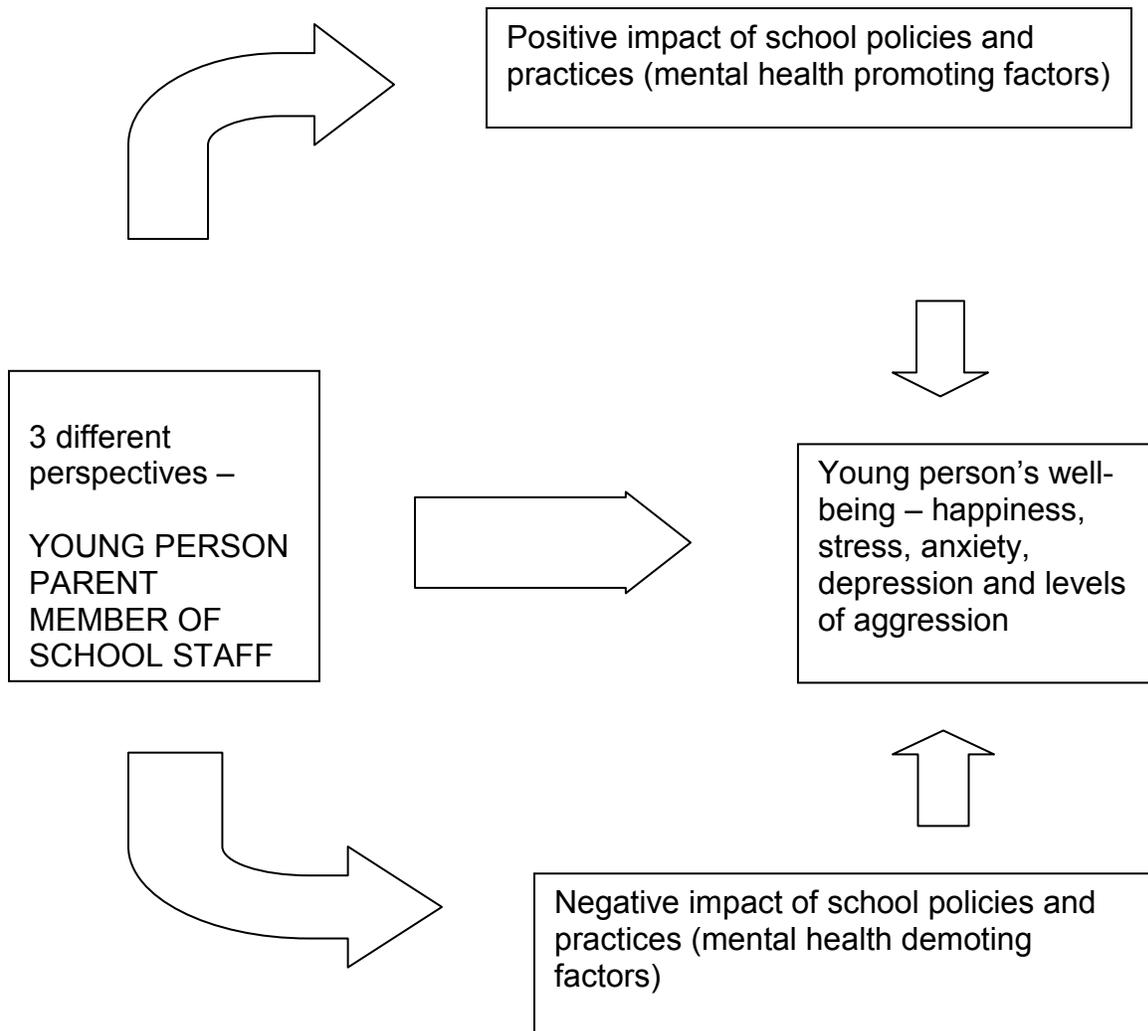
By aiming to describe the perspectives from three different participants in each case study, this research hoped to investigate each young person's well being and the impact of their school environment on this, both positively and negatively.

## 1.5 Research Questions

From these aims and examination of the relevant literature as discussed in Chapter 2, the following research questions were derived:

i) Which emotions do young people with autism or Asperger syndrome commonly feel in school?

ii) Do young people with autism and Asperger syndrome show any manifestations of mental health difficulties in school or home contexts?

iii) How do the young people concerned, their parents and school staff, differ in their perceptions regarding the young people's mental health?

iv) What factors lead to stress and mental health demotion for young people with autism and Asperger syndrome and are any of these affected by the school environment?

v) What are mainstream secondary schools doing that successfully promotes the mental health of this group of young people?

vi) How do the young people themselves, their parents and school staff differ in their views and perceptions regarding which school based factors promote and demote the young people's mental health?

## 1.6 Anticipated Outcomes

In line with my professional practice informing the development of the research questions, I also aimed to carry out research which would inform practice. My motivation for carrying out this study included a desire to improve the situation of young people with autism and Asperger syndrome in similar positions to those I worked with as an Educational Psychologist. Attention to the detail of the experience of mental health problems in this group and factors that promote and demote mental health could lead to a greater understanding of this important area. Such increased understanding could eventually contribute to policies and practices in schools that improve the mental health of this group of young people, possibly reducing problems with behaviour, and social and educational exclusion.

Ghaziuddin (2005a) argues that, whilst it may not be possible to cure autism, tackling the associated mental health difficulties in people with autism or Asperger syndrome leads to an improvement in their quality of life, facilitates better learning in school and impacts positively on the person's family. This clearly is a subject that is worthy of further investigation.

## 1.7 Structure of the Thesis

This thesis reports the progress of the study towards these aims and outcomes. The next chapter describes relevant literature in the area of autism and mental health and how this has informed the research. The third chapter describes the methodology, research design and methods used. The fourth chapter presents the results of the study. The final chapter discusses the limitations of the current piece of research, assesses what conclusions can be drawn and how these relate to the literature. It also identifies next steps for both research and professional practice in this important area.

# CHAPTER 2:

# LITERATURE REVIEW

## 2.1 Introduction

Following on from the research questions outlined in section 1.5, this chapter reviews the relevant literature to provide a context for the research. To provide background there is a brief discussion of mental health difficulties in adolescence and the increasing role of schools in mental health promotion for this age group.

The main focus of the chapter surrounds research investigating mental health difficulties in people with autism or Asperger syndrome. This consists of four key areas. Firstly, studies which consider the prevalence of various kinds of mental health difficulties in those with autism or Asperger syndrome are discussed and evaluated. Then the impact of mental health difficulties on this group and those around them is briefly discussed.

The next two sections tackle factors that influence the mental health of those with autism and Asperger syndrome, with a strong emphasis on the environment, particularly the school environment, in keeping with the research questions. Also in keeping with the research questions, there is an emphasis on both mental health promotion as well as causes of mental health difficulties. Possible reasons for the increased rate of mental health difficulties in people with autism or Asperger

syndrome are considered, along with the research evidence provided in support of each reason, but various ways of promoting the mental health of young people with autism or Asperger syndrome that are recommended in the literature are described.

To conclude, areas within the literature that need further exploration are identified and from these, key elements which have influenced the design of the current study are discussed.

## 2.2 The Mental Health of Young People

Grand claims have been made for the vital role that positive mental health plays in our lives and our society. Weare (2007, p.245) writes that "mental health is a basic human right, and is fundamental to all human and social progress. It is a basic requirement for a happy and fulfilled life for individual citizens, for effectively functioning families and for social cohesion."

Despite the value of good mental health, it does appear that many young people today suffer from significant mental health problems, particularly in adolescence. A large-scale epidemiological survey, concerning the mental health of children and young people in Great Britain, carried out for the Office of National Statistics (Green et al., 2005), found that 11.5% of 11 to 16 year olds had a clinically recognisable mental disorder. A previous survey by the same authors revealed that there is also

often a marked increase in mental health difficulties at the start of adolescence (Meltzer et al., 2000).

Various explanations have been proposed for this increase including the number of transitions that occur during adolescence (Leffert and Petersen, 1995), biological, cognitive and social changes (Lob and Wragg, 2004), a change in family and peer relationships (Fombonne, 1995; McLaughlin and Clarke, 2010) and the increasing demands of the school system (Fombonne, 1995). However, research also indicates that many adolescents negotiate these transitions without significant difficulties (Hurry et al., 2000; Lob and Wragg, 2004; Dogra et al., 2009).

Although young people's mental health difficulties often remain unrecognised (Mental Health Foundation, 1999; National Institute for Health and Clinical Excellence (NICE), 2005), mental health difficulties in adolescence have a high likelihood of persisting into adult life and are associated with an increased likelihood of further psychiatric conditions developing later on (Fombonne, 1995). Poor mental health is associated with a variety of negative outcomes for young people including poor educational attainment, absences from school, poor physical health, increased rates of offending and lower rates of employment (Green et al., 2005; Herman et al., 2009). In addition to the obvious detriment to the young people concerned, there are also significant social and economic costs to society (Mental Health Foundation, 2005; National Advisory Council report, 2010).

However there is much more to mental health than the absence of mental illness (Shooter, 2008). Various definitions of mental health have been proposed. One of the most frequently quoted is from the Bright Futures report (1999, p.6):

*"Children who are mentally healthy will have the ability to*

- *Develop psychologically, emotionally, intellectually and spiritually*

- *Initiate, develop and sustain mutually satisfying personal relationships*

- *Use and enjoy solitude*

- *Become aware of others and empathise with them*

- *Play and learn*

- *Develop a sense of right and wrong; and*

- *Resolve (face) problems and setbacks and learn from them."*

A different definition was proposed in the National CAMHS Review published by the Department for Children, Schools and Families and Department of Health (DCSF / DoH) (2008, p.14-15):

*"Mental health and psychological well-being are not about being happy all the time. They are about having the resilience, self-awareness, social skills and empathy required to form relationships, enjoy one's own company and deal constructively with the setbacks that everyone faces from time to time."*

It could be argued that many people with autism or Asperger syndrome will find it very difficult to achieve some of these definitions of mental health, as a result of their underlying difficulties with socialisation and communication. Several features of the definition from the Bright Futures report including developing relationships, being aware of others and empathising, are core areas of difficulty for those with autism and Asperger syndrome. Therefore, according to this definition, those with autism or Asperger syndrome would be much more likely to be identified as having difficulties with mental health. Indeed, there are problems with diagnosis of mental health difficulties in those with autism and Asperger syndrome, including this overlap of 'symptoms' (discussed further in section 2.4), and, as a result, with establishing the prevalence of mental health difficulties in this group (discussed in more detail in section 2.5.2). The extent to which young people with autism are in fact more likely to suffer from mental health problems is discussed further in section 2.5.1.

In addition, for some young people with autism and Asperger syndrome, focusing on such areas might lead to stress rather than improved well being. A person with autism or Asperger syndrome may be more comfortable with a definition of mental health that focuses less on social interaction and more on developing meaningful activities related to their interests (which may in some cases be more solitary than others would choose but still mental health promoting).

It seems unlikely that those with autism and Asperger syndrome are the only group of young people to be adversely affected in this way by definitions of mental health. Those with a range of other needs, such as learning or physical disabilities, may also find it hard to achieve the elements of the Bright Futures definition proposed earlier in this section.

In line with this argument, Dogra et al. (2009, p.20) criticise such definitions for failing to "acknowledge the diversity of human responses to different experiences and the diversity of human individuality and ability" and emphasise the idea of a continuum between emotional well-being and mental illness. At one end of the spectrum is complete mental health and at the other end severe mental illness.

Other authors such as Secker (1998) and MacDonald (2006) have criticised any definition of mental health as being very culture and value laden. This leads them to impose the values of the writer onto the lives of others, and exclude many whose culture is different. In addition they focus on the individual, rather than on the environment that the individual exists in, which may have a significant impact on an individual's mental health.

It could be argued that selecting only those young people with a medical diagnosis of autism or Asperger syndrome to participate in the study is somewhat contrary to an ecological approach, and that it would be preferable to select an inclusive group of young people of a particular age, regardless of diagnosis. However, there are a

number of arguments against this. As previously noted, the viewpoints of those with autism and Asperger syndrome on mental health may be affected by their differences (for example they may not derive the same benefit from building relationships). In addition, young people with autism and Asperger syndrome are more at risk of mental health difficulties than their neurotypical peers (as described in section 2.5.1) and although adults with autism have written about their experiences in schools as promoting or demoting their mental health, no studies have been found which seek to determine the views of young people with autism or Asperger syndrome regarding mental health promotion and demotion in school settings. I consider that these factors justify the use of a medical diagnosis to select the young people to participate in an ecological study.

In contrast, to the focus on definitions of mental health, an ecological approach considers the factors that promote and demote mental health within the environment (Secker, 1998; du Bois et al., 2003; MacDonald, 2006; Herman et al., 2009). This may be more fruitful than programmes designed to promote the skills of individuals who have difficulties or the treatment of those who are defined as mentally ill. As part of this ecological approach there has been a move towards mental health promotion through creating environments which develop the mental health of whole populations (Hall, 2010).

It has been increasingly common to use published frameworks (such as those produced by MacDonald and O'Hara, 1998, or Hornby and Atkinson, 2003) for reviewing health promotion activities, and identifying opportunities for further development. Schools are viewed as a key environment for mental health promotion and their role in this is discussed in the next section.

## 2.3.1 The Role of Schools in Mental Health Promotion

Mental health promotion in schools in the United Kingdom is a topic on which a significant amount has been published in recent years. Space restrictions do not permit a full discussion of all published research in this area. As the main focus of the current piece of research concerns the mental health of young people with autism or Asperger syndrome specifically, this section is a necessarily brief introduction to the area of mental health promotion in schools more generally.

Mental health has in recent years become a key focus for schools (Mental Health Foundation 1999; O'Hanlon, 2000; Department for Education and Skills (DfES) 2001; Hornby and Atkinson, 2003; Weare, 2008; Hall, 2010). Although this drive to promote positive emotional well-being in children in schools is certainly not new (Dixon, 2010), it has become ubiquitous with a raft of initiatives such as Social and Emotional Aspects of Learning (SEAL) (2005) and Targeted Mental Health in Schools (TaMHS) (2010) which are congruent with the mental health promotion

approach described above (Hall, 2010). However, a focus on mental health promotion in schools is not without its difficulties, or its critics. Ecclestone (Ecclestone and Hayes 2009; Ecclestone 2010) has questioned the lack of debate and limited evidence base for some claims made. There is a lack of research and evaluation regarding mental health promotion in the United Kingdom and Europe more generally and most research in the area comes from the United States (as Wells et al., 2003; Weare, 2007, and Coleman, 2009, have reported). It can be difficult to evaluate programmes due to the wide variability of programmes and outcome measures (Wells et al., 2003).

Clearly within any study, the size of the sample being studied and the nature of this sample (for example, factors such as the age of participants and any diagnosis) has a significant influence on the interpretation of the study's results, affecting both the validity and generalisability of the conclusions. If there are only a few people in the study, the risk is that they may in fact be a sub-sample of a bigger and more diverse population. This makes it hard to generalise from the study's conclusions.

For example, Tobias (2009) and Osborne and Reed (2011) both carried out research into the inclusion of young people with autism in mainstream secondary schools, which is cited in section 2.8.2. However, in Tobias' study only five parents and ten young people participated and all were connected to the same secondary school whereas Osborne and Reed had a sample size of 105 pupils from 91

different schools. The generalisability of the latter study is greater as a result of the larger sample size and much wider range of schools involved. Similarly, small sample size is a problem affecting the generalisability of many of the studies concerning the prevalence of mental health difficulties in autism. This is discussed further in section 2.5.2. Throughout the literature review, sample size and characteristics are noted when this is considered especially pertinent to the conclusions drawn.

Despite these concerns there are some compelling reasons for conducting mental health promotion in schools. These include the fact that there are links between positive mental health and academic success (Cowie et al., 2004; Weare 2008; Layard and Dunn, 2009; Herman et al., 2009). The presence of mental health problems makes teaching more difficult  (Atkinson and Hornby 2002; Herman et al., 2009) and affects teachers' own well-being (Rothi and Leavey, 2006). Evidence suggests that in many cases parents (Department of Health (DoH), 2006; Weare 2007) and young people themselves (Cowie et al., 2004; DCSF/DoH, 2008) approach a teacher when there are concerns about a young person's mental health. There is also a moral argument that mental health promotion is intrinsically worthwhile (MacDonald and O'Hara, 1998; Cowie et al., 2004)

Although there are some compelling reasons to conduct out mental health promotion in schools, several factors can impede such work including the dominant role of the

National Curriculum (O'Hanlon, 2000) and of testing and league tables (Finney, 2006; Shooter, 2008). Aligned with this some staff in schools view mental health promotion as outside their remit and locate problems within individual children (Atkinson and Hornby 2002; Music, 2007; Tyler, 2010) and a great number of authors report a lack of teacher knowledge in this area (Atkinson and Hornby, 2002; Weare and Gray, 2003; DoH, 2006; Rose et al., 2009; Finney, 2009). As a result those seeking to promote mental health within schools are often separated from the main work of the school, carrying out reactive rather than preventative work and their actions do not influence the schools' work more systematically (Spratt et al., 2006; Music, 2007). Perhaps as a result of these concerns, Rowling (2009) argues for the need to view the school itself as a crucial factor and to use knowledge from educational research and school processes when trying to promote mental health in schools.

### 2.3.2 Factors that Promote Young People's Mental Health in Schools

From considering the literature in the area, there does seem to be convergence on key features of programmes that promote mental health in school, many of which are as likely to impact on those with autism and Asperger syndrome as on their peers. These are briefly listed below. In many cases these features are advocated by huge numbers of writers on the subject. Where this is the case, a small number of the most pertinent references have been selected.

Promotion of mental health in schools is supported by:

- o Mental health promotion programmes that start early and last for many years (Wells et al., 2003; Weare, 2007; Fraser and Blishen, 2007; Rowling, 2009)

- o An approach where different levels of the schools' work are targeted (Hornby and Atkinson, 2003; Roffey, 2008). For example, Hornby and Atkinson (2003) describe their framework for promoting mental health in school which operates at four different levels – the school ethos, whole-school organisation and policies, pastoral provision and procedures and classroom practice.

- o A whole school approach where mental health is part of all the school's work and its underlying ethos (DfES, 2001; Cowie et al., 2004; Roffey, 2008; Weare, 2008; Rowling, 2009; Herman et al., 2009; Layard and Dunn, 2009; NICE, 2009). This ethos needs to include an emphasis on valuing all in the school (Atkinson and Hornby, 2002) and a culture of inclusiveness (NICE, 2009).

- o A well maintained physical environment (Weare, 2008; Duckett et al., 2008)

o Pastoral support and guidance, perhaps including individual attention on a regular basis with a trusted adult for some students (Atkinson and Hornby, 2002; Duckett et al., 2008; NICE, 2009; McLaughlin and Clarke, 2010).

o Teaching key skills to promote social and emotional competence within individuals (Weare, 2008; Layard and Dunn, 2009; NICE, 2009). The relative balance of this is disputed however, with some authors arguing that the other 'whole-school' factors are more important and that by focusing on the individual's apparent deficits, interactions that may be demoting their mental health in the school environment may be ignored (see for example O'Hanlon, 2000; McLaughlin, 2008; Herman et al., 2009; McLaughlin and Clarke, 2010).

o Having a focus on developing and maintaining friendships, for example through developing social skills and having systems of peer support (Atkinson and Hornby, 2002; Cowie et al., 2004; Duckett et al., 2008; Roffey, 2008; NICE, 2009).

o Involving parents and the community (DfES, 2001; Weare 2008; Roffey, 2008; NICE, 2009; Rowling, 2009)

o Promoting the well-being of staff (Weare and Gray, 2003; Weare 2007; Roffey, 2008; Coleman 2009; NICE, 2009; Rowling, 2009)

o Providing training for staff in promoting well-being (St Leger, 1999; Weare, 2008; NICE, 2009; Rose et al., 2009; Rowling, 2009)

o Clear and visionary management and leadership to promote well-being (Weare and Gray, 2003; Cowie et al., 2004; NICE, 2009; Roffey, 2008; Rowling, 2009; West Burnham, 2010)

o Supporting school transitions (Herman et al., 2009)

o Reducing bullying (DfES, 2001; Atkinson and Hornby, 2002; NICE, 2009)

o Promoting feelings of competence and building self-esteem (Herman et al., 2009)

o Listening to young people and involving them when planning programmes and making decisions that may impact on their well-being (Woolfson et al., 2008; Coleman 2009; NICE, 2009).

Clearly, research has identified a number of the key features of mental health promotion in schools. One final aspect of mental health promotion, which is related to several of the features listed above, but is perhaps so central it requires a little

more detailed discussion is the importance of the notion of connectedness (a complex notion but perhaps briefly summarised as the importance of relationships and feelings of belonging and participation) (McLaughlin, 2008; Roffey, 2008; Herman et al., 2009; McLaughlin and Clarke, 2010; Roffey, 2010).

McLaughlin and Clarke (2010) reviewed a large number of studies looking at the well-being of children aged 10 to 14 years in school. They concluded that feeling connected to school and feeling cared for by people at school during adolescence promotes well-being and is a key protective factor against mental health difficulties. The nature of the daily interactions in the classroom and the relationships that form through them have a major impact on well-being through enhancing or inhibiting a sense of connectedness (O'Hanlon, 2000; Roffey, 2010).   This notion of connectedness leads us to conclude that mental health promotion is about people and the quality of the relationships between them.

> *"The emotional well-being of young people is deeply bound up in the processes of inclusion, teaching and learning, and community building in schools and classrooms. It is inseparable from the quality of relationships between teachers and pupils and pupils and pupils."* McLauglin (2008, p.365)

**2.4 The Diagnosis of Mental Health Needs in Young People with Autism and Asperger Syndrome**

Although autism is no longer viewed as a mental illness (Peeters, 1997) recent reports by prominent clinicians working with people with autism and Asperger syndrome indicate that people with autism and Asperger syndrome are particularly vulnerable to mental health difficulties, which often emerge in adolescence and early adulthood (Wing, 1992, 1998; Ghaziuddin, 2005a; Barnhill, 2007; Tantam 2007). Some argue that the behavioural deterioration that can occur in children with autism at the time of adolescence may be related to the emergence of mental health difficulties (Ghaziuddin et al., 2002) and first hand accounts have also linked a worsening of mental health problems to the onset of puberty (Grandin, 2006).

Despite growing acknowledgement of the presence of mental health difficulties in the literature surrounding autism, identifying and diagnosing mental health difficulties in young people with autism and Asperger syndrome can be problematic.

Four main reasons have been proposed for this. The first is difficulties with communication. People with autism have particular difficulties expressing and communicating emotion (Lainhart and Folstein, 1994; Perry et al., 2001; Ghazuiddin et al., 2002; Ghazziuddin, 2005a; Stewart et al., 2006; Helverschou et al., 2009) which may be compounded by a lack of insight into their own emotional states (MacNeil et al., 2009). They may not report an anxiety state (Tantam, 2007) or low

mood (Stewart et al., 2006) even when these appear to be present. Secondly, few standardised instruments exist for the diagnosis of psychiatric disorders in this population (Ghaziuddin, 2005a; Helverschou et al., 2009). Thirdly, there is substantial overlap between the behaviours prominent in autism and symptoms of some mental health problems which makes it hard to identify whether the behaviours displayed are a product of a mental health difficulty or part of the autism itself (Tantam, 2000; Helverschou et al., 2009; Gould, 2010). Finally, many authors have postulated that some features of autism such as repetitive questioning and rigidity in routines are coping mechanisms in people who find the world a bewildering and anxiety-inducing place (Groden et al., 1994; Howlin, 1997, 1998; Tantam and Prestwood, 1999; Deudney, 2004). This can make anxiety disorders or other mental health difficulties hard to diagnose as their main effect may be an apparent increase in the severity of the core features of autism (Tantam, 2000).

All these reasons make diagnostic overshadowing and misdiagnosis likely to occur. Diagnostic overshadowing (Mason and Scior, 2004; MacNeil et al., 2009) is the tendency to overlook symptoms of an additional mental health difficulty when a person has a disability and see them as part of the disability itself. Many clinicians fail to recognise and diagnose mental health difficulties in people with autism and Asperger syndrome (MacNeil et al., 2009; Lopata et al., 2010). In some cases, people have been given an incorrect diagnosis of a mental health disorder when actually they have autism. For example, Cooper and Hancock (2009) report a case

study of a child with high-functioning autism who was misdiagnosed with depression, despite there being no change in her level of functioning since a young age. Alternatively the converse may be true. Sikora et al. (2008) have demonstrated how, using standard diagnostic tools, depression can be misdiagnosed as autism. However, as MacNeil et al. (2009) point out, determining that an individual has a comorbid mental health disorder alongside their autism clarifies what help the person needs, and if the diagnosis is incorrect, their needs may not be met.

As a result of the confusion outlined above, a change in the person's usual presentation of autism or a deterioration in their levels of daily functioning, such as increasing levels of withdrawal from social contact (Ghaziuddin, 2005a; Tyler, 2010), or an increase in intensity or change in the character of special interests (Ghaziuddin et al., 2002) is usually considered important in diagnosis. It may be that those who see young people on a daily basis, such as school staff, are in the best position to identify these subtle changes in behaviour (Rose et al., 2009).

## 2.5.1 The Prevalence of Mental Health Difficulties in those with Autism and Asperger Syndrome

In recent years an increasing number of studies have sought to ascertain prevalence rates of various mental health conditions within a variety of populations of adults and

children with autism or Asperger syndrome. Considering these studies together, there are many general conclusions that can be drawn.

Almost all studies have found high rates of a variety of mental health difficulties in comparison to either control groups or population norms. Sometimes the rates for psychiatric comoribidity have been very high. For example Mazefsky et al. (2008) found rates of 90% in adults in the United States, although the sample size in this study was particularly small, involving only 17 adults. Working with children in the Netherlands, Muris et al. (1998) found rates of 84% (again with a very small sample size of only 44 children and a wide age range of 2 to 18 years) and de Bruin et al. (2007) rates of 81%, this time in a slightly larger sample of 94 children with a smaller age range (6-12 years).

Two large surveys carried out in the United Kingdom have considered mental health in young people with autism and Aspgerger syndrome. Green et al. (2005) carried out a large-scale survey into the mental health of children and young people aged 5 to 16, involving nearly 8000 interviews in total. They found that 30% of children with autism had another clinically recognisable mental disorder (compared with 9% of the general population) and 16% had an emotional disorder, usually an anxiety disorder, compared with 3% of the general population. Higher prevalence rates were found in a recent survey carried out by the National Autistic Society (NAS), which used parental report and gained 558 responses. Rates of anxiety were 85% and

depression 36% (Madders, 2010). This may be partly due to the overrepresentation of higher functioning young people in the second survey and also to response bias, as the response rate was 7% and those with difficulties in this area may be more likely to respond to a survey on mental health difficulties and autism and they may be more likely than others to be requiring the support of the NAS.

Perhaps surprisingly, there does not appear to be agreement regarding which mental health difficulties are most commonly faced by those with autism or Asperger syndrome. Most commonly, researchers have found that both anxiety and depression rates are raised, but anxiety is more common than depression. For example, in the United States, Mazefsky et al. (2011), studying 10-17 year olds (although with a sample size of just 38), found rates of 55% for anxiety disorders and 29% for depression. In Norway, Gjevik et al. (2011) with a slightly larger sample of 71 young people with autism aged 6 to 17 years, found anxiety rates to be around 42% and depression rates of 10%. Tantam (2007), working in the United Kingdom, quotes prevalence rates of 43% for anxiety and 18% for depression in an adult clinic sample of 213 with high-functioning autism or Asperger syndrome. However, a few studies of children have found high rates of anxiety but note that rates of depression did not exceed population norms in their samples (Green et al., 2005; Mattila et al., 2010). A third position, and in complete contrast, some prominent clinicians (Wing, 1992, 1998; Ghaziuddin et al., 1998) have reported depression as the most common psychiatric problem in people with autism or Asperger syndrome and Bakken et al.

(2010) in a sample of people with autism and intellectual disability in Norway found slightly higher rates of depression than anxiety.

One possible explanation for these differences is the various ages of participants in the different studies. Tantam (2007) notes an increase of anxiety related problems in those with autism and Asperger syndrome around the ages of 11-13 years and then secondary depression developing at ages 16-18 years, with other disorders such as catatonia appearing in adulthood. It may be therefore that anxiety is most common in children and depression more common in late adolescence and adulthood. However, in most studies, anxiety does appear to be the most prevalent difficulty.

Further research has found that obsessive-compulsive disorder (Reaven and Hepburn, 2003; Deudney, 2004; Hutton et al., 2008; Tantam and Girgis, 2009), specific phobia (Leyfer et al., 2006; Gjevik et al., 2011), social anxiety (Kuusikko et al., 2008; Hurtig et al., 2009) and social phobia (Joshi et al., 2010) are common forms of anxiety in children and young people with autism. Both major depression and bipolar disorder (Tantam, 2000; Munesue et al., 2008; Tantam and Girgis, 2009) are more common in adults with autism or Asperger syndrome. Catatonia is also present (Takaoka and Takata, 2007; Hutton et al., 2008). There appears to be genetic linkage between bipolar disorder and autism (Tantam, 2007; Tantam and Girgis, 2009). Other comorbid disorders that seem to have raised prevalence include attention deficit hyperactivity disorder (ADHD), which some studies have found in

over 50% of young people with autism (Stahlberg et al., 2004; Mazefsky et al, 2011), and psychosis (Bakken et al., 2010).

It is worthy of note that findings of increased incidence of mental health difficulties in high-functioning individuals with autism have not always been complemented by similar results in studies involving people with autism and intellectual disabilities (Tsakanikos et al., 2006; Underwood et al, 2010). However, the picture remains unclear with others such as Mayes et al. (2011) (who carried out a study involving a large sample of 1390 children aged 6 to 16 years including 350 with a diagnosis of autism) finding high prevalence rates of anxiety (67%) and depressed mood (42%) in children with autism whose IQs were below 80. However, this study did find even higher rates in young people without such learning difficulties.  Lower prevalence rates found in some studies may be related the high use of medication in this population (nearly 70% of the sample investigated by Tsakanikos et al., 2006), or because of problems of diagnosis in those who are less verbal (Ghaziuddin, 2005a). Alternatively, there may be genuinely increased prevalence of mental health difficulties in more able people with autism because they are more aware of their difficulties and receive less support and understanding (Tantam, 2007).

**2.5.2 Problems Determining the Prevalence of Autism and Mental Health Difficulties**

It is clear from the above summary of research that estimated prevalence rates vary widely across studies. This is likely to due to the fact that research differs with regard to the age of individuals, diagnostic criteria and sampling methods (Stewart et al., 2006). In addition, many of the studies that attempt to investigate the incidence of mental health difficulties in people with autism have methodological weaknesses, which are discussed below.

A large proportion of prevalence studies have used samples recruited in psychiatric hospitals or clinics which by definition are likely to have more people with psychiatric difficulties amongst them than the general population (de Bruin et al., 2008; Sukhodolsky et al., 2008; Munesue et al., 2008; Hofvander et al., 2009; Joshi et al., 2010; Mayes et al., 2011). In some studies, a high proportion of the participants are on medication (for example, this was true of nearly half of Mazefsky et al.'s (2011) sample). Other studies did not verify the diagnosis of autism or Asperger syndrome and researchers have relied on reports from parents or carers.

Sample sizes in many studies are small (Muris et al., 1998; Green et al., 2000; Gillott et al., 2001; Farrugia and Hudson, 2006; Munesue et al., 2008; Mazefsky et al., 2008), which combined with the reliance on convenience samples that researchers may have access to in their clinical work, makes it hard to generalise to people with

autism or Asperger syndrome elsewhere. In some studies the participants have been told when being recruited for the study that it is about mental health difficulties, which, when combined with a low response rate, may lead to bias (Muris et al., 1998; Farrugia and Hudson, 2006). Many studies have no control groups and rely on population norms.

There are also problems with the assessment of mental health in people with autism or Asperger syndrome. As Kanne et al. (2009) point out, a variety of measures have been used across the different studies which makes it hard to compare results. Most of these have been standardised on typically developing children, due to the lack of standardised measures for those with autism (Bellini, 2004; Reaven, 2009; Helverschou et al., 2009). However, in recent years checklists have been devised to assess comorbid mental health difficulties in both adults (Helverschou et al., 2009) and children (Leyfer et al., 2006) with autism. More research is needed regarding the use of these checklists, although an early report has been provided by Bakken et al. (2010).

A further problem is that often little agreement is found between the ratings of parents regarding symptoms of mental health difficulties and reports from young people with autism or Asperger syndrome themselves. In many studies, parents give much higher ratings of their children's mental health difficulties than their children themselves (Konstantareas, 2004; Vickerstaff et al., 2007; Gadow et al., 2008; White

and Robseron-Nay, 2009; Lopata et al., 2010; Mazefsky et al., 2011). Some have suggested that parents themselves have higher levels of anxiety and as such may be more likely to report this in their children (Kussikko et al., 2008; Sukhodolsky et al., 2008). Others indicate that young people have difficulty identifying and reporting the symptoms of conditions such as anxiety and depression as they are less self-aware (Mazefsky et al., 2011). However in other studies, children and adolescents with autism report symptoms of anxiety and depression more commonly than their parents (Meyer et al., 2006; Hurtig et al., 2009).

Similar differences emerge when parent and teacher reports of mental health difficulties in children or adolescents with autism or Asperger syndrome are compared. Vickerstaff et al. (2007) found that teacher / parent reports did not differ significantly, whereas Gadow et al. (2008) found little agreement. Hurtig et al. (2009) found that teachers reported more symptoms than parents but Kanne et al. (2009) found that parents reported much higher prevalence of affective and anxiety disorders than teachers. An interesting control group was used in this study (siblings, which were therefore rated by the same parent and teacher pairs) and this group were given lower ratings by parents than their siblings with autism. Parents and teachers also had higher agreement on the symptoms of autism than on signs of mental health difficulties. The authors therefore conclude on the basis of these two facts that although rater bias may provide part of the explanation for the

difference between parent and teacher ratings, it is also likely that such difficulties are strongly affected by the environmental context.

It appears that all that can really be concluded from these vastly differing results is that the use of many informants may be particularly important, probably both as a result of bias in ratings and the impact of environmental context on the expression of mental health difficulties. As a result when considering the diagnosis of comorbid mental health difficulties in those with autism, many authors recommend the use of a number of different informants in research and clinical practice (Hurtig et al., 2009; Kanne et al., 2009; MacNeil et al., 2009; Lopata et al., 2010). Despite such findings, in many research studies, there is a complete reliance on parental or carer report to provide a picture of the mental health of young people with autism or Asperger syndrome. In better studies, information from other individuals such as teachers (Gadow et al., 2005) and sometimes the young person themselves (Green et al., 2000) is sought, but few studies make use of observational techniques in assessment, or interviews which seek to ascertain how mental health difficulties are actually experienced by the individuals and their families.

Studies in this area could also be criticised for an over-reliance on the use of questionnaires and checklists with many including Sukhodolsky et al. (2008) and Hurtig et al. (2009) using this approach. As Gjevik et al. (2011) point out, it seems likely that the problematic task of distinguishing between the core features of autism

and those which reflect underlying mental health problems is more likely to be achieved using a semi-structured interview where complex issues can be probed.

In fact, many studies investigating mental health difficulties in young people with autism and Asperger syndrome involve administering a large number of questionnaires without proper clinical diagnosis of either autism or mental health difficulties and then looking for correlations between factors and diagnoses. We could conclude that many of the studies noted above tell us more about the vagaries of the diagnostic classification system and the questionnaires themselves than of the realities of life for people with autism or Asperger syndrome and mental health difficulties. However, when these studies are considered together, despite their flaws, they provide a body of evidence which indicates fairly conclusively, that adults and young people with higher-functioning autism or Asperger syndrome are at increased risk for mental health difficulties compared to the general population.

## 2.6 The Impact of Mental Health Difficulties on Young People with Autism and Asperger Syndrome

Symptoms of mental health difficulties in adolescents or adults with autism or Asperger Syndrome are often similar to those displayed by the general population (Tantam and Prestwood, 1999). In addition, anxiety symptoms often manifest themselves as extreme distress at trivial changes in the environment, problems with

change of schedules, and difficulties adjusting to new people or surroundings (Ghaziuddin, 2005a). Repetitive behaviours can escalate into very bizarre behaviour as anxiety increases, leading to an eventual retreat into a fantasy world (Etherington, 2010b). Some writers have also linked aggression and externalising behaviour difficulties in autism with high levels of anxiety (Kim et al., 2000; Ghaziuddin 2005a; Farrugia and Hudson, 2006; Balfe and Tantam, 2010; Mattila et al., 2010).

Depression in people with autism or Asperger syndrome also has a similar manifestation to the general population, affecting motivation and energy for other previously enjoyable activities, crying, changes in sleep pattern and appetite, poor concentration, memory, irritability, negative attitude, self-injury and in extreme cases talk of suicide or suicide attempts (Lainhart and Folstein, 1994; Ghaziuddin et al., 2002; Deudney 2004; Ghaziuddin 2005a; Attwood, 2006; Brereton et al., 2006; McCarthy, 2008). There is often an increase in social withdrawal leading to greater isolation than the person usually experiences (Deudney, 2004; Ghaziuddin 2005a; Paxton and Estay, 2007; McCarthy, 2008; Etherington, 2010b), which is supported by the reports of people with autism and Asperger syndrome who have described how withdrawing from social situations can help to reduce stress (Andrews, 2002). Depression can also lead to aggressive outbursts (Ghaziuddin et al., 2002; McCarthy, 2008), an obsessive focus on high-interest activities (Ghazuiddin, 2005a; Paxton and Estay, 2007) and a change in the character of special interests to morbid or dark subjects (Ghaziuddin, 2005a; Attwood, 2006; Tyler, 2010). Psychotic

behaviour (Ghaziuddin, 2005a) and catatonia (Gould, 2010) can occur in severe cases.

It is perhaps not surprising therefore, that clinicians such as McCarthy (2008) report that mental health difficulties can significantly affect the functioning and daily lives of people with autism and Asperger syndrome. They are likely to show regression of previously acquired skills (Ghaziuddin, 2005a) and be less able to cope with change and unpleasant sensory experiences (Gillott and Standen, 2007). Mattila et al. (2010) found that major developmental disorders and anxiety disorders were associated with lower levels of functioning in people with high-functioning autism and Asperger syndrome and that the level of functioning decreased as the number of comorbid psychiatric disorders increased within the people in their sample.

Reports from clinicians are supported by graphic accounts from adults with autism of the debilitating anxiety and depression they have experienced as teenagers or young adults (see for example Williams, 1992; Grandin, 2006; Brown, 2011). Brown (2011) has a harrowing, but nevertheless fairly typical story, writing of her constant state of anxiety in school where she became aware of her differences and her lack of friends. As she became older she began to have panic attacks, bouts of depression, thoughts of suicide and problems with self-harm and alcoholism. She writes (Brown, 2011, p.118):

*"There's something unpredictable that gets into my mind and changes me from feeling happy to feeling sad in an instant. It's like flicking a switch, it's that quick, and then I'm sad without any warning and left wondering what's happening to me. I guess there are certain occurrences that trigger it, but all of sudden it's upon me, like a mist that has come down and enveloped my mind. Sometimes I feel like there is a monster that gets inside my head and pushes me aside. All the sadness I am feeling seems to get bigger and bigger until it's all I can think about. It feels like it will always be there and I don't know how to make it go away and to stop myself from feeling so sad."*

Evidence also suggests a negative impact on the families of those young people who have autism or Asperger syndrome and comorbid mental health difficulties including problems in relationships with parents (Kim et al., 2000; Ghaziuddin et al., 2002; Brereton et al., 2006), families losing contact with their friends (Kim et al., 2000; Madders, 2010) and a lack of family holidays (Kim et al., 2000). In the recent NAS survey 88% of the parents of children with autism and mental health difficulties reported that their child's difficulties had had a negative impact on their own mental health and 91% reported a negative impact on the family as a whole (Madders, 2010).

Mental health difficulties in those with autism can also lead to problems in school including a deterioration in relationships with teachers and peers (Kim et al., 2000),

school refusal (Kurita, 1991; Attwood, 2006) and significant behavioural difficulties (Brereton et al., 2006; Madders, 2010). In some cases serious mental health difficulties and associated challenging behaviours can lead to costly out of authority placements for young people who have no additional learning needs, particularly at secondary age (Jones et al., 2008). In other cases high levels of stress build up during the school day but remain under control until dramatic outbursts when the young person arrives home (Carrington and Graham, 2001; Batten et al., 2006).

If mental health difficulties are left untreated they can severely impact on the life of a person with autism and continue into adulthood (Farrugia and Hudson, 2006). Although treating such difficulties does not cure autism, it often results in a reduction in aggression (Kim et al., 2000) and an improvement in quality of life for the person with autism and their family (Ghaziuddin et al., 2002). Clearly therefore, this is a topic worthy of study.

### 2.7.1 Factors that Demote the Mental Health of Young People with Autism and Asperger Syndrome

A range of theories are posited in the literature to describe why young people with autism and Asperger syndrome are apparently more at risk of high levels of stress and mental health difficulties than their neurotypical peers. These include problems with changes and transitions, difficulties with social interaction, awareness of

difference, bullying, lack of awareness amongst school staff, sensory sensitivities, cognitive distortions, genetic factors and increased experience of life events, such as ill health or family breakdown. These explanations are supported by varying levels of research evidence and are discussed below.

**2.7.2a Changes and Transitions**

Many clinicians report that changes and transitions, even the most minor changes of personnel, objects or places, can lead to distress and even crises in young people with autism or Asperger syndrome (Attwood, 2006; Tantam, 2007; Turk, 2008). One reason for this could be that change interferes with the rituals and obsessions associated with the autism spectrum  (Myles and Adreon, 2001; Tsakanikos et al., 2007). As noted above, multiple transitions occur at adolescence (Leffert and Petersen, 1995), so this may be a particularly difficult time for those with autism or Asperger syndrome.

Transition between schools in particular are a key source of anxiety and stress for those with autism and their parents (Jones et al., 2008; Parsons et al., 2009). The transition from primary to secondary school can be particularly traumatic for children with autism as they suddenly have to cope with a complex environment with varied routines, peers, rooms, teachers and expectations (Barratt, 2006; Watson et al., 2006; Tobias, 2009). This is supported by a qualitative study by Humphrey and

Lewis (2008) investigating the views and experiences young people with autism and Asperger syndrome in mainstream secondary schools in England. Routine and predictability were important and apparently trivial but unplanned changes led to high levels of anxiety. The authors wrote:

> *"For our participants, order and predictability appeared to act as a 'security blanket' that allowed them to function. Trying to maintain some semblance of order and predictability in the noisy, bustling and chaotic environment of secondary school proved to be particularly difficult in many cases."*
>
> (Humphrey and Lewis, 2008, p.37)

However, in contrast to such assertions, Parsons et al. (2009) found that once the transition to a new school is made, negative fears were not realised and levels of anxiety reduced for many young people with autism and their families.

**2.7.2.b Difficulties Communicating and Interacting with Peers**

Friendship difficulties are part of the profile of autism and significant social deficits in children with high-functioning autism and Asperger syndrome have been found in school contexts (Macintosh and Dissanayake, 2006a and b). In a large scale survey in the United Kingdom, Green et al. (2005) found that 42% of those with autism had no friends compared to only 1% of the population as a whole. Other studies using

different methods also found those with autism in mainstream schools have poorer quality friendships (Locke et al., 2010), fewer friendships than their peers (Wainscot et al., 2008), and in many cases no friends at all (Mazurek and Kanne, 2010). Interestingly, three studies (Chamberlain et al., 2007; Humphrey and Symes, 2010; Kasari et al., 2011) investigating the friendships of those with autism or Asperger syndrome, using different methods, have found a similar pattern. The majority of this group had significant problems with peer relationships and were on the periphery of social networks, but a small number in each study enjoyed good quality friendships.

Difficulties with social skills and interacting with peers has been linked to anxiety and depression in neurotypical children (Harrington, 1993; Ginsburg et al., 1998; Deater-Deckard, 2001; DfES, 2001). Given the difficulties with social interaction and friendships described above, it is possible to theorise that much of the anxiety and depression in young people with autism is linked to problems relating with peers. Many authors have reported how many children and adolescents with autism and Asperger syndrome are interested in making friendships with peers, and sometimes desperate for these, despite their social interaction difficulties (Whittaker et al., 1998; Bauminger and Kasari, 2000; Howard et al., 2006). In their study of 16 children with autism, Ochs et al. (2001) used observation (arguably a more valid method than self report which may require levels of introspection or communication skills that those with autism may not have) and found that, despite their difficulties in interpreting

others' behaviour, many children with autism in mainstream schools were aware of peers teasing, ignoring or rejecting them, and found these actions distressing.

Problems with friendship can increase as a young person with autism or Asperger syndrome moves into adolescence (Tantam, 2000; Beebe and Risi, 2003; Howlin, 2003; Attwood, 2006; White et al., 2009b; White et al., 2010a; White et al., 2010b). Kuusikko et al. (2008) found that children with autism or Asperger syndrome report an increase in social anxiety as they entered adolescence, whereas other children report a decrease. High levels of stress (Attwood 2003), social isolation (Howlin 2003), social phobia (Joshi et al., 2010) anxiety (Howlin 2003; White et al., 2010) and depression (Whittaker et al., 1998; Beebe and Risi 2003; Attwood 2006; Paxton and Estay, 2007; White et al., 2010) may follow repeated social failures and rejections in those with autism or Asperger syndrome.

First hand accounts of those with autism have linked loneliness and isolation, with anxiety, depression and in some cases thoughts of suicide (Powell, 2007; Muller et al., 2008). Anxiety can have a bi-directional relationship with the social functioning of the young person with autism, as high anxiety levels can worsen the young person's social skills still further (White et al., 2010a). It could be argued that this is also likely to be the case for other mental health difficulties such as depression.

However, despite its obvious plausibility, there is little research directly linking problems relating to others with mental health difficulties in adolescents with autism or Asperger syndrome. However, in a very small sample of just 22 young people with Asperger syndrome aged 6 to 19 years in mainstream schools in the United States, Konstantareas (2004) found that a lower level of social skills was associated with a higher level of depression, and better ability to get along with others and a higher number of close friends were connected to lower levels of depression and a higher level of mood respectively. Also, Whitehouse et al. (2009), again in a small sample of just 35, found that in adolescents with Asperger syndrome in Australia, poor quality friendships, characterised by high levels of conflict and betrayal, predicted high levels of loneliness and depression.

Several studies suggest that it may in fact be young people's self perceptions of their difficulties with social skills, that affect their mental health, rather than their actual competence in this area. For example Bellini (2004) found a link between self-reported social skill deficit and social anxiety, but no link between parent reports of social skills and social anxiety. Similarly, when considering 7 to 13 year olds with high-functioning autism and Asperger syndrome, Vickerstaff et al. (2007) found that low self-perceived social competence predicted a higher levels of depressive symptoms as rated by the child, parent and teacher, but no significant associations were found between social competence as rated by either the young persons' parent or teacher and depressive symptoms. However, the generalisabilty of this study is

compromised by its small sample size of only 22 children aged 7 to 13 years and causal relationships between the data are unknown.

Young people with autism or Asperger syndrome's awareness of their social skills difficulties is part of a wider awareness of being different to others which may impact significantly on their mental health. This is discussed in the next section.

**2.7.2c Increasing Awareness of Difficulties and Difference**

Lim (2011), a person with Asperger syndrome, has described how at school her differences were highlighted by peers who called her 'weird' and 'crazy'. She became aware she was different and did not like the way she was but was unable to change. Over time, this deeply affected her self-esteem. Evidence suggests that these experiences are not unique and young people with autism may become more aware of their differences from others as social identity becomes more important to their peer group during adolescence (Carrington and Graham, 2001; Howlin 2003). Many authors have suggested that becoming aware of being different may lead to young people with autism becoming anxious or depressed (Jordan and Cornick, 2000; Attwood, 2006; Meyer et al., 2006; Paxton and Estay, 2007; Kuusikko et al., 2008; White and Robseron-Nay, 2009). Some young people with autism or Asperger syndrome may try to hide their differences, which Carrington and Graham (2001)

have termed 'masquerading'. This masquerading may in turn contribute to further stress and mental health difficulties.

There does seem to be some variation in the levels of self awareness of difficulties and difference in young people with autism and therefore the corresponding susceptibility to anxiety and depression. Indeed, Chamberlain et al. (2007) report that children with autism experienced a state of 'happy obliviousness' and saw themselves as more socially involved than their peers reported. Mazurek and Kanne (2010) argue that the cognitive mechanisms underlying the development of internalising mental health difficulties, such as anxiety and depression, require a degree of self awareness, which means that those with greater cognitive and social abilities, who are more self aware, may be more at risk of developing such difficulties. There is some evidence to support these claims both from Mazurek and Kanne's own study, which involved a very large sample of 1202 children with autism aged 4 to 17 years, and Konstantareas (2004) who found that a higher level of awareness of disability (as rated by parents) was related to higher level of anxiety and depression.

A person with autism has described these differences thus:

> *"I have come across people with more serious delays than I have, with considerably fewer cognitive skills, and it may surprise you to know I*

*sometimes envy them. I figure I am smart enough to know what I am missing, where the big gaps of information and experience are, and yet these people may not. They are seemingly without a care in the world, and this, I think, is simply because they seem to have no idea what they are missing. I know precisely what I am missing, because I see it all around me – what I am missing, and what I missed – but not where or how I missed it. I am tempted to think ignorance really is bliss."* (Jansen, 2004, p.316)

Exploring this in secondary schools in the north west of England, Humphrey and Lewis (2008) used diaries and semi-structured interviews to obtain views and experiences of young people with autism and Asperger syndrome. Many had a negative self perception alongside feelings of being different and a desire to 'fit in' with others. In school there was an interesting link made by the pupils between feelings of difference and the support they received. Whereas some perceived the support they received as helpful and reducing anxiety, others said they did not like people supporting them as this hampered their ability to 'fit in'. In some cases schools responded to this by offering support in a more subtle way. This study is interesting as it provides more information about the possible impact of being aware of difference and how it emerges in the context of a mainstream secondary school. However, awareness of difference and mental health difficulties were not directly linked.

**2.7.2d Bullying**

The difficulties in social communication and interaction already discussed can increase the vulnerability of young people with autism to bullying because they often behave in socially inappropriate ways (Mazurek and Kanne, 2010) and lack social support networks (Humphrey and Lewis, 2008; Humphrey and Symes, 2010). It is perhaps not surprising therefore, that a great deal of research, using various different methods, has found that bullying is very frequently directed at those with autism or Asperger syndrome (for example Attwood, 2004, 2006; Wainscot et al., 2008; Humphrey and Lewis, 2008).

A survey carried out by the National Autistic Society found that 2 in 5 children with autism had been bullied in school, and this figure was even higher for those with high-functioning autism or Asperger syndrome (Reid and Batten, 2006). Although it is possible that parents of those children who were having more problems in school may have been more inclined to respond to the survey, the fact that there were 1400 responses in total mitigates against this, as it is unlikely, given this very large sample size, that a range of viewpoints would not be represented. In a study carried out in Canada, 77% of parents of children with autism (mean age 11 years) reported that their child had been bullied at school within the last four weeks (Cappadocia et al., 2011).

Many clinicians and people with autism or Asperger syndrome themselves have proposed that experiencing bullying contributes to developing a mental health difficulty for those with autism or Asperger syndrome (Andrews, 2002; Attwood, 2006; Tantam 2007). There is some research evidence to support this proposition. The NAS study described above drew links between bullying and mental health in that, of those whose children had been bullied, 63% of parents felt that the experience had negatively affected their child's mental health, often linking bullying with self harm and suicidal feelings (Reid and Batten, 2006). However, there was no evidence of this other than parental report. In Cappadocia et al.'s (2011) study, the young people with autism who were bullied were eleven times more likely to have internalising mental health problems than those with autism who were not bullied, although causal mechanisms underlying this link are likely to be complex.

These results are supported by clinical reports and studies using qualitative methods. In their report on 1200 adult cases of autism, Tantam and Girgis (2009) conclude that experiences of bullying and victimisation, which those with autism are frequently subject to, increase the chances of developing mental health difficulties in adolescence and young adulthood, particularly in 'higher functioning' people with autism. Humphrey and Symes (2010) investigated the impact of bullying on the mental health of young people with autism and Asperger syndrome in mainstream secondary schools in England. For some, although they had only been bullied by a small number of individuals, their levels of trust of any of their peers had broken

down to such an extent that any contact with them caused emotional distress and anxiety.

However, again, research evidence does not always support the links between bullying and mental health. Konstanareas (2004) found no link between bullying and various measures of anxiety and depression in children aged 6 to 12 who attended mainstream schools in the United States. One possible explanation for the results of this study is that bullying in childhood impacts on mental health later on, as Tantam and Girgis (2009) have suggested.

**2.7.2e Lack of Training and Awareness Amongst School Staff**

Although it was proposed some years ago that all who teach children with autism should have some understanding of autism and its implications for teaching and learning, and should be able to modify the learning environment and curriculum to meet their needs (DfES, 2002), this is not always the case. Many staff in mainstream schools have had little or no training in autism (Jones et al., 2008) and there is evidence that staff in mainstream secondary schools in the United Kingdom are generally less knowledgeable about autism than their primary colleagues (Barnard et al., 2000).

Lack of training and awareness of autism amongst teaching staff is a great concern

to parents and young people. Surveys of parents of children with autism and Asperger syndrome have found that the change they most want to see is improved training and understanding of autism for school staff especially secondary subject teachers (Batten et al., 2006). It is also a concern to professionals. In a survey of professionals who worked with children with autism across the United Kingdom for the Autism Education Trust, the need to develop the knowledge and understanding of school staff was the most frequently mentioned challenge in providing for children on the autism spectrum (Jones et al., 2008).

As a result of this lack of training and awareness, young people who have good academic skills and apparently competent use of language are often expected to 'fit in' in ways which is very stressful for them (Howlin, 1998; Tantam, 2000; Jones et al., 2008) and the extent of their difficulties in non-academic areas may go unrecognised (Whittaker, 2007; Jones et al., 2008). Their challenging behaviours are frequently misunderstood (Ashburger et al., 2010) and not seen as a product of their autism (Whittaker, 2007). As a result they can be labelled as naughty or disrespectful (Tobias, 2009).

These problems can also be exacerbated when the school ethos does not engender positive attitudes towards vulnerable students. Schools vary considerably in their flexibility and openness to children with autism (Howlin, 2003) and this may affect a young person's emotional well-being. Those with autism may be viewed as the

responsibility of the special needs department (Osler and Osler, 2002) or teaching assistants (Emam and Farrell, 2009) rather than the wider teaching staff. Of relevance to this are the findings of Frederickson et al. (2010) who found that in schools without an autism resource base only 42.1% of class teachers and 52.6% of Special Educational Needs Co-ordinators (SENCOs) had received training in autism, in contrast to all the teaching assistants. They concluded that as a result of this increased level of training for teaching assistants, there is a danger of the education of young people with autism in mainstream schools being the responsibility of the teaching assistant appointed to support them, rather than their teachers.

Many of the above points are supported by the findings of Humphrey and Lewis (2008) who carried out a multiple case study of four mainstream schools in the north west of England, involving 19 students with autism or Asperger syndrome. Its strength lies in the variety of data collection methods used, including interviews with young people, their parents and a variety of school staff, observation throughout the school day, document analysis and the use of diaries. The ethos of the school and the level of commitment of the school's leadership to valuing diversity had an impact on the young people's experiences of inclusion. In some schools staff felt supported and able to meet the needs of young people with autism, there was limited acceptance and participation for these young people and tensions between staff were evident, particularly SENCos and Heads of Year. The extent to which work was differentiated varied across teachers and some young people had little or no

interaction with class teachers as they relied on the teaching assistant to teach the young person or asked the teaching assistant about their progress rather than checking directly. It is perhaps not surprising therefore that young people with Asperger syndrome in the study themselves sometimes reported that although secondary school teachers may know their subject they do not know about Asperger syndrome or how to deal with it (Humphrey and Lewis, 2008).

An explanation for the problems that many teachers appear to have with teaching those with autism is proposed by Emam and Farrell (2009). From their case study of 17 children with autism in schools in England they found that the difficulties faced by those with autism were also very challenging for those teaching them. In particular their inability to understand the teacher's perspective, emotions, jokes or figurative language and their inability to show emotions which provided teachers with feedback all restricted the ways in which teachers were able to teach and made them spend longer delivering the same message. This led to tensions in the interactions between these young people and their teachers, reduced the quality of relationship between them and made the job of teaching them harder.

These conclusions are supported by the work of others, such as Jordan (2008) who writes of the laborious ways in which students with autism and their teachers must seek to understand each other and also by Barrett (2006, p.98) who writes that her "experience suggested that it was not the young people's pattern of behaviour that

most disturbed teaching professionals but the challenge this brought to the kind of relationship they could share with them."


### 2.7.2f Sensory Sensitivities

Some young people with autism or Asperger syndrome have differences in sensory perception which can be very stressful (Groden et al., 1994). They can become distressed by ordinary, everyday auditory or visual stimuli that other people do not notice (Vermeulen and Vanspranghe, 2006). Busy, noisy school environments in particular, are very difficult and prone to such sensory overload (Jones et al., 2008), as sensory sensitivities can mean that the noise of an everyday classroom is distracting or even painful (Mesibov and Shea, 1996). Links have been found between sensory over-responsivity and anxiety disorders in children with autism although causal mechanisms remain unclear (Green and Ben-Sasson, 2010). Others have reported how young people with autism or Asperger syndrome can become so afraid of potential sensory sensitivities or sensory overload that aggressive outbursts (Mesibov and Shea, 1996), an anxiety disorder (Attwood, 2006) or depression (Paxton and Estay, 2007) may develop.

In their studies of the experiences of young people with autism and Asperger syndrome in mainstream schools, Humphrey and Lewis (2008) and Tobias (2009)

report that noise can be anxiety provoking, but there is little other recent research linking sensory sensitivities in school settings directly with mental health problems.

## 2.7.2g Cognitive Distortions

Cognitive styles commonly found in people with autism such as polarised all-or-nothing thinking, inaccurate attributions and limited ability to problem solve are very similar to the thinking styles of those with anxiety or depression (Greig and MacKay, 2005; Paxton and Estay, 2007). Adults with autism have also written about how dwelling on failures after the event or thinking about bad events that may or may not happen in the future can also lead to stress and anxiety (Brown, 2011; Wilson, 2011).

Vermeulen and Vanspranghe (2006) report that people with high-functioning autism or Asperger syndrome often have a self-critical style, which puts them at risk of low self-esteem and this in turn can be a factor in the development of depression. Low self-esteem in those with autism or Asperger syndrome can often be as a result of feeling different from others (Lim, 2011).

A few research studies provide some limited evidence for these assertions. Meyer et al. (2006) found a link between negative attributions made by some young people with Asperger syndrome in response to ambiguous social vignettes and both self

and parent report of comorbid emotional and behavioural symptoms as well as self report of social difficulties. They concluded that the manner in which children with Asperger syndrome interpret social situations may cause them to develop and maintain symptoms of anxiety and depression. Farrugia and Hudson (2006) found that negative automatic thoughts were higher for young people with Asperger syndrome than children in a control group and that there were correlations between this kind of thinking and anxiety and behaviour problems. So the more negative the automatic thoughts measured by one questionnaire, the higher the anxiety levels measured by another and the more behavioural problems measured by another and the higher life interference measured by a fourth.

**2.7.2h Genetic Factors**

Some studies have found an increased family history of depression, anxiety and / or other mental health difficulties in the families of children with autism (Bolton et al., 1998; Ghaziuddin and Greden, 1998; Stoddart, 2005, Ghaziuddin, 2005b, Mazefsky et al., 2008; Lee, 2009). For example, Mazefsky et al. (2008) found that in their sample of adults with autism, at least 71% had a first degree relative with a mood disorder and at least 39% had a first degree relative with an anxiety disorder.

However, many of these studies used small samples (only 17 adults with autism and their relatives in Mazefsky et al.'s (2008) study). There have also been some issues

in recruitment, for example Ghazuiddin (2005b) and Lee (2009) used convenience samples which makes it hard to generalise the results of that study and in Stoddart's (2005) study the description of recruitment indicates that people may have been more likely to engage with the study if they had prior mental health issues. Mazefsky et al. (2008) did not use a control group at all and compared figures to population norms. Another potential source of error in this study is that parents reported both on themselves and their adult children with autism.

Another possible explanation for familial links between autism and mental health difficulties is that the stress of parenting a child with autism could contribute to mental health problems in family members. However, there is some convincing evidence against this. Firstly, some studies have compared groups of children with autism both with and without depression and found differences in the family history of depression amongst these two groups (Ghaziuddin and Greden, 1998; Mazefsky et al., 2008). Secondly, both Bolton et al. (1998) and Mazefsky et al. (2008) found that the onset of mood disorders, in relatives of people with autism was not confined to the period after the birth of their child with autism, again indicating that the raised rate of depression in families of individuals with autism is not likely to be solely due to the difficulties of having someone with autism in the family.

Despite the limitations of some studies, when considered together, research indicates that genetic factors do play a role in the links between mental health difficulties and autism.

**2.7.2i Life Events**

Green et al. (2005) carried out an Office of National Statistics Survey of the mental health of children aged 5 to 16 years in Great Britain, using careful sampling from the Child Benefit database. This involved nearly 8000 lengthy interviews with parents and in some cases with young people themselves, alongside postal questionnaires sent to teachers. This comprehensive study found that children with autism were more likely than the general population to have experienced two or more stressful life events, such as loss of parental income, parental mental illness or family breakdown. In addition, people with autism and Asperger syndrome can experience more changes of school, losses and separations as a result of attempts to find appropriate educational environments (Tantam, 2000).

Negative life events can make children and young people vulnerable to depression (DfES, 2001) and research suggests that this is also true of children with autism perhaps even more so because of their dislike of change (Ghaziuddin et al., 1995).

**2.7.3 Conclusions Regarding Factors that Demote the Mental Health of Young People with Autism and Asperger Syndrome**

In this section, a number of possible reasons for the increased incidence of mental health difficulties in young people with autism or Asperger syndrome have been discussed and the evidence for them evaluated. Although clear arguments have been made for many of the factors, these are not always supported by strong research evidence. Some, such as genetic factors, appear to be beyond the control of schools, but others are related to the environment of schools, their staff and their pupils. These may give a starting point for working with schools in an ecological approach to mental health promotion. However, in addition to considering aspects of the environment that might demote mental health, it is also important to consider aspects that promote it (MacDonald and O'Hara, 1998) and this is the focus of the next section.

**2.8.1 Factors that Promote the Mental Health of Young People with Autism and Asperger Syndrome**

Clinicians and researchers have suggested a range of interventions to promote positive mental health in people with autism or Asperger syndrome. I will discuss possible interventions under the five main approaches for working with children and young people who are depressed or anxious proposed by the DfES (2001).

## 2.8.2 Dealing with Underlying School Problems

Beardon and Worton (2011) argue that the environment has a crucial role in the promotion and demotion of mental health for those with autism and Asperger syndrome and therefore making changes to the environment in which these people operate may be more fruitful than attempting to alter a person's autism or Asperger syndrome itself or address aspects of skill deficit such as social skills or anger management.  Clearly, for young people with autism and Asperger syndrome a key environment which has a significant impact on their well-being is their school. Most mainstream schools in the United Kingdom now have some experience of meeting the educational and social needs of children with autism spectrum conditions. Indeed the Department for Education (2010) reported that there were 56,260 pupils in English schools at School Action Plus or with a Statement Special Educational Needs whose main need was autism

There is, therefore, much literature on supporting and including young people with autism in mainstream schools, although this does not often explicitly link strategies to promoting well-being. However, we could argue that this is implicit in that providing an 'autism friendly' environment can reduce stress and anxiety and therefore improve the mental health of those with autism or Asperger syndrome. A great many areas of research are relevant and some of the main recommendations are summarised below, highlighting any explicit links to mental health.

Watson et al. (2006) and Tobias (2009) link support for transition to secondary school, preparing both the young person and school staff and changing the school environment when necessary to reductions in anxiety. Once the transition has been made, many have advocated having a structured, ordered and predictable environment with consistent routines (Humphrey and Lewis, 2008), including helping the young person to avoid crowded corridors and providing a clearly defined space for personal equipment and belongings (Cowie et al., 2004). Williams and Hanke (2007) note that a quiet school environment is particularly valued by those with autism. Reducing noise levels within and outside the classroom, having an area for periods of solitude and minimising distractions can all help (Attwood, 2003; Tobias, 2009). The use of quieter, calmer spaces as a refuge can also reduce anxiety (Humphrey, 2008; Humphrey and Lewis, 2008; Tobias, 2009).

A positive and welcoming school ethos (Humphrey and Lewis, 2008; Tobias, 2009) and positive attitudes from the senior management of the school to inclusion (Humphrey and Lewis, 2008; Jones et al., 2008) are important. Young people themselves are aware of the importance of school ethos (Williams and Hanke, 2007). Pastoral support can enable young people to discuss stressful incidents, help them reduce their anger and develop social understanding (Tobias, 2009) and may be vital in times of crisis (Howlin, 2003). In a further development of this, Christie et al. (2008) report how personal tutorials (regular individual meetings with a member of school staff, who has been trained to listen to the young person's personal

concerns and be supportive and non-judgemental, in a quiet environment) are popular with children with autism and can improve their social and emotional development.

It is vital to that school staff understand the needs of those with autism (Jones et al., 2008; Tobias, 2009) so that they can interpret the meaning of the behaviour the person with autism displays (Jordan, 2008). Training should help staff develop an understanding what it might be like to experience autism (Barrett, 2006) and should be provided for all staff within the school, including managers and support staff as well as teachers (Burdus and Waltz, 2007). Indeed Osborne and Reed (2011), who studied 105 pupils across 91 different mainstream secondary schools throughout England and Wales, found that training in autism and Asperger syndrome for teachers improved the social behaviours and sense of school belonging of those with autism and Asperger syndrome. It seems likely that once school staff receive training and can understand and start to interact better and build relationships with young people with autism, the young people themselves feel much more positive about school and start to develop their sense of belonging and 'connectedness' discussed earlier.

Williams and Hanke (2007) used a technique called "Drawing the Ideal School" with young people with autism and found that the behaviour of adults in school was especially important to them. Staff who were smiling, happy and friendly, not

shouting or being angry, knew each pupil and enjoyed being with pupils were seen as part of the ideal school. Some pupils gave graphic details about the adverse impact on their well-being that attending a non-ideal provision would bring.

As part of their understanding of autism, school staff need to be aware of individual children's strengths and weaknesses, and be able to act flexibly to provide the support needed (Connor, 1999; Jones et al., 2008; Jordan, 2008; Tobias, 2009; Frederickson et al., 2010). Such flexibility involves adapting curriculum delivery, routines and the physical environment as required (Jones et al., 2008) and facilitates genuine inclusion. It also focuses on young people's strengths and talents rather than solely on their difficulties (Jones et al., 2008; Jordan, 2008).

This is supported by an interesting questionnaire study carried out by Whittaker (2007) in which 173 questionnaires were included, a 49% response rate. This study compared the views and experiences of parents of children with autism and Asperger syndrome who rated themselves as satisfied with their children's education with those who were dissatisfied. The extent to which parents felt that school staff understood and empathised with their children's difficulties and the perceived flexibility of the school's responses to their children's needs were the two factors which most sharply differentiated the two groups of parents.

Schools are becoming more aware of the importance of the role of peers in both including children with autism and promoting their well-being in school. Bullying should be tackled effectively to maintain the well-being of those with autism and Asperger syndrome in school (Attwood, 2004; Batten et al., 2006). Peers can receive general awareness raising sessions (Etherington, 2009; Etherington, 2010a; Frederickson et al., 2010) or be trained to become peer supporters for a named young person with autism (Etherington, 2010a). In a similar vein, the use of an adapted 'Circle of Friends' technique has also been found to reduce anxiety (Whittaker et al., 1998) and increase feelings of safety, happiness and well-being (Etheringon, 2007) in young people with autism and change the attitudes of peers towards them (Gus, 2000).

However, the disclosure of the autism or Asperger syndrome diagnosis to peers remains controversial. Ochs et al. (2001) found that children whose diagnosis was fully disclosed received more consistent social support and less rejection from peers on the playground and in the classroom. Nevertheless, it is possible that some other factor was different in these cases, for example perhaps the children and their peers were older. In their study of young people in mainstream secondary schools, Humphrey and Lewis (2008) concluded that providing peers with information about Asperger syndrome did facilitate positive relationships and reduced levels of ignorance and intolerance, but for some young people any disclosure affected their ability to be seen as 'normal' and fit in with others. In a similar vein, Barratt (2006)

states that the final decision on sharing the news of a young person's diagnosis with their peer group should remain with the young person themselves and their parents or carers.

Teaching assistant support can reduce emotional and behavioural difficulties in those with autism and Asperger syndrome in mainstream secondary schools (Osborne and Reed, 2011). However, at the same time many young people also need help to become more independent, often through a focus on their specific difficulties with organisational skills (Tobias, 2009).

### 2.8.3 Social Skills Training

The ability to form friends engenders a sense of belonging that affects how all children cope with crisis, and their levels of well-being, particularly at adolescence (Herman et al., 2009; McLaughlin and Clarke, 2010). Friends in childhood can support children when there are stressful changes, reduce the risk of bullying and lessen the risk of depression in adulthood (Layard and Dunn, 2009).

Research suggests that this is also true for young people with autism and Asperger syndrome who attend mainstream schools. Cappadocia et al. (2011) found that children with autism who have fewer friendships in school are more likely to be bullied. Humphrey (Humphrey, 2008; Humphrey and Lewis, 2008) reports that

friendships help young people with autism or Asperger syndrome to feel safe by supporting them if they are exposed to bullying or social isolation and increases their resilience to feelings of depression. Humphrey and Symes (2010) found that the young people themselves perceived friends as having the prominent influence over their well-being.

Social skills training has been advocated for neurotypical children who have been diagnosed with depression, due to the importance of social skills in the aetiology of depression (Harrington, 1993). It would seem even more likely that social skills training is relevant to young people with autism or Asperger syndrome who are at risk of mental health difficulties. Indeed, recent surveys of the parents of children with autism and Asperger syndrome have found that many wanted further development of their child's social skills to be a high priority for their school (Reid and Batten, 2006; Whittaker, 2007). It is perhaps not surprising therefore that schools in the United Kingdom also report high use of social skills training for this group and the desire to conduct more (Frederickson et al., 2010).

There remains contention, however, about the usefulness of social skills programmes. Various authors (recently including Beaumont and Sofronoff, 2008; Cotungo, 2009; DeRosier et al., 2010; White et al., 2010b) have demonstrated positive gains in social skills from social skills programmes, at least in the short term. However, others have pointed out that despite the popularity of such programmes

for children with autism, the gains made are not permanent and skills learnt are not generalised (Ghaziuddin, 2005a). Programmes are often quite short, lasting a few weeks or months. For example in the White et al. (2010b) study, the gains in social skills made were not seen in all settings and were not maintained at three month follow up.  Many studies rely on parental report to measure success and in cases where the parent has a vested interest in improvement or has been directly involved with the programme, this may tend to lead to positive results. Few use observation of the young person in social settings to evaluate their impact. In a recent review of the literature Cappadocia and Weiss (2011) found some positive results, but concluded that evaluation needed to be carried out to determine which target skills and which teaching techniques have the most impact for different age groups and to highlight whether there is maintenance of learnt skills and generalisation to other settings.

However, whatever the outcomes regarding the effectiveness of social skills training programmes in improving social skills, there is currently very little evidence directly linking positive results of social skills training with a reduction in mental health difficulties for young people with autism or Asperger syndrome.

## 2.8.4 Counselling Approaches

People with autism and Asperger syndrome often have difficulties with counselling due to their lack of empathy, difficulty generalising to new situations and problems with insight (Hare, 2004). However counselling can help to resolve misinterpretations of the world held by those with autism or Asperger syndrome which can lead to anxiety (Tantam, 2000; Vermeulen and Vanspranghe, 2006). Many authors also recommend teaching relaxation strategies as a useful coping strategy for stress and anxiety in people on the autistic spectrum (Howlin, 1997; Attwood, 2003; Paxton and Estay, 2007; Etherington, 2010b).

Some alterations need to be made to help those with autism or Asperger syndrome access counselling. Sessions may need to be more structured, shorter, and with information represented in visual forms (Paxton and Estay, 2007). People with autism usually benefit from a more structured way of questioning involving visual techniques such as scales and sorting systems and producing specific written plans about next steps (Vermeulen and Vanspranghe, 2006).

Cognitive behaviour therapy is the most frequently recommended form of counselling for people with autism and Asperger syndrome and this is discussed in the next section.

## 2.8.5 Cognitive Behaviour Therapy

Cognitive Behaviour Therapy (CBT) is being increasingly recommended for treating a range of mental health disorders including depression and anxiety in neurotypical children and adolescents (Reinecke et al., 2003). There are many areas of overlap between CBT and the objectives of mental health promotion (du Bois et al., 2003) and some have argued that learning to manage difficult situations and regulate one's own behaviour through CBT is mental health promoting (Fitzpatrick, 2004).

CBT is particularly appropriate for people with autism or Asperger syndrome as it can be used to challenge cognitive distortions (Fitzpatrick, 2004; Paxton and Estay, 2007) and it does not rely on building a relationship with a therapist to effect change or make use of metaphors, both of which may be hard for a person with autism (Hare, 2004). Despite this, it does appear to be necessary to modify traditional CBT programmes to meet the needs of those with autism. Possible modifications include adopting a more directive approach than is usual with high levels of predictability and structure, involving family members to promote generalisation, focusing on problems related to autism as well as the mental health needs, using visual explanations, incorporating the young person's interests, increasing the emphasis on practical coping strategies and reducing the use of abstract language, having a longer period of assessment, using more therapist modelling and providing more written information (Kenny et al., 2008; Russell, 2008; Moree and Davis, 2010; Madders, 2010). Recent CBT programmes such as those devised by White and her

colleagues in the United States incorporate many of these adaptations (White et al., 2009a; White et al., 2010a).

Given appropriate modifications, CBT is now a recommended approach for treating depression and anxiety in people with autism (Paxton and Estay, 2007) and there is increasing evidence of its effectiveness (White et al., 2009b; Whyte, 2009). Several published case studies have demonstrated reductions in anxiety symptoms or other mental health difficulties after the implementation of CBT techniques (for example Hare, 1997; Reaven and Hepburn, 2003; Lehmkuhl et al., 2008; Sze and Wood, 2008). Other studies have used modified CBT group interventions, again with some success (Chalfant et al., 2007; Kenny et al., 2008), although Kenny et al. (2008) caution against the use of groups due to the personal nature of discussions around mental health difficulties such as anxiety and the need to tailor the approach to individual needs. Two action research studies have involved the use of CBT in schools to meet the emotional and behavioural needs of young people with autism and Asperger syndrome (Fitzpatrick, 2004; Greig and MacKay, 2005). However, it is interesting to note that in two recent evaluations of CBT programmes, parental but not self reports of anxiety have reduced (Reaven et al, 2009; Wood et al., 2009). It may be that the programmes have in fact caused a reduction in parental anxiety, or that the parents had a vested interest in the programme working, and having participated in it, were keen to prove that it was a success.

It should also be noted that it has been reported that there is a lack of trained psychologists to implement CBT with young people with autism in the United Kingdom and demand for treatment far outstrips supply (Jones et al., 2008).

**2.8.6 Medication**

Medication can be used to tackle behaviour problems in those with autism (Morgan and Taylor, 2007; Tsai, 2007). It has also been claimed that medication can improve the quality of life of those with autism and comorbid mental health difficulties (Tsai, 2007) and reduce anxiety (White et al., 2009b). However, further research is needed in this area (Ghaziuddin et al., 2002; Royal College of Psychiatrists, 2006).

In particular, Morgan and Taylor (2007) caution against the use of medication in place of adequate care for people with autism and they also report the dangers of possible side effects due to medication. Adults with autism or Asperger syndrome have also highlighted these problems (Andrews, 2006; Grandin, 2006). In a chilling first hand account Andrews (2006) describes significant problems with bullying at secondary school and the highly sedating medication he was prescribed as a result, which affected his school performance but did not reduce the bullying.

To counteract this, many clinicians have stressed that medication should always be part of a multifaceted package of intervention for the person with autism who has

mental health difficulties (Ghaziuddin et al., 2002; Royal College of Psychiatrists, 2006, Tsai, 2007; Turk, 2008). One possible approach is the use of medication in the short term to facilitate the commencement of behavioural interventions. In any event, the individual should be involved in the treatment process as much as possible (Tsai, 2007).

## 2.8.7 Conclusions Regarding Factors that Promote the Mental Health of Young People with Autism and Asperger Syndrome

In summary, although some research has been carried out into factors that demote the mental health of young people with autism, research into mental health promotion for this group is more scant, and in many of the studies discussed above links to mental health are implicit. Research has focused mainly on the reduction of mental health difficulties through CBT interventions and has not looked at mental health more widely.

It should also be noted that although various different approaches to promoting mental health in young people with autism and Asperger syndrome have been discussed, they are not mutually exclusive. Some may be more appropriate as part of an ecological approach to promote the well-being of all; others may be necessary if a young person with autism shows signs of stress, anxiety or depression. Which will help most is likely to depend on that person's individual needs and the severity

of their difficulties. For example, Jones et al. (2008) highlight how in the first instance environmental modifications may be sufficient to manage anxiety, but some who are highly stressed may need medication and their family, school and health services working together to reduce sources of stress and treat symptoms.

**2.9 Conclusions and Implications of the Literature for the Current Study**

Research has indicated that young people with autism and Asperger syndrome may be more at risk of mental health difficulties than their neurotypical peers. A range of explanations has been suggested for this increased incidence, but often there is little research evidence linking many of them to mental health difficulties. There is also limited research into mental health promotion for this group, with a focus instead on treating mental health difficulties through medication and CBT, rather than altering the environment to make it 'mental health promoting'.

As Macdonald and O'Hara (1998) argue, we need to focus not just on those with mental health difficulties, but on the context and conditions in which mental ill health can develop. One such context for mental health promotion is the school (Rowling, 2009). A compelling reason for this kind of approach is that when attempts are made to hear the voices of those with autism and Asperger syndrome and mental health difficulties, a common theme is that of difficult environments which cause stress and

demote mental health (Andrews, 2006, Beardon and Edmonds, 2007; Beardon and Worton, 2011).

Despite this fact and references in the literature to school environments being a significant cause of stress for adolescents with autism or Asperger syndrome, there is limited research directly investigating the impact of schools on the well-being and mental health of these young people. Recent studies such as those by Humphrey and Lewis (2008), Emam and Farrell (2009) and Osborne and Reed (2011) have investigated the interactions and experiences of young people with autism and Asperger syndrome in mainstream secondary schools in the United Kingdom from a variety of perspectives, but their main focus has not been mental health difficulties. The current study aims to fill this gap by considering mental health promotion and demotion for young people with autism and Asperger syndrome in a particular setting, the mainstream secondary school.

It is clear from this review that more research is needed into effective support for people with autism who have mental health difficulties, and this has been demanded by a recent campaign by the National Autistic Society (2010). The current study aims to address these concerns by considering both promoting and demoting factors for mental health as advised by MacDonald (2006).

However, how the research is conducted is as crucial as its focus in determining the results gathered. Many studies have investigated the prevalence of various mental health difficulties in different populations with autism or Asperger syndrome, but these have often relied on looking for correlations amongst the results of a battery of parental questionnaires administered to small clinic based samples, and as a result do not add significantly to our knowledge about the experience of mental health difficulties for this group.

In contrast to such an approach, Secker (1998) makes some useful recommendations for research into mental health promotion including maintaining a focus on the environment in which people demonstrate their mental health skills, exploring lay understandings of mental health and using qualitative research methods. These areas are still worthy of focus and applying to the mental health of those with autism and Asperger syndrome in mainstream schools. Indeed there have been calls for more 'insider' accounts of people with autism and their families to help professionals develop their understanding of those with autism, their experiences and viewpoints from authors who have conducted studies in this manner with young people with autism (Carrington and Graham, 2001; Billington, 2006; Humphrey and Lewis, 2008). Seeking out such accounts is likely to be a useful starting point for fruitful research in the area of mental health difficulties and autism and as a result this study attempts to provide a more detailed account of the experiences and viewpoints of young people with autism and those around them.

Many researchers have highlighted the differences between parents, school staff and young people in their reporting of mental health difficulties in young people with autism and Asperger syndrome (Vickerstaff et al., 2007; Hurtig et al., 2009; Lopata et al., 2010; Mazefsky et al., 2011), although sample sizes in these studies have often been small (Vickerstaff et al. had a sample size of only 22, Mazefsky et al. a sample size of only 38). However, no studies have been found that consider the perspectives of parents, school staff and the young people themselves regarding mental health promotion and demotion for this group. Therefore comparing the perspectives of these three groups is a central element of the research questions.

In summary four key elements of the reviewed research have influenced the research questions and design of the current study. Firstly, there is a focus on the environment as important for mental health promotion, in this case the school environment. Secondly, there is a focus on factors which both promote and demote mental health. Thirdly, there is a focus on the details of the views and experiences of the participants in the study. Finally the study compares the similarities and differences between the perspectives of three key groups – young people with autism or Asperger syndrome and their parents and school staff. The next chapter focuses on the research design and methods used to ensure that these four elements were all included and to answer the research questions posed in section 1.5.

# CHAPTER 3:

# METHODOLOGY, DESIGN AND METHODS

## 3.1 Introduction

In concluding the literature review, Section 2.9 identified four key areas for further research to focus on. These were:

- Schools as mental health promoting environments for those with autism and Asperger syndrome

-  Factors that both promote and demote mental health within schools

- Obtaining "insider accounts" regarding autism and mental health and

- Considering both the viewpoints of both young people themselves and those who know them well, such as parents and school staff.

This chapter describes how the methodology, design and methods of the current study ensured that these four areas were tackled and considers how the research questions listed in section 1.5 were addressed.

To structure this chapter I have used the stages of research design recommended by Denscombe (2010, p.111): purpose and aims, design – strategy, design – philosophy, methods detailing who will be included in the study, methods detailing how the data will be collected, analysis, evaluation, ethics and outcomes. The only change that I have made to Denscombe's structure is deliberately reversing the

order of the two design sections. I have made this change because in my opinion the philosophy underlies and informs the strategy for research design, and is therefore most appropriately placed first.

## 3.2 Purpose and aims

The research aimed to investigate the perceptions of young people with Asperger syndrome, their parents and school staff regarding the young people's emotional well-being and which factors within school impacted positively and negatively on the young people's mental health. Aims of the study are not discussed in more detail here, the reader is referred to Chapter 1 where the aims, background and research questions are presented.

## 3.3.1 Design – Philosophy

Denscombe (2010, p.117) asserts that:

> *"Philosophical assumptions constitute the foundations for research in the way that*
>
> - *they underpin the perspective that is adopted on the research topic*
> - *they shape the nature of the investigation, its methods and the questions that are asked*
> - *they specify what type of things qualify as worthwhile evidence*

- *they point to the kind of conclusions that can, and cannot, be drawn on the basis of the investigation."*

Scott and Usher (1999, p.10) claim that philosophical issues are central to the research process because they indicate what researchers "silently think" about research. Therefore it is important for those writing about their research to make their philosophical position clear (Scott and Usher, 1999; Denscombe, 2010). In my discussion of the methodology and design of the current study, I will first set out the philosophical paradigms which underlie my research questions. Two key areas to consider when looking at key philosophical assumptions are a researcher's epistemology and ontology (Mertens, 1998) and these will be considered in this section.

Briefly, ontology is concerned with beliefs about the nature of social reality, and whether there is one objective reality we can try to discover or multiple realities that are socially constructed by individuals. Epistemology is the ways in which it is possible to gain knowledge about this reality or realities. Different epistemologies lead to different theories of explanation (Pring, 2000).

Within the positivist paradigm, one reality exists and it is the researcher's task to discover this (Robson, 2002). The model of research used in natural science is used to investigate the social world in which researchers should be objective and

detached (Usher, 1996; Denscombe, 2010). Different researchers in the same situations are expected to come to the same conclusions (Scott and Usher, 1999) and generalisation of findings is pursued (Usher, 1996).

In contrast, in the interpretivist or constructivist paradigm researchers perceive reality as being socially constructed, hence there are multiple realities (Glesne and Peshkin, 1992; Robson, 2002; Denscombe, 2010). Research findings are created through interaction between the researcher and the researched (Pring, 2000; Robson, 2002). The application of methods from natural science to investigate social phenomena is rejected and meanings are sought in preference to generalisations (Usher, 1996).

This description of the above paradigms is necessarily brief and ignores the fact that in real research the lines between paradigms are often blurred (Miles and Huberman, 1994; Oakley, 2000). However it does provide a setting for discussing the current piece of research.

In order to discuss the philosophical basis of the current study in some context, I will now provide a brief description of my journey in understanding and accepting the different paradigms outlined above. Glesne and Peshkin (1992, p.9) write that "We are attracted to and shape research problems that match our personal view of seeing and understanding the world."

Carried out over fifteen years ago, my undergraduate work was rooted firmly in a positivist framework. However, my experience of working as an Educational Psychologist in schools has led me to an understanding of the unrealistic expectations of much positivist research to complex real-life settings. My role has also led me to a greater appreciation of the fact that different people in any situation each tend to have a very different understanding of the problem, and that research needs to reflect this, which slides me to an ontology which fits a more interpretivist viewpoint.

My journey has perhaps been paralleled by the profession of Educational Psychology generally, which many have claimed appears to be moving away from a positivist position (Greig 2001; Fox 2002). It also echoes the story of Marinosson (1998) who writes of his process of learning to abandon much of what he had learnt during his training in psychology after working as an Educational Psychologist so that he could adopt a different methodology which could investigate the complexities of school culture and the social world of children.

This study aimed to investigate the experiences of a group of young people in a particular setting and explore the different viewpoints and realities of the young people and their parents and school staff. Reducing these complex issues to

statistics risked losing "rich, deep, valid data" (Oakley 2000, p26).  As such, this piece of research is rooted in a more interpretivist or contructivist paradigm.


### 3.3.2 Design – Strategy

Cohen, Manion and Morrison (2007) list a number of styles of educational research including ethnographic research, historical and documentary research, case studies, surveys, experiments and action research. This section considers some possible research designs in relation to the research questions and justifies the decisions made.


One possible approach that could have been used for the study was a survey. A survey enables data from many people to be gathered, which, if sampling is done carefully, allows generalisations to be made. This approach may have been effective in providing information regarding the prevalence of such difficulties in this population. However, it was unlikely to provide the most illuminating answers to my research questions where the richness and depth of information is key. In addition, the topic under consideration may have been both too sensitive and too complex to be reduced to survey questions, as participants may have been reluctant to record on paper sensitive information and may have misinterpreted questions. It is interesting that Green et al. (2005) had difficulty when their wide-ranging, large-scale

survey tackled the area of children's mental health due to the complexity of the subject matter.

Other potential designs were also deemed unsuitable. An experimental methodology would have been an inappropriate method for answering the research questions as they are broadly descriptive, focusing on people's views and experiences rather than the effectiveness of one particular mental health intervention or issues of causality. Similarly, an action research approach was considered inappropriate for the research questions, which involve describing the current situation rather than implementing an intervention.

Instead a case study design was selected. There are various features of a case study approach that indicate its suitability. A case study design is most relevant when research questions require an in-depth description of actual human events and behaviour and when the context of the phenomenon is important (Yin, 2009). It focuses on how people understand themselves, their feelings, perceptions and experiences (Gillham, 2000). Case studies can capture complexities and give an opportunity for the voices of participants to be heard (Edwards and Talbot, 1999). As Denscombe (2010, p.165) concludes "When the questions concern matters such as emotions, feelings, attitudes and relationships, it might invite the use of in-depth case studies with qualitative data."

A few case studies are recorded in the literature surrounding mental health and autism. Some have sought to describe the manifestations of emotional difficulties in those with autism or Asperger syndrome (see Stewart et al., 2006, for a review) and others have focused on the use of CBT with a single person with Asperger syndrome and its results (for example, Hare, 1997; Greig and MacKay, 2005). Humphrey and Lewis (2008) carried out in-depth case studies of four mainstream secondary schools in the north west of England focusing on the inclusion of young people with Asperger syndrome and high-functioning autism. However no case studies found consider the promotion and demotion of mental health for young people with autism or Asperger syndrome in schools.

For the purpose of this study a case was a young person with autism or Asperger syndrome. Within each case the primary focus was that person's emotional well-being and mental health, the perspectives of this taken by the young person themselves, their parents and school staff, and what promoted or demoted their mental health in the school context.

It is possible to study multiple cases and draw a single set of 'cross case' conclusions; such a study is regarded by Yin (2009) as more robust than a single case. Caution is warranted as Miles and Huberman (1994) note that a study with more than 15 cases can become unwieldy and the data are usually 'thinner'. In

addition designing for comparison purposes affects the flexibility of the research process (Miles and Huberman, 1994; Richards, 2009).

The current study consisted of a series of eleven triangulated case studies. Using multiple case studies allowed comparison to be made across cases to provide richer, deeper information about the nature of mental health difficulties in young people with autism and Asperger syndrome and what promoted and demoted their emotional well-being. Cases were compared to consider common themes but no attempt was made to minimise the difference between cases in order to draw generalisations through statistical analysis. Instead, it was precisely the differences between the cases that were the focus for further analysis and discussion.

It is important to note that the very act of undertaking the case study may well have disrupted the case (Gillham, 2000). In this instance the process of interviewing may well have prompted participants to reflect on the situation and may have led to some changes to subsequent behaviour. For example, one parent who was interviewed asked me to send her the list of factors which were proposed to have some positive impact on the mental health so that she could reflect on them and discuss them with her child's school.

### 3.4.1 Methods – Participants

The decision was made not to select young people on the basis that school staff believed that they had mental health needs for two main reasons. Firstly, some young people who had significant mental health needs, but who internalised their difficulties and showed few outward signs in school, may have been missed. This group is particularly interesting and relevant to the study. Secondly, cases in which the young person's emotional well-being was good, were also able to provide relevant answers to the study's research questions, particularly those about how schools promote mental health. This approach is supported by writers on collective case study such as Miles and Huberman (1994) and Stake (2000). They highlight the value of choosing a range of cases to provide balance, variety and comparison information rather than just selecting the most striking examples.

Schools were selected to be part of the study on the basis of three main criteria. These were, firstly, that they were mainstream schools, secondly, that they were close to where I worked and therefore minimal time would be spent travelling (a key factor in a large county) and, finally, those in the schools themselves (specifically gatekeepers such as Headteachers and SENCOs) agreed to participate. Letters were sent out to the Headteachers of all six mainstream secondary schools in two adjacent towns in the north of England (see Appendix 1 for a copy). The letters were followed by telephone calls to the Special Educational Needs Co-ordinators (SENCos) in some of the schools to discuss the research and what commitment was

required. Both the SENCos that I was able to speak to by telephone agreed to participate and because of the difficulties gaining access, a further school elsewhere in the county was also recruited for the study. This school was selected because I was the Educational Psychologist for the school, knew the SENCo well and could gain access more easily.

The three schools in the study were all large comprehensives. Reflecting the local area, the socio-economic status of pupils in the schools was above average and a majority were of white British heritage. Further details regarding the schools in the study are included in Appendix 14.

Discussions with the three SENCos who had agreed to participate led to a list of potential participants being drawn up. The SENCos provided names of Key Stage Three young people who had a diagnosis of autism or Asperger syndrome in their school. These were then cross checked with the database of children with autism which was held by the Autism Outreach Team of the Local Authority. In total thirteen potential young people were identified, one of whom had already taken part in a pilot interview (see section 3.4.2 for more details) and therefore did not participate in the main study. In another case, the SENCo requested that I did not contact the family. This young person was having some difficulties in school and the SENCo felt that the research interviews might lead to additional pressure on the family. This was rather disappointing, as it was likely that this case may have been one of the most

relevant to the research. Walsh (2005) reports that it can be difficult to obtain access when research topic is sensitive, as gatekeepers may wish to avoid undesirable attention, and this is a possible explanation in the current instance. In the remaining eleven cases it was agreed that I would contact the family to discuss the research and gain their consent.

Letters were drafted to send to parents to provide them with information about the study. One letter was sent to parents (see Appendix 2), but due to time constraints, as a result of my impending leave of absence, in other cases I telephoned the families to explain the study, focusing on the areas covered by the letter and asked them if they wished to participate. This method of recruitment proved very fruitful. I started to build a good relationship with several of the parents over the telephone, which helped when the interview process started. All parents contacted agreed to take part in the interviews and consented to their children doing so. Time constraints also precluded the letters I had originally drafted to be sent to young people (Appendix 3) so instead young people were initially told about the study by their parents and teachers. Again, the letters provided a useful template to structure my discussions with young people about the study, held prior to the interviews. Once parents had given consent, in each school the school SENCo indicated which adult would be the appropriate person to interview about the young person's emotional well-being. As some members of school staff were involved in several different interviews, six different members of school staff were interviewed in total (two from

each school). Further details about gaining informed consent can be found in section 3.7, in the Ethics section of this chapter.

In total the study comprised eleven cases, nine boys and two girls, a gender ratio which broadly speaking reflects the ratio diagnosed with higher functioning autism or Asperger syndrome. Time limitations to recruit schools and families, travel to and carry out interviews and analyse data precluded further recruitment to the study. However, if further cases had been included, some of the rich data may have been lost and a more survey style methodology, contrary to the research aims may have had to be adopted. Focusing on the eleven cases across three schools allowed a good breadth of experiences and range of viewpoints to be displayed and permitted comparison between cases. In addition, these eleven cases represented almost all Key Stage 3 young people with autism and Asperger Syndrome within these three schools, because all except one of the young people with such a diagnosis from the schools participated in the main study or pilot.

For each case, there were three study participants, the young person themselves, their parent and a member of school staff who knew them well. Further details of the eleven cases and study participants are found in the table below.

**Table 1. Summary of Participant Basic Details** (adapted from Miles and

Huberman, 1994, p.32)

| Young person | School | Diagnosis | Additional (Medical) Diagnosis | Year Group | Statement of SEN? | Parent interviewee | School interviewee |
|---|---|---|---|---|---|---|---|
| Pilot | III | Asperger Syndrome | None | 8 (should be 9) | Yes | Mother | Teaching Assistant A |
| 1 | II | Asperger Syndrome | None | 7 | No | Mother | SENCo A |
| 2 | I | Autistic Spectrum Disorder ) | Learning difficulties | 7 | No | Mother | SENCo B |
| 3 | I | Asperger Syndrome | Dyspraxia | 7 (should be 8) | Yes | Mother | SENCo B |
| 4 | III | Autistic Spectrum Disorder | Learning difficulties | 7 | Yes | Mother | Teaching Assistant B |
| 5 | III | Asperger Syndrome | None | 9 | No | Mother | Teaching Assistant A |
| 6 | I | Autistic Spectrum Disorder | Dyspraxia | 8 | Yes | Mother | SENCo B |
| 7 | III | Autistic Spectrum Disorder | Learning Difficulties | 7 | Yes | Mother | Teaching Assistant B |
| 8 | II | Asperger Syndrome | None | 9 | No | Mother | Learning Mentor A |
| 9 | I | Asperger Syndrome | None | 9 | No | Mother and Father | Teacher A |
| 10 | I | Asperger Syndrome | Dyspraxia | 9 (should be 10) | Yes | Mother | SENCo B |
| 11 | III | Autism | None | 8 | Yes | Mother | Teaching Assistant A |

## 3.4.2 Methods - Data Collection

Case studies can use a variety of sources of evidence, most commonly documentation, archival records, interviews, direct observation, participant observation and physical artefacts (Yin, 2009). From these potential sources, interviews were chosen on the basis that they were the most likely method to provide the rich, detailed information required to answer the research questions and seek to explore the meanings of situations to those involved. Many authors (including Edwards and Talbot, 1999, and Gillham, 2000) claim that semi-structured interviews provide the rich data required for case study research.

The level of structure provided in interviews is linked to the depth of response sought (Robson, 2002). Semi-structured interviews are flexible and allow the researcher to probe meanings deeply (Burman, 1994; Edwards and Talbot, 1999; Robson, 2002). A semi-structured approach was chosen because it enabled me to gain the richness of information required and allowed clarification of the complex and sensitive subject matter, but retained some structure to allow comparison within and between cases.

Other researchers carrying out similar studies have also used interviews as a research method. Humphrey and Symes (2010) investigated the views and experiences of young people with autism and Asperger syndrome in English secondary schools regarding bullying. They noted that "Interviews, as a research method in studies involving individuals with AS, provide a voice for participants and

a window into their thoughts, feelings and experiences in a field dominated by impersonal experimental studies" (Humphrey and Symes, 2010, p. 83).

I decided to use individual as opposed to group interviews because many people with autism and Asperger syndrome find the social demands of group situations stressful and would be unlikely to give clear responses in a group (Paxton and Estay, 2007) and on such a personal and sensitive topic, participants would probably be more honest and open when interviewed individually. In addition, the design involving triangulation around each case meant that group interviews were unlikely to provide the data required to answer the research questions.

Other methods of data collection were considered and rejected. Observation was rejected as an approach for this study as it is so time consuming (Gillham, 2000; Walford, 2001). It is unlikely that I would have been able to observe all possible aspects of mental health problems and schools' promotion and demotion of these without extensive observation of each young person throughout many school days and home visits. This would have been very invasive of privacy, and therefore probably aversive to the young person concerned.

The use of diaries by the young people was considered in some depth and piloted. Others, notably Humphrey and Lewis (2008), have used diaries in research with young people with autism or Asperger syndrome who attend mainstream secondary

school. These have some advantages over interviews, such as the opportunity to gain opinions over a period of time and the lessening of contact with an unfamiliar person which many people with autism or Asperger syndrome may find stressful. However, the lack of ability to probe meanings from diaries (unless they are accompanied by a full interview) meant that these were not chosen to be the main tool for data collection. However, they could be included in future studies of this type.

The use of a structured interview schedule or checklist to determine whether any of the young people had clinically significant levels of mental health difficulties such as anxiety or depression was also considered and rejected. This has already been carried out in several other studies described in sections 2.5.1 and 2.5.2 and in the current piece of research, understanding how anxiety and stress were perceived, experienced and managed by this group of young people and those around them was the focus.

In carrying out the interviews, I was mindful that the skill of the interviewer significantly affects the quality of the data gained (Powney and Watts, 1987). Although I had plenty of experience in interviewing young people with autism, their parents and their teachers in my Senior Specialist Educational Psychologist for Autism role, I was aware of the need to move from my practitioner role to that of researcher, if the research was to be successful. This involved a shift from seeking solutions to making enquiries (Marinosson, 1998).

Other ways in which I tried to ensure the effectiveness of the research interviews were building rapport so that participants felt able to disclose information to me (Glesne and Peshkin, 1992; Lewis and Lindsay, 2000), reassuring all participants that there were no wrong answers (Glesne and Peshkin, 1992), ensuring that prompts and probes were used carefully and consistently (Powney and Watts, 1987; Gillham 2000; Robson, 2002). Care was also taken to use appropriate language to describe emotions. McLaughlin (2008, p.353) describes the "bewildering array of terms" used to describe work in this field including emotional literacy, positive mental health and emotional well-being, and notes that these are often linked to the profession in which the author is working. She recommends 'emotional well-being' as being the most encompassing and I also chose this term for use with parents and school staff.

Interviewing children for educational research is complex and even more so when the young people concerned have communication difficulties. If interviews are not adapted sufficiently to meet the needs of participants the responses obtained and the validity of results may be affected and more importantly, interviews may cause undue distress to participants. Therefore, I adapted the interviews in a number of ways. Carrying out both the parent and school staff interviews before the young person's interviews in the majority of cases allowed me to ask parents and school staff about the young person and how they would respond to being interviewed. I could ask about their special interests, so that I could discuss these with the young

person, whether they were aware of the diagnosis and anything that might unsettle them.

Interview questions were designed carefully, taking account of anticipated comprehension levels (Greig and Taylor, 1999; Nesbitt, 2000; Vermeulen and Vanspranghe, 2006) and keeping the language as literal as possible. When necessary I adapted the language and literacy demands of the interview as it progressed so that the participants could access the questions easily (Greig and Taylor, 1999). Rating scales and practical tasks such as sorting elements were used because there is evidence that young people with autism or Asperger syndrome find these motivating (Hare, 1997), they respond best to information in visual forms (Paxton and Estay, 2007) and may prefer to quantify an emotional response rather than express their ideas verbally (Attwood, 2006).

I was aware that people with autism or Asperger syndrome may take longer to process information (Paxton and Estay, 2007) and stressed not knowing the young person's views or school to counteract the possible assumption of the young person that the adult always knows the answer (Lewis, 2004). Attempts were made to ensure validity and authenticity at the time of the interview as it was anticipated that verification of transcriptions or conclusions by the young people would be very difficult (Costley, 2000).

There is sometimes a concern that young people participating in research, especially those with additional learning needs or other difficulties, tend to agree with the interviewer too readily, in an attempt to please (Lewis, 2004). This study therefore made a deliberate attempt to avoid this problem by legitimising from the outset the right of the young people participating to answer both 'no' and 'I don't know / don't understand' as well as 'yes' to the questions asked. This was achieved by encouraging the young people to sort items onto cards indicating positive or negative responses, thus permitting any of these responses. There was also the option of an 'I don't know / don't understand' card for the young people to use or point towards at any time during the interview, which gave the young person the option to explain non-verbally that that they did not understand if necessary. This card also removed the pressure to produce a 'correct' response each time. During the process of analysis, the potential for a positive bias was also considered carefully.

The interview schedules for the parents, school staff and young people are included in Appendices 4,5 and 6 respectively. Care was taken to ensure that the interview questions related to the research questions and answered them fully, by producing a table which links specific research questions and interview questions for each of the three interviews (see Appendix 7). The basic structure was the same for all interviews, based on that described by Robson (2002) and included a description of the purpose of the interview, gaining informed consent, the main body of the

interview and then ending and thanking participants. Robson (2002) notes that the order of the questions can be varied in semi-structured interviews and I did this when necessary to be flexible to the needs of the interviewee. However, in general the interview schedules were altered little, as this would have made comparison within and between cases more difficult (Miles and Huberman, 1994; Richards, 2009). As the interviews comprised a mixture of open and closed questions, the open ones were asked earlier on so that the answers given were not influenced by ideas presented in the closed questions. I also put some positive questions towards the end of the interview so that it ended on a positive note.

The content of the interviews was derived from the literature discussed in Chapter 2 of this thesis; in particular the items included in sorting tasks were carefully derived from relevant research. For example, when considering possible manifestations of mental health difficulties to ask the young people and their parents and school staff about, the literature in section 2.6 was considered in detail, including, but not limited to, Deudney (2004) and Ghaziuddin (2005a). To avoid confusion with the signs of autism or Asperger syndrome, and in keeping with the literature, the emphasis was firmly on identifying whether there had been a recent change in the young person's behaviour which might indicate an overlay of mental health difficulties in addition to the young person's usual behaviour (Tyler, 2010). When considering possible mental health promoting and demoting factors to include in sorting tasks, the literature highlighted in sections 2.7 and 2.8 was reviewed and key features

identified. These more structured interview questions allowed exploration of the links between the experiences and viewpoints of the participants and the literature discussed in Chapter 2. Throughout these tasks however, the emphasis was on expanding on and discussing the decisions made and gaining further ideas from participants about any areas that had been omitted. In line with this approach, the framework provided by Hornby and Atkinson (2003) was used with parents and school staff to facilitate open-ended discussion on what promotes mental health for the young person.

A full pilot study was not carried out but three pilot interviews (parent, young person and member of school staff) were carried out in advance of the main research. Yin (2009) recommends that convenience and access should be the main criteria for selecting pilot cases. In my pilot case the young person was articulate and able to assess the interview, his parent had a doctorate herself and was aware of what was required, and I had previous experience of working with the school and member of school staff concerned. The pilot interviews enabled me to ensure that no practical considerations had been overlooked, clarify the length of time taken for the interviews and test the use of recording equipment in context. I was also able to ensure that the interview questions were comprehensible to participants and elicited sufficient data to answer the research questions. I asked for feedback on the pilot interviews from all three participants. As well as the feedback gained, the pilot

interviews also provided an opportunity to reflect on the shift from the role of Educational Psychologist to that of researcher.

Some fairly minor changes were made to the interview schedules as a result of the pilot interviews. These included the addition of 'lighter' questions at the start of each interview, changes made to reduce overly repetitive questions in the parent and school staff interviews, and probes were clarified on the interview schedule to enable me to investigate open questions more deeply. As a result of the feedback provided by the young person who participated in the pilot interviews I changed the categories for sorting tasks to make them easier to understand and use. Finally, I became aware that some information was not tape recorded, for example where cards had been sorted, although I had taken care to record this by hand. So in future interviews, I read out the results of practical tasks when they had been completed so that they were recorded.

In summary, for the main study, I collected the data by carrying out 33 individual interviews, one with each of the eleven young people, and for each young person, a parent and a member of school staff who knew them well. The interviews were carried out in school for young people and school staff and at home or place of work for the parents. All interviews were carried out in quiet, private rooms and interruptions were kept to a minimum. The interview schedules were followed closely. Interview length varied according to the role of participants with parents'

interviews lasting the longest on average. The length of parent interviews varied, with those who perceived their child's well being more negatively generally having longer interviews. Ten of the eleven parent interviews were between 38 and 60 minutes. Interviews with school staff were slightly shorter, with the majority being in the range 34 - 42 minutes, and most young people's interviews were in the range 27 – 33 minutes.  All interviews were recorded.

## 3.5 Analysis

Given that 33 interviews had been carried out, a considerable amount of data reduction and analysis was needed to elucidate the main findings of the research and carry out the process of "subsuming particulars into the general"  (Miles and Huberman, 1994, p.255). Yin's (2009) four principles of high quality analysis in case studies guided my approach. Firstly, I aimed to ensure that any interpretations accounted for all the evidence available. Secondly, I considered whether there were alternative explanations for the data other than the conclusions I was drawing. Thirdly, I tried to focus on the most important aspects of the study rather than side issues and finally I tried to use my prior knowledge of the literature when making decisions about analysis. In addition, as Yin (2009) also recommends, I tried to ensure that all of the cases were treated fairly and that any conclusions drawn were not biased by one or a few cases.

This section describes the analysis in detail, as without this it is difficult to evaluate or compare research (Braun and Clarke, 2006). Two main approaches to data reporting and analysis were used. Firstly, data indicating reported frequencies of feelings and behaviours gained from closed questions and rating scales was displayed in tables so that an overall picture could be gained of the profile of the group of young people as a whole.

The second approach involved analysing the interview data through a lengthy process of transcription, coding and searching for themes. The process used was similar to that described by Braun and Clarke (2006). Braun and Clarke (2006) define thematic analysis as identifying, analysing and reporting themes or patterns within data which relate to the research questions. They describe some features of thematic analysis that make this a suitable approach for answering the research questions outlined in section 1.5. It is a flexible approach that fits within a constructionist paradigm and can usefully summarise the key features of a large amount of data whilst retaining richness of detail and highlighting similarities and differences across the data. Others working in this area (such as Humphrey and Symes, 2010) have used Braun and Clarke's approach to data analysis.

Initially, interview data were partially transcribed with phrases from the interview relevant to the research questions being typed into a matrix for each case. The data were transcribed under four main headings, reflecting the research questions,

focusing on the young person's emotions in school, any manifestations of mental health difficulties, what schools do that promotes positive emotional functioning and what they do that demotes mental health. Each phrase was marked by the time on the recording it occurred to enable it to be easily retrieved. This process was initially tested on the data from the pilot interviews. However, as the interview schedules were different for the pilot interviews than for the main research, further analysis on the data from these was not carried out and they were not included in the main analysis of results or when drawing conclusions. Although the data within each case from each of the three participants in the case were placed side by side they were too lengthy to compare, so further analysis was required.

As noted by Braun and Clarke (2006), transcription improved my familiarity with the data and from this an initial list of around 20 codes was derived. Next the transcribed data were moved to one or more of the different codes using the cut and paste function on a word processing programme. As this process continued, new codes were added rapidly to the list to ensure that all data could be coded. A miscellaneous code was used sparingly as a holding facility and gradually items from this were moved into new codes as they were created. By the end of this process 83 different codes had been created, some of which might have been expected prior to the research, and others not. Throughout the process I attempted to remain "open to surprises" (Ely et al., 1997, p.238), to ensure that all perspectives

were reported and any contradictory data were included (Braun and Clarke, 2006; Yin, 2009).

Braun and Clarke (2006) distinguish between an inductive and a theoretical (sometimes known as deductive) approach to thematic analysis, both of which can be used to identify themes and patterns within the data. An inductive approach means the themes identified are strongly linked to the data themselves whereas a theoretical or deductive thematic analysis is driven by the researcher's theoretical interest in the area.

This deductive approach to analysis, perhaps involving deciding the framework for analysis and categories entirely in advance, can provide a strong link to theory and a way to manage large amounts of qualitative data (Hayes, 1997). However, this means that new material not linked to the predetermined themes will not be included in the analysis. Therefore I considered that such an approach was not appropriate for my study as it was fairly exploratory and there had been little previous research in the area. As a result I may have missed some interesting insights if I had determined all the categories beforehand.

However, in the current study, although the codes were generated as the data were examined, rather than beforehand, a small number of the codes stemmed directly from the more structured questions asked during the research interviews. As

Edwards and Talbot (1999) note it is not useful to see too clear a distinction between deductive and inductive models of research and much research combines both deductive and inductive elements.

Care was taken that context was provided for each example in each code so that the true meaning of what someone had said could be understood (Braun and Clarke, 2006). This meant that whole paragraphs were often recorded rather than short phrases, which could easily be taken out of context. Each data extract was labelled with a note of the case it came from and the time on the recording so that it could be rechecked later on. Also, within each code data were put under headings to indicate whether or not the person talking was a parent, member of school staff or young person. When all data extracts had been coded, time was spent checking that the data extracts had been correctly placed. The codes themselves were also reviewed to ensure that they were not too fine or too coarse (as recommended by Richards, 2009). The final list of codes is included in Appendix 8.

This process allowed me to see more widely across the data, taking a vantage point above individual interviews or comments (Richards, 2009). Comparing the volume of data under the different headings of parents, school staff and young people, gave a rough indication of which codes were more frequently discussed by each group. An example for the data set for Code 67 – Friendship Difficulties – is in Appendix 9 with the identifying initials removed to protect anonymity.

Notes and memos were made throughout the process of data collection and analysis, to aid reflection and prompt analysis (as advised by Robson, 2002). As more cases were analysed, it became apparent that in some cases a particular code, or some aspect of it, was perhaps a key theme to emerge from the research.

Spider diagrams were used to see how the categories related together and to consider emerging themes. Also, as recommended by Braun and Clarke (2006), the names of the different codes were printed out onto individual pieces of paper and rearranged visually so that similar codes could be grouped together into different themes. Common meanings emerged as codes were rearranged and merged (Richards, 2009).

This process has been described by Fereday and Muir-Cochrane (2006, p.7):

*"Connecting codes is the process of discovering themes and patterns in the data…. Similarities and differences between the separate groups of data were emerging at this stage, indicating areas of consensus in response to the research questions and areas of potential conflict."*

However, to move beyond simply describing the data it was necessary to revisit the research questions. It then became apparent that much of the data gathered, although interesting, was not directly related to the research questions. By focusing

again on which data gave answers to the research questions, I was able to gain a more succinct description of the reported feelings and behavioural manifestations of the young people and eight themes that promoted or demoted mental health for these young people in school. In selecting themes I was aware that they should run through most or all of the data, or if they were present only in a minority of cases, have heavy emotional or factual impact (Ely et al., 1997)

The reports of the three people describing the situation for each young person were then compared to gain an insight into the different perspectives held by those in different roles. Common themes were searched for both across case studies and across roles using a variety of tables. These displayed data in different ways, which allowed comparisons to be drawn and patterns and meanings to be found (Miles and Huberman, 1994). For example, ratings of the young person's feelings by each of the participants concerned with a case were placed into a table so they could be compared. A subsequent table investigated the similarities and differences between parents and school staff ratings of emotions across each case (Appendix 10). Further tables were used to display and evaluate the findings from some of the sorting tasks. For example, Appendices 11 and 12, show the strategies that the young people, parents and school staff rated as helping the young person feel relaxed and happy in school. Other tables considered whether or not there were any similarities in the manifestations of mental health difficulties, potential sources of stress, or features that helped the young person as reported by the different people

within each case. Included as an example of these, Appendix 13, indicates the number of factors deemed helpful by each participant and displays how much agreement there was concerning the reported factors within each case.

These tables are not included in the main body of the results as within the process of analysis, the information in the tables was considered alongside responses to more open questions, in which many participants gave fuller, richer answers. Such an approach is in keeping with the research questions and aims of the study. However, much of the data contained within them is reported in the sections 4.6, 4.7 and 4.8 and reflected on within the sections 5.5 and 5.6. They are referred to here and a selection of them are placed in Appendices to illustrate the process of analysis and highlight how it involved some data display, particularly when considering the answers to research questions III and VI which involve comparison between viewpoints.

## 3.6 Evaluation

When evaluating what confidence we can have in the findings of any research it is important to consider validity and reliability. Those who approach research from different philosophical backgrounds define these terms in different ways. For example, Robson (2002) argues that to ensure reliability we need to carry out research thoroughly and honestly so that if another researcher were to repeat it consistent results would be obtained, whereas Edwards and Talbot (1999) claim that

such consistency is not always obtainable across different contexts and instead argue for reliability in terms of building a rich and detailed picture through good quality data. Validity is arguably more crucial to those working within an interpretivist paradigm and is generally viewed as being related to the credibility and trustworthiness of research (Robson, 2002).

Although there are many advantages to using semi-structured interviews in research as outlined earlier, there are also limitations to the use of interviews as a method which affect their validity and need to be taken into account both when analysing interview data and evaluating studies that use interviews. These mainly stem from the fact that interviews are social interactions and the data generated by them are made collaboratively by the interviewer and interviewee (Fontana and Frey, 2000; Richards, 2009).

Interviewees may not tell the truth, either intentionally, or because a lack of knowledge or their perceptions of what the interviewer already knows (Powney and Watts, 1987; Walford, 2001). This is especially likely to arise if the questions relate to topics that the interviewee is embarrassed about (Walford, 2001) which may be particularly true when mental health, emotions and behaviours are the subject matter. A second threat to the reliability of interview data comes from the other part of the interaction: the interviewer themselves. Factors such as interviewing style, inconsistencies across interviews, characteristics of the interviewer such as age,

gender, race and socio-economic status and the opinions of the interviewer can have a significant impact (Powney and Watts, 1987).

Two main solutions are proposed in the literature counteract these limitations. These are reflexivity (Fontana and Frey, 2000) and triangulation (Walford, 2001) and are discussed in detail below.

Bias (in terms of the researcher's assumptions) is a threat to validity (Robson, 2002) and a major way to tackle this within interpretivist research is through reflexivity. This is a constant process of reflection on the role of the researcher in creating data at each stage of the research process (Tindall, 1994; Nesbitt, 2000; Richards, 2009). As part of this, it is important that researchers acknowledge their beliefs and the impact of these on their research (Glesne and Peshkin, 1992; Paechter, 2003; Denscombe, 2010).

I have worked hard to reflect on my conduct at each stage of the research. As an Educational Psychologist, I consider that being a reflective practitioner is a strength of my professional work. I transferred this approach to my research and regularly attempted to question any assumption I might be making and consider alternative explanations. In this section of the thesis I reflect on and evaluate the impact of my role as a researcher in each of the following stages – choosing the research

questions, research design, recruiting participants, interviews, analysis and writing about the research.

Although I was an outsider in the schools in which I carried out the research, as a Specialist Educational Psychologist for Autism working across a large county I had previous experience of talking to young people of this age with autism and Asperger syndrome, their parents, teachers, SENCos and teaching assistants on numerous occasions prior to the research. Embarking on the research I was aware of many common viewpoints and many common difficulties they faced. My extensive knowledge of the topic area was both a strength and a weakness in carrying out the research. My background knowledge helped me to formulate relevant research questions, design the research appropriately and carry out the interviews sympathetically. But, such knowledge and experiences are also problematic when it comes to conducting unbiased research, being open to new explanations and challenging assumptions (Glesne and Peshkin, 1992; Edwards and Talbot, 1999; Denscombe, 2010).

When reflecting on my values, and how these influenced the research questions, it became clear to me that my bias towards inclusion, already noted in the introductory chapter, was an underlying factor driving the research. I believe that it is children's right to be included in their local school, although I concede that at present mainstream placements are unfortunately not the best option for a small minority. In

my professional role, I work towards developing skills, changing attitudes and providing resources, whenever I can, to make inclusion a reality. As already noted, the research questions focused on helping to promote the inclusion of children with autism or Asperger syndrome in mainstream schools. This viewpoint may have led me to carry out the research and interpret data somewhat differently from someone who had different values relating to inclusion.

My work as an Educational Psychologist focused most closely on those young people for whom the interaction between their needs and the school system was putting them, their families and teachers under considerable strain. Therefore in examining my expectations, it was clear that one of the outcomes I expected from the research was that many of the young people in the study would be having difficulties with their mental health.

When designing the interview schedule I took care to reflect at length about what should be included and how to structure the questions, being aware that this would determine what data was collected (Miles and Huberman, 1994). Carrying out the interviews themselves also required a high level of reflexivity. I tried to be aware of my biases and views when carrying out interviews and also to develop an awareness of myself as interviewer and how I was perceived by the participants. I placed a high priority on building a rapport with my interviewees, particularly given the personal nature of the topic. I was aware that young people with autism or

Asperger syndrome might appreciate a slightly different approach to being interviewed than others, and took care to reassure them about the facts of what would happen and length of the interview and what would happen next. I also planned to allow them to spend time talking about a topic of particular interest to them, but this was in fact, rarely necessary.

I attempted to monitor my communication, both verbal and non-verbal, throughout the interviews to avoid as much as possible giving unintended messages about my views or what responses I was expecting, as recommended by Robson (2002). Reflections on the interview process were made both immediately after each interview, in order to impact on subsequent ones and also when listening to the recordings during the analysis phase. I looked for evidence of leading questions, adding my own knowledge to discussions and interpreting what people said for them.

Following a reflection on my values and perspectives as described above, I tried to avoid over-emphasising data that were consistent with these at the expense of other data and looked for instances that challenged my beliefs. When analysing the parent interviews in particular, I became particularly aware of what Miles and Huberman (1994, p.263) refer to as "elite bias", which is the danger of giving added weight to data from articulate or well-informed interviewees and attempted to view everyone's responses as being of equal value and importance. Finally, whilst writing up I tried to

monitor which participants I was quoting and which I was not and consider reasons for this. I also worked to ensure that any quotes selected were representative of the broad data set, or if this was not the case, to note this when presenting them.

Alongside reflexivity, another method of ensuring validity is triangulation. This is "the use of different vantage points" (Tindall, 1994, p.145) and is an attempt to overcome the biases and limitations inherent in all researchers, perspectives and methods and hence improve validity by reducing the likelihood that an artefact of the method, source or researcher used has produced the findings (Tindall, 1994). Triangulation can be achieved in several ways including using a variety of methods, gathering information from several perspectives or the use of more than one researcher (Edwards and Talbot, 1999).

The triangulation achieved by having more than one perspective (young person, parent, member of school staff) on the themes in each case is crucial to the current piece of research and improves the validity of the research findings. Although accounts from different people in the same context may not fit neatly together they add to the richness and depth of description (Tindall, 1994). However, the lack of a variety of methods to provide further triangulation is an aspect of the study's design that could be improved. This is discussed further in section 5.7.2.

## 3.7 Ethics

Stake (2000, p.447) makes a valid point when he notes that "Qualitative researchers are guests in the private spaces of the world. Their manners should be good and their code of ethics strict."

Two main features of this study meant that ethical considerations were particularly vital: firstly, the vulnerable young people involved and secondly, the topic itself, which concerns personal and emotional experiences. As a result I worked hard to ensure that ethical concerns were paramount at each stage of the research. Ethical approval was sought from the University following the relevant protocols. The ethical guidelines published by the British Psychological Society (2009) and British Educational Research Association (2004) were consulted and acted upon; many of the recommendations they make are included in the paragraphs below in which I outline some of the key ethical concerns regarding the research and steps taken to address them.

Although to carry out the study I needed to gain the approval of gatekeepers, in this case senior members of staff in the schools concerned, gaining truly voluntary and informed consent from those participating in the study was also vital. It was important to ensure that each participant was aware of the specifics of what the study involved, what I was looking for and for what purpose (Pring, 2003) and that he or she had a choice about whether to participate and could withdraw at any time,

including retrospectively. Following the approach used by Humphrey and Symes (2010), who interviewed pupilsaged 11-16 years on the autism spectrum in mainstream secondary schools about bullying, I sought consent for the young people's participation at three levels (school, parent and young person). When gaining young people's consent I was aware that there are issues of power concerning the participation of young people in research, particularly on school sites. Both Morrow (2005) and Denscombe (2010) report that young people in schools are likely to view research as another piece of school work which their parents and teachers have agreed to and hence feel unable to say no.  Communication problems can make it difficult to gauge the understanding of those with disabilities and hence gain informed consent (Cuskelly, 2005) so I took great care to ensure that the young people who participated were aware of what the study entailed by using clear, simple and literal language, encouraging them to ask if they did not understand and answering any questions they had about the research.

Throughout the interview process I was aware that interviews are a significant intrusion into people's privacy (Powney and Watts, 1987) and that undue intrusion should be avoided (Lindsay, 2000; Robson, 2002; Denscombe, 2010). When interviewing parents I asked where would be best for them, offering the choice of home, school or elsewhere, in an attempt to reduce the intrusion caused by the process. I ensured that rooms were quiet and private and that young people were interviewed in familiar environments (Greig and Taylor, 1999).

I was aware that, particularly in this study given the personal nature and sensitivity of the subject matter, I should not exert power or influence over participants to answer any questions which they did not wish to do so (British Psychological Society, 2009) and I made this clear to all participants, on two occasions allowing young people who did not want to answer a question to move on to the next one. For similar reasons, the subject matter of the interviews had the potential to generate strong emotions in those being interviewed. As a result, I followed the approach adopted by Humphrey and Symes (2010) and planned to discontinue the interview and seek support from school staff for the young person if they became upset, although this was not required.

I was also aware that for young people with autism and Asperger syndrome, speaking to an unfamiliar adult might be stressful. To avoid this I worked with school staff and in some cases parents, to help them prepare the young person appropriately. In interviews with parents and staff carried out prior to the interviews with the young people, I asked, regarding each young person, what helped to put them at ease and whether anything in particular might distress them during the interview. I also asked about their interests so that I could incorporate these into our conversations. Finally, I tried to avoid scheduling interviews at a time of the school day which would adversely affect the young person's routine and cause anxiety. This preparation appeared to be effective and although a small number of the young

people appeared nervous at the start of the interviews, all were able to complete them and many appeared to have enjoyed the experience.

As my usual role in schools is to act as a support in meeting the special educational needs of children, it was possible that participants might erroneously believe that I could change some of the things they were discussing. To avoid this I made my role as researcher clear at the start of the interview and planned to direct the participant to the appropriate source of advice (which I did on one occasion) or halt the interview in order to discuss the subject if the participant was very distressed (which was not necessary).

Limits of confidentiality and anonymity were discussed with all participants prior to the interviews. I advised participants that any illegal or harmful behaviour disclosed would have to be passed on to the appropriate agency, although this did not occur during the research. I was careful not to disclose data about one participant to others in the study although I was asked about the young people's interviews by one parent and one member of school staff. When reporting my research findings, I have been careful not to provide information which allows individual children, parents, school staff or schools to be identified, even if this meant leaving out relevant aspects of context (Pring, 2003). I discussed issues concerning data storage with participants prior to the interview, have kept the raw data securely and will destroy it following a period of time after the completion of the study.

## 3.8 Outcomes

In a constructivist paradigm what is researched is to be understood only within the context within which and through which it has been constructed, thus precluding generalisations to different settings (Pring, 2000). It is not possible to generalise from a multiple case study (Stake, 2000; Yin, 2009), and therefore, the methodology of this study does not allow results to be generalised more widely to other schools and young people.

However, the study aims to provide some understanding of the emotional well-being of these particular young people with autism and Asperger's syndrome and how their schools promote and demote their mental health. Given the limited previous research in the area, the study attempted to provide pointers for future research in the area and evaluated what schools did which was successful in promoting the well-being of those with autism and Asperger syndrome, so that good practice can be shared. Ultimately I hope that this research makes a small contribution towards improving the quality of life for those with autism and Asperger syndrome and their families as discussed in section 1.6. The results obtained using the methods described above are discussed in the next chapter.

# CHAPTER 4:

# RESULTS AND DISCUSSION

## 4.1 How the Results are Presented

In this chapter, the findings of the research are presented. The interviews provided sufficient evidence to answer each of the research questions posed in section 1.5, which are discussed in turn. As a result, this chapter focuses on presenting and comparing the reports of young people, parents and school staff regarding the young person's feelings in school, any manifestations of mental health difficulties displayed and their opinions concerning school based and other factors that promote and demote the young person's mental health.

First, the reports of the feelings of the young people in the study are described. Tables are used to present the results of rating scales of feelings completed by young people, parents and school staff. Then reported manifestations of emotional distress are listed in tables to indicate how frequently they were reported by young people, parents and school staff. These are also described, using quotations from interviews so that the different behaviours can be understood in more detail. Following this, the overall picture of emotional well-being for the eleven young people who participated in the study is described and the differences between how parents, school staff and young people differed in their reports of feelings and manifestations of mental health difficulties are highlighted.

It was possible to elucidate eight pairs of factors that promote and demote emotional well-being in school for this group of young people. These are listed and then discussed in detail, using quotations from the interviews so that the precise nature of the factors and their impact on the young people can be understood. In the final section, differences between the views of the young people, parents and school staff differ in their opinions of what promotes and demotes the emotional well-being of the young people in school are reported.

In many cases, direct quotations from the interviews are used to allow the participants' words to be interpreted by the reader, where space permits. In most instances, many different quotations from the interviews could be used to illustrate the points made, but the most pertinent one or two were selected to represent what was said. Quotations are accompanied by a note of the person's role within the case – parent, young person or school staff – however, the cases are not numbered in order to further protect the anonymity of those who were interviewed (given that there were three participants for each case and they can be cross referenced). If the young person's name is mentioned in a quotation, this is substituted by the initials [YP] to preserve anonymity.

**4.2.1 Young People's Reports of their Feelings in School**

When asked to indicate on a rating scale, how they felt that day and last week, the young people responded as follows:

**Table 2. Young people's ratings of their feelings in school (part 1).**

|  | How do you feel in school today? Number of young people who answered | How did you feel in school last week? Number of young people who answered |
|---|---|---|
| Very relaxed and happy | 3 | 1 |
| In between 'a little relaxed and happy' and 'very relaxed and happy' | 1 | 0 |
| A little relaxed and happy | 5 | 5 |
| A little stressed, sad or worried | 1 | 0 |
| Very stressed, sad or worried | 0 | 2 |
| I can't answer as it varies from lesson to lesson | 1 | 2 |
| I don't know or don't want to answer | 0 | 1 |

The table provides quite a positive picture with the majority of young people reporting that they were very or a little relaxed and happy depending both at the time and the previous week. The young people were slightly more positive about their feelings at the present than in the previous week. One possible explanation for this, which some of the young people referred to, was that when considering the previous week they thought back through the whole week and tended to remember and highlight a difficult incident that occurred during the course of the week.

Some of the young people explained that their emotions varied over the course of the school days, depending on the activity they were undertaking at the time, or if something bad happened:

*"It depends what time period you mean. If I'm in English I'll be that one [a little relaxed and happy], if I'm at break or dinner I'll be that one [very relaxed and happy]."* (Young Person)

*"I enjoy school generally, but, sometimes, sometimes, issues stress me out."* (Young Person)

When the young people were also asked to indicate how frequently they experienced certain feelings they responded as follows:

**Table 3. Young people's ratings of their feelings in school (part 2).**

| Feeling | Most days in the last few weeks | At least once in the last month | Not in the last month, or never | I don't know / don't understand |
|---|---|---|---|---|
| I felt happy | 11 | 0 | 0 | 0 |
| I enjoyed myself at school | 9 | 1 | 0 | 1 |
| I felt panicky | 1 | 3 | 6 | 1 |
| I became upset when there was a change I wasn't expecting | 1 | 3 | 7 | 0 |

Again the young people reported a mainly positive picture of their feelings in school with for example, all eleven of them saying that they felt happy most days in the last weeks The young people themselves did not talk during the interviews about feeling sad in school, instead stress, worry or anger were mentioned.

### 4.2.2 Parent's Perceptions of their Children's Feelings in School

Parents were asked to rate how often their child was relaxed and happy, stressed or anxious or sad in school on a scale. The table below shows the results:

**Table 4. Parents' ratings of their children's feelings in school.**

|  | Almost never (less than once a week) | Occasionally (at least once a week) | Often (at least once most days) | Almost always (most of the time during each day) | I don't know |
|---|---|---|---|---|---|
| How often is [young person] relaxed and happy in school? | 0 | 2 | 3 | 5 | 1 |
| How often is [young person] stressed or anxious in school? | 3 | 5 | 2 | 0 | 1 |
| How often is [young person] sad in school? | 6 | 2 | 1 | 0 | 2 |

Nearly half of the parents interviewed rated their child, as 'almost always relaxed and happy in school'. One said, that her child was

*"I would say almost always relaxed and happy [in school], [YP]'s pretty laid back actually and nothing, nothing really bothers him'* (Parent).

However, another said that although her child was probably often relaxed and happy he

*"goes from happy to meltdown very very quickly"* (Parent).

The question about being stressed or anxious in school did appear to resonate with parents. Seven of the ten parents that answered said that the child was occasionally or often stressed or anxious but the picture that emerged was of occasional periods of stress in young people who were relaxed and happy most of the time. It was often felt that the young person was stressed or anxious in response to specific incidents or events in school rather than this being a permanent state of emotion for them.

Several of the parents appeared surprised about the question regarding sadness in school and more than half of them reported that their child was never or almost never sad in school.

## 4.2.3 School Staff's Perceptions of the Feelings of Young People with Autism and Asperger Syndrome

As with parents, school staff were asked to rate how often the young person was relaxed and happy, stressed or anxious or sad in school on a scale. The table below shows the results:

**Table 5: The ratings given by school staff of young people's feelings in school.**

|  | Almost never (less than once a week) | Occasionally (at least once a week) | Often (at least once most days) | Almost always (most of the time during each day) |
|---|---|---|---|---|
| How often is [young person] relaxed and happy in school? | 1 | 2 | 5 | 3 |
| How often is [young person] stressed or anxious in school? | 4 | 3 | 3 | 1 |
| How often is [young person] sad in school? | 8 | 2 | 1 | 0 |

For the young people that were rated as almost always relaxed and happy the picture was extremely positive. One of them was described like this:

*"almost always [relaxed and happy in school]. He is engaged in the lesson, he smiles, he has a sense of humour. I can't ever remember seeing him distressed really."* (School staff)

For the four young people were rated by school staff as being almost always or often stressed or anxious in school, the picture was of emotions that varied throughout the school day. One young person was described thus:

*"It tends to be short outbursts really with him, and then he's sent to the Head of Year and when he comes back he doesn't seem to, he's a little anxious for a while and then he does calm down"* (School staff)

Again sadness was not commonly reported, with eight of the eleven members of school staff interviewed describing the young person as never or almost never sad.

### 4.3.1 Manifestations of Mental Health Difficulties

When the young people were also asked to indicate how frequently they performed certain behaviours, experienced certain physiological states or had certain thoughts that might indicate their levels of emotional well-being, they responded as follows:

**Table 6: Young people's reports of manifestations of mental health difficulties.**

| Thought or Behaviour | Most days in the last few weeks | At least once in the last month | Not in the last month, or never | I don't know / don't understand |
|---|---|---|---|---|
| I slept very well | 7 | 1 | 2 | 1 |
| I couldn't concentrate on something I used to be able to concentrate on | 3 | 1 | 6 | 1 |
| Everything seemed too much effort | 0 | 5 | 4 | 2 |
| I deliberately hurt myself | 0 | 2 | 8 | 1 |
| I didn't feel like eating any food all day | 0 | 2 | 9 | 0 |
| I had a bad tummy ache or headache | 1 | 4 | 5 | 1 |
| I was successful in what I was asked to do | 8 | 2 | 0 | 1 |
| I couldn't stop thinking about something bad that happened in school or something bad that might happen | 2 | 3 | 5 | 1 |
| I felt things were hopeless | 0 | 2 | 8 | 1 |
| I disliked myself | 0 | 1 | 9 | 1 |
| I felt like hurting other people | 1 | 4 | 5 | 1 |

When parents and school staff were asked to indicate whether certain behaviours were true of their child in the last three months they responded as follows:

**Table 7: Parents' and school staff's reports of manifestations of mental health difficulties exhibited over the previous three months.**

| Behaviour | Number of parents reporting this | Number of school staff reporting this |
|---|---|---|
| Crying | 3 | 3 |
| Change in special interest to morbid or dark topics | 1 | 1 |
| Appears to be becoming more and more autistic, e.g. more and more focus on high interest activities to the exclusion of others, less and less social contact, more and more repetitive behaviours | 2 | 1 |
| Not motivated by activities s/he previously enjoyed | 3 | 1 |
| More stressed than usual when change occurs | 1 | 3 |
| More easily distracted than usual | 1 | 4 |
| Schoolwork has deteriorated | 1 | 3 |
| Fidgeting or pacing around more than normal (for the young person) | 3 | 4 |
| Friendship changes, not interested in 'old' friends | 2 | 2 |
| Decrease in levels of self care and hygiene | 2 | 0 |
| Risk taking, e.g. drugs, alcohol | 0 | 1 |
| Much more sensitive or irritable than usual | 6 | 3 |
| Apathy – everything seems an effort | 4 | 2 |
| Talks or attempts of self-injury or suicide | 1 | 1 |
| Change in eating or sleeping patterns | 0 | 0 |
| Unexplained stomach aches, headaches or tiredness | 1 | 0 |
| Often looks very pale or very flushed | 2 | 0 |
| Focuses on the negative in each situation | 3 | 4 |
| Says things are hopeless | 0 | 1 |

To minimise confusion between the signs of autism and those of mental health difficulties, I stressed to parents and school staff that the questions were about changes to the young person's usual presentation. For example, the young person might be often easily distracted so a positive response to this question indicated that the young person had recently become even more easily distracted than was typical for them.

Tables 6 and 7 indicate that all three groups – young people, parents and school staff – reported very few manifestations of mental health problems. Those that were mentioned are discussed below in three sections covering physiological, behavioural and cognitive manifestations.

### 4.3.2 Physiological Manifestations of Mental Health Difficulties

There were very few reports of problems with sleeping, eating or pain which appeared to be related to stress in the young people. Although a few of the young people said that they had a stomach ache or headache, or difficulty eating or sleeping, they usually attributed this to some other cause, such as a brief physical illness.

### 4.3.3 Behavioural Manifestations of Mental Health Difficulties

One of the most common manifestations of stress noted by parents and school staff was fidgeting or pacing around. Several parents and school staff noted that the young person's fidgeting and pacing had worsened in the last few months and others commented that this was true of the young person generally although it had not worsened in the last few months. These descriptions were typical:

*"When he comes home he'll, he'll, he'll walk up and down and he'll wrestle his hands. He won't sit down and settle to anything. So then I'll say [YP] what's the matter? And then he'll get and then he finds it really hard because he's quite stressed he'll find it really hard to actually verbalise it… and then we have to sit down and go through things and then it comes out."* (Parent)

*"When he's stressed he starts pacing up and down and becomes very twitchy and anxious."* (School staff).

Appearing to become more autistic was a possible manifestation of mental health difficulties which the young people themselves were unable to directly comment on. It was mentioned by two parents and one member of school staff as being typical of the young person. In addition, two parents and two members of school staff described how the young person became quiet and withdrawn when under stress.

They described the young person going very quiet, leaving the room in school to be on their own or withdrawing to their bedroom at home.

In four cases the member of school staff described a situation where the young person's schoolwork had recently deteriorated. Young people were described as not being interested in the lesson, being easily distracted, fidgeting and refusing to work. In one case both the parent and young person themselves also mentioned reduced interest in school work and being distracted in lessons.

Aggression and anger featured heavily in discussions about young people's behaviour in school. Aggressive behaviour was reported concerning six of the nine boys by either a parent or member of school staff or both and four were described as showing signs of aggression by both their parent and the member of school staff interviewed. In addition, six of the nine boys interviewed (four of those listed by parents or school staff as having aggressive behaviour and two others who were not mentioned by parents or school staff as being aggressive) explained that they had recently felt like hurting other people when they had felt stressed. Aggression was not mentioned concerning the two girls in the study.

Different frequencies of aggressive behaviour were described across cases. In three cases it was quite minimal, or had mainly occurred in the past, but the other three young people regularly displayed physical aggression towards others at school or at

home. When angry, the young people had sometimes been extremely aggressive and behaviours included throwing chairs or desks, hitting or punching other young people in school or family members at home, kicking and swearing.

In three cases aggressive behaviour often occurred as soon as the young person returned home rather than at school.

> *"The minute he comes in from school….., I get all the negatives, the minute he walks in… I suppose he's got to offload those"* (Parent)

One young person also discussed this:
> *"The thing is with school is you get on the bus on the way home, you get on the bus in the morning you come to school, people can bully you, diss you, do whatever they like to you, normally it doesn't affect me, but then when I get home or when I'm going home on the bus, if we're sharing the bus, all the problems will well up and basically at home I'm not very happy about that."* (Young person)

Six parents and three members of school staff described the young person as being more sensitive or irritable than usual in the last three months and it seems likely that this was linked in some cases to aggressive behaviour.

Crying or lack of interest in previously enjoyed activities were not commonly reported. Self-harm or suicide was mentioned regarding three of the eleven young people in the study. Two of the young people said that they had deliberately hurt themselves at least once in the last month, both attributed this to feeling cross. One explained quite clearly:

*"Well you see instead of taking anger out on other people I just take it out on myself…. I hit things…. Door frames and stuff."* (Young person)

In a different case, both the parent and the member of school staff indicated that the young person talked about self-injury and suicide regularly when he was upset, because he did not like himself and his diagnosis.

## 4.3.4 Cognitive Manifestations of Mental Health Difficulties

Four of the young people talked in some detail about how they sometimes spend a lot of time thinking about their anxieties and the effect that this has on their lives. They reported problems concentrating as thoughts drift onto their worries, problems sleeping when they had a lot on their mind and not being able to stop thinking about something bad that might happen.

Often this appeared to be worries about whether or not the young person had behaved appropriately in a situation they found difficult, or alternatively anxieties about what might happen in the future. One parent discussed how worries about past incidents concerned the young person:

*"You'll get I did this and I had this conversation and he says 'Does it matter? Does it matter that I said that? And he's replaying the anxiety about what he might have said or done 'Was it important?' Shouldn't he have said that? ' Should he have said that?' What should he....' So he's trying to make sense of it I think in a way."* (Parent)

The main problem mentioned by the young people themselves regarding future worries was remembering to do homework. One young person talked about how:

*"When I forget something it just stays in my mind… or something I have to face…. What would happen if I didn't do my homework?… Or forgetting to bring something."* (Young person)

Three parents and four members of school staff highlighted that the young person tended to focus on the negative in each situation. As one parent put it:

*"Yeah, everything's a calamity, it's always no no no good, nothing works."* (Parent)

However, there was one young person who had the opposite approach. When he considered possible features of school that might make him feel stressed, worried or sad in school he explained that he could only think of things when they were happening.  This was confirmed by the member of school staff who described him:

*"We don't find him bothered about… you know too much. It bothers him about that situation but once we've sorted that situation out he can move on"* (School staff)

It has been noted that some people with autism or Asperger syndrome become interested in morbid topics when they are affected by mental health difficulties. Such concerns were rarely true of the young people in this study. None of the young people themselves spontaneously discussed such topics and they were mentioned very briefly by one parent and one member of school staff.

**4.4 Variation in Emotional Well-being Over Time**

Although this was not asked directly, in more than half of the cases the parent or member of school staff described periods of time in the past when the young person

was much more or much less settled, and as a result their behaviours were dramatically different to their current presentation. Four parents spontaneously mentioned how much worse the situation was at primary school. In one case the problems had also persisted into Year 7, but improved thereafter. This parent explained:

*"If you'd asked me these in Year 7 most of these would be… there were some terrible times, you know where I thought if he was in his room, is he going to throw himself out of his window? You know that would have been quite bad, I used to have thoughts like that so it was that bad. It's a lot better we don't have that anymore."* (Parent)

In this case, as the change had been since the young person started secondary school, it was also observed by school staff:

*"He doesn't kick off or anything like that. I remember him doing that. We used to get a lot of complaints from teachers cause he used to have a stress ball. You know we used to give him things to do like this. He used to tap all the time and it used to drive the teachers mad… but he doesn't need anything like that anymore, he seems to be really really settled"* (School staff)

However, the cases varied and emotional well-being did not always improve on entry to secondary school. In one case, the young person's behaviour worsened on entering Year 7 and in another, the member of school staff and the parent described worsening behaviour at the end of year 7 and beginning of Year 8.

**4.5 Variation Between Cases Regarding Emotional Well-Being**

Using the information provided by parents, school staff and the young people themselves, it is possible to cluster cases into three groups. Three of the young people were reported to be extremely happy in school much of the time. In two of these cases both the parent and member of school staff reported that the young person showed no manifestations of mental health difficulties in school. In the third case the parent reported only two manifestations and both the parent and the member of school staff interviewed described the young person as being relaxed and happy almost all the time. In two of these cases it was noted that they had been very unhappy and stressed in school at some point in the past.

Six of the young people usually coped well in school, but had specific areas of difficulty which caused them stress. Often, these difficulties were reported mainly by parents and involved particular lessons, friendships, times of day or members of school staff. These are discussed in detail in the following sections. Some difficulties

had a significant impact on the young person's well-being and when incidents occurred their mood could alter quite markedly.

In the remaining two cases, the young people appeared to be exhibiting signs of high levels of stress on a daily basis in school and at home. These two young people's behaviours were different from each other and from the other young people in the study. They are discussed in a little more detail below.

One young person showed signs of stress, which manifested themselves in aggression towards others in school, withdrawal from others at school and at home and sometimes retreat into a fantasy world. His mother explained that she knew when he was unhappy because:

> *"It's the same as the same as just before he's going to get cross…. He goes very quiet. If you ask him what's up with you he won't answer you and then he starts crying because he can't express how he feels."* (Parent)

When talking about this young person the member of school staff commented that she did not think he was ever relaxed and described how he appeared to have hunched up body language as if constantly on edge and had regular angry outbursts. He had thrown desks and tried to strangle another student. The member of school staff interviewed also expressed concern for the safety of herself and

others as a result of the young person's aggressive behaviour. The young person himself talked about wanting to hurt other people and also incidents of self harm which he engaged in to prevent himself from doing so.

His mother described his aggression, noting that he went rigid, red and quiet,

> *"before he explodes…..If anybody gets in the way they can get hit, they can get punched, whatever whatever races through his head at that moment. He does need taking out of the situation then and calming down."* (Parent)

In addition to the aggression mentioned by all three within the case, withdrawing from others and an increase in the signs of autism were reported by both the parent and member of school staff. The parent explained things thus:

> *"We go out less and less. .. just scurries upstairs and watches the telly or whatever it is….. He opts out of things, if you say, we're going to do something, no he won't do it. Groups at school he'll go maybe once and then he won't go again. He just keeps himself to himself a lot more and won't do things and he is very repetitive he will play with the same thing over and over and over again."* (Parent)

In addition, the member of school staff noted that he sometimes appeared to retreat into a fantasy world, talking about running away from the war.

*"He lives in almost like an alternative world sometimes I think."* (School staff)

The other young person who appeared to be stressed every day behaved quite differently. He often presented as very anxious in school, often crying, needing reassurance and seeking the attention of adults. He also became angry and aggressive but usually only on arrival home from school.

*"It's how he comes home, probably at least once a week, he will come home stressed. He's usually sort of I think bottled it in and then he'll explode. … ….Shouts, swears, kicks something, just generally, anything that's in his way is a target be that animal, vegetable or mineral, young brother, anything."* (Parent)

In this case, the parent and member of school staff also described in detail how he focused on the negative and dwelt on his worries so that they were magnified out of proportion. His mother reported that he was receiving help for this at present, working with a Clinical Psychologist.

*"It's [YP]'s perception, I mean, I'm not saying he's lying, it's just that he's changed in the course of the day he's gone over it and over it. In the school environment it might be something very trivial, but by the time he's come home it's worse than world war three. It's massive. And for him it is massive."* (Parent)

*"What [YP] does is he exaggerates everything, every issue. However tiny in reality to him it's massive and that would be a good thing to change if he could stop overreacting to everything and to just see rationally that's it's not so major really."* (School staff)

Both his parent and teacher described how he had low self-esteem and regularly talked about self-injury and suicide when he was upset, because he did not like himself and his diagnosis.

*"Why have I got Asperger's, I hate myself, I am going to kill myself…. He can't stand being what he is and he doesn't want to. Which is where this talk of self-injury and suicide comes in, he doesn't feel, he doesn't want to be like he is anymore."* (Parent)

The member of school staff explained that:

*"He talks a lot or he just gets anxious and cries and worries about homework, possibly because of what other people are doing compared to him."* (School staff)

The young person himself confirmed his teachers' account when asked about a time when he had disliked himself in the last month:

*"It was a homework issue because I hadn't done very well in something, everyone managed to successfully put me down."* (Young person)

To summarise, in two cases, the young person's behaviour was giving those around them great cause for concern. However, it would be wrong to say that these young people's feelings and behaviours were typical of the group as a whole, most of whom had only intermittent stresses at school and three of whom were reportedly extremely happy and settled.

The next section compares the perceptions and opinions of parents, school staff and the young people themselves concerning the young person's feelings and behaviours.

**4.6 Differences in the Perceptions of Young People and their Parents and School Staff Regarding the Young Person's Mental Health**

In this section, comparisons are made between the ratings of feelings and the descriptions of behaviours that may indicate emotional distress given by parents, school staff and the young people themselves.

In virtually every case, there was good agreement in the ratings of feelings given by parents and school staff. When asked to rate how often the young person was relaxed and happy in school, of the ten parent / school staff pairs who completed the question four gave the same rating and five of the remaining six rated only one point different from each other on the (four point) scale. When asked to rate how often the young person was stressed or anxious in school, of the ten parent / school staff pairs who completed the task, five gave exactly the same rating and four of the remaining five gave a score just one point different on the scale. Similar levels of agreement were found for ratings of sadness in school. Although in some cases there were slight differences of opinion between parents and school staff in the ratings of young people's feelings in school, there was no general pattern as to whether parents or school staff rated the young person as more or less happy, stressed, or sad.

The young people themselves rated their feelings on a different scale from the parents and school staff so it was not possible to compare their rankings directly. However, there did also appear to be some agreement. Considering the young

people who rated themselves as very relaxed and happy at the time of the interview, in each case the parents and school staff rated them as almost always or often relaxed and happy in school. In comparison the young people who rated themselves as a little relaxed and happy at the time of the interview were given more variable ratings by parents and school staff.

All three groups of respondents reported that stress and worry were more frequent emotions for this group than sadness. In addition, all three groups often reported that the young person was calm in school for much of the time, but became stressed or anxious in response to specific situations.

In each of the eleven cases, the parent and member of school staff reported a very similar number of manifestations of mental health difficulties. In four cases they reported exactly the same number and in all cases the difference in number of manifestations reported was no greater than 3 (out of a maximum of 19 possible manifestations). This rough measure could indicate that within each case, parents and school staff, had a similar level of concern about the young person.

However, the actual manifestations reported by parents and school staff were often quite different. Parents were more likely to report that the young person was more sensitive or irritable than usual or that there were signs of apathy. School staff were more likely to report a deterioration in schoolwork or that the young person was

becoming more easily distracted. Equally, the manifestations reported by the young people did not tend to correlate well with those reported by parents and school staff. In fact in only three of the ten cases in which the young people completed the task were one or two of their reported manifestations echoed by their parent or the member of school staff talking about that young person. (An example being if the young person said that they found it difficult to concentrate on something they could usually concentrate on and the teacher said they were more easily distracted than usual.) A notable exception to this was that anger and aggression were mentioned by many parents, school staff and young people.

To summarise, in all cases, despite the differences in the precise reported manifestations of emotional and behavioural difficulties, parents, schools staff and the young people themselves painted a similar picture of how the young person was doing emotionally in school, which enabled a general impressions to be obtained of each young person's well-being.

**4.7 Aspects of School Life that Promote and Demote the Mental Health of Young People with Autism and Asperger Syndrome**

Analysis of the transcribed interviews following the process described in section 3.5 led to the emergence of a number of key factors which promoted or demoted mental health or well-being for the young people in the study. These factors were chosen

because for each pair, participants reported that the promoting factor was positively affecting the emotional well-being of many or all of the young people in the study and the demoting factor appeared to be adversely affecting the emotional well-being of some or all of the young people.

**Table 8: Factors reported to promote and demote young people's mental health in school**

| Promoting Factor | Demoting Factor |
| --- | --- |
| Positive ethos and attitude to inclusion | Negative attitudes towards inclusion |
| Staff aware of and understand the young person's needs | Poor understanding of the young person's needs |
| Peer Friendships | Friendship difficulties |
| Appropriate support for learning | Insufficient or inappropriate support |
| Adult attention | Insufficient pastoral care |
| Quiet | Noise and disruption |
| Predictability | Change |
| Support for organisational skills | Difficulties with personal organisation |

The next section discusses each of these factors in turn, providing more detail about the factor itself and explaining how it affected the young people in the study. Where possible, quotations from the interviews are used to illustrate the nature of the factor and / or how it affected the well-being of one or more of the young people. Some of

the factors had more supporting evidence than others and this is also noted in the discussion.

**4.7.1a Positive Ethos and Attitude Towards Inclusion**

Young people, parents and members of school staff mentioned the good school ethos as important for the young person's well-being. Four main features of a positive ethos and attitude towards inclusion were mentioned.

Firstly, there was an emphasis on being caring and supportive with four of the five parents who mentioned school ethos using the word 'care' or caring' to describe the school. Secondly it was emphasised by parents and staff that all levels of the school, from the Headteacher to the students, were influenced by the school's ethos:

> *"I think the school ethos is terribly important and that's one of the reasons for [YP] going to [school].... in that they do support and value diversity and it does filter through the school in my experience… the whole school ethos is very supportive and it does filter through the students"* (Parent)

> *"We try to be an inclusive school. It comes from the leadership team and emanates down."* (School staff)

*"Pastoral care definitely is fantastic in this school, at every level which I think is quite unusual in a school that the Headteacher takes an interest. It's not just left to the Learning Support Department to handle, which is lovely, and I think that's quite unusual actually."* (School staff)

Thirdly, there was an emphasis on effort and cost on the part of the school to include the young person, this was appreciated by several parents who described how hard school staff had worked to include their child:

*"They seem to do everything to try and, to try and make him relaxed and happy."* (Parent)

Finally parents and school staff also described how flexible arrangements had been put into place to meet the needs of individual young people. Parents in particular appeared to value this flexibility within the school to meet their child's individual needs and reported the impact of such flexibility on their child's emotional well-being. One parent described how when it was time for an overnight school trip and her child's friend was in another form due to be going on a different date, the arrangements were changed around so that the two forms went together which enabled her child to feel confident enough to participate.

Another described a number of adaptations the school had implemented to support her child:

*"Something… that is very important in terms of schools, the way they cope, is their flexibility, for example, they are supposed to wear long sleeved shirts with a button. Well [YP who has dyspraxia] can't do that, so they say he can wear short sleeved shirts. They don't say, this is the rules, you do it and there's quite a lot of thing that they have been very flexible about because [YP] hasn't been able to handle… . They can look at what a child's having problems with, and they don't just think, this is the way we do it, they think, how can we include this child and still fit in with the school, because that's very important for [YP] to fit in….. They arranged to make a special sandwich for [YP] that they just put out as he got to the front of the queue. They said, it doesn't matter if he doesn't choose it, it's just that he'll know there's always something he can eat and… that makes a huge difference."* (Parent)

### 4.7.1b Negative Attitudes Towards Inclusion

There were only three criticisms of the school's ethos or attitudes towards inclusion, one from a parent, one from a member of staff and one from a young person. Between them these criticisms covered two of the three schools in the study. It is

important to note that in the remaining 30 interviews negative comments were not made about these aspects of inclusion and ethos.

In one school, which parents and school staff had mentioned as having a positive ethos, one of the young people criticised the Headteacher and senior staff for their lack of involvement with students:

*"I think the senior staff or maybe [headteacher] could get more involved… with individuals."* (Young person)

In this case the member of school staff also explained in detail how a small number of staff who did not think the young person should be in the school made the young person feel very stressed. She explained:

*"We've got quite a lot of old school staff here, they're not up to change and kids like [YP] shouldn't be here in their view"* (School staff)

A parent of a child at a different school said:

*"I'm not sure that the school, or that the Head of the school, actually believes in integration for kids with special needs, so in that sense, although, I suppose he'd say he did, but I'm not convinced that he does…. I think they*

*more just manage it as best they can really. I don't think that he's convinced that integration is the right way to go."*

*[Interviewer] "So you sort of feel that underneath, if he was allowed to, he'd say, I don't want this child because they've got extra needs?'*

*"Yeah, yeah I believe that, I strongly believe that."* (Parent)

It was this school where both parents and school staff reported that the young people were not getting enough support to meet their needs and where communication between the special needs department and other areas of the school was highlighted as a problem by two of the parents.

**4.7.2a Staff Aware of and Understand the Young Person's Needs**

In all eleven parent interviews the parent explained that 'School staff understanding the young person's needs and autism / Asperger syndrome' helped their child to feel relaxed and happy in school. Many parents then explained that they felt that there was a good understanding of autism or Asperger syndrome amongst school staff at their child's school and that this was crucial to his or her well-being. One said that she had never felt that teaching staff did not understand autism or her child's needs.

However, most commonly parents reported that the majority of staff understood their child's needs although there were a few exceptions.

In ten of the eleven interviews, members of school staff reported that 'School staff understanding the young person's needs and autism / Asperger syndrome' helped the young person to feel relaxed and happy in school. Members of school staff explained how information about each young person's needs was given to all the teaching and non-teaching staff that needed to know, using various methods including online Individual Education Plans or pupil profiles, and sending regular notes around to subject staff if problems arose for the young person. One school also sent around pen portraits to all subject staff highlighting areas that caused anxiety for the young person:

> *"We provide a pen portrait at the beginning of the year which is something we do with the children. We sit down [SENCo] and I do it between us and we interview them and we say what do you find difficult, this is for teachers and what would you like the teachers to do to help you, and it's their chance to give their input really so they don't have to do it to all their teachers and we circulate those in September to all the teachers, so all the teachers know, if he says he has a problem with getting homework done, they know it's written down and you know that 's what it comes from him in his own words, and that communication is so important isn't it, that everybody knows, and we would*

*prompt him obviously but its supposed to be in his own words so we will be able to say to prompt him to say what makes him anxious and he will be able to put those things"* (School staff)

Seven of the eleven young people agreed that 'School staff (teachers and other adults) understanding what helps you to do well in school' made them feel relaxed and happy in school. Two of the young people explained this further:

*"They know the student well. A teacher I once had, well, saw that I was fiddling and getting distracted, gave me some blu tack to fiddle with."*
(Young person)

*"They're all a friendly group and they're like, they like, seem to know seem to know what, if people have got like problems in the class."* (Young person)

### 4.7.2b Poor Understanding of the Young Person's Needs

Six parents and five members school staff agreed that 'School staff not understanding autism / Asperger syndrome or the young person's individual needs made the young person feel stressed, worried or sad in school. As well as leading to high levels of stress, there was often a deterioration in the young person's behaviour

when he or she encountered the teacher(s) concerned. In one case this had led to the young person being withdrawn from a particular subject.

No parent thought that this problem affected all staff within the school. Two reported that the only staff who understood their child were those in the school's Special Needs department, two felt that understanding was patchy, with some subject teachers understanding and others not, and the others highlighted individual members of staff, the exception rather than the norm, whose did not understand their child's needs. Related to this, in two cases (from different schools) parents explained that some members of staff had not been aware of their child's diagnosis.

One parent explained:

*"I don't think the maths teacher understands what her condition is, 'cause she's clearly not dealing with it."* (Parent)

Another parent highlighted how she had disagreed with the school about her son's behaviour problems. What they had viewed as 'naughty' she thought it was more likely to be due to the fact that his autism had not been understood by school staff:

*"If you actually chip away at it, it's actually, it is related to his autism eventually…He gets angry cause he doesn't understand."* (Parent)

This was supported in the interview with her son, who reported that he had been very stressed last week as he had been told off but did not know why.

Another parent of a child in the same school also thought that her child's behaviour related to autism was misunderstood:

> "[YP] will sort of tell you straight how it is and not , teachers sometimes think that he is rude and cheeky but he's not. If they ask him a straight question he will give them a straight answer. He won't skirt around the issue. He won't worry about hurting your feelings because he probably won't realise that he has. Teachers don't understand that…. I would say that the few that probably do understand [YP] are in the minority." (Parent)

The member of school staff described the young person in a very similar way:

> "I think that the biggest thing about [YP]…. is the way that that it's so easy not to see the ASD side of him. .. Because he's fairly bright and people just see that as defiance." (School staff)

In this instance it was thought by both the parent and the member of school staff that because the young person was bright his behaviour was less well understood. The parent said:

> *"I would like to change the teachers, some of the teachers perceptions of [YP] because [YP] is quite bright and because for some of the subjects he's in the top group, they don't understand, there's a lack of understanding with some teachers that [YP]'s actually got problems."* (Parent)

Several parents also highlighted how more training was needed:

> *"I would like the school to be more aware of the condition. Knowledge, experience and training not just from the special needs co-ordinator but also all the teachers."* (Parent)

> *"If I could change one thing it would be, I think I would make it compulsory for all teachers within all schools to learn more about autism."* (Parent)

Most of the members of school staff interviewed explained that all staff in their schools understood autism, although in five interviews, school staff hinted that not quite all of their colleagues understood, highlighting a minority of teachers who did not understand:

*"There are certain people who don't always understand that [YP] has got this thing – I think sometimes that's why I was saying about these odd teachers, they haven't quite grasped ….they're obviously not treating him like he does and allowing for that kind of thing"* (School staff)

*"The majority [understand his needs] but there are some that don't you know that I think need to, because there's more and more kids coming through like that."* (School staff)

Three of the eleven young people indicated that 'Teachers or other adults in school not understanding what helps you' had made them feel stressed, sad or worried in school. In addition two others also commented negatively on the support they had received from school staff. In each case, the young person reported incidents concerning particular teachers rather than a general pattern of being misunderstood.

### 4.7.3a Peer Friendships

Friendships were probably the most common topic for discussion during the interviews, for parents, school staff and the young people themselves. Four parents spoke positively about their child's friendships. In three of these cases the young person had made tremendous progress in terms of making new friends in school in

recent years and this had coincided with a reported increase in their happiness in school. In each of these cases the young person and member of school staff interviewed also mentioned the young person's friends.

Three of the four young people whose parents spoke positively about their child's friendships were rated as almost always relaxed and happy by parents (the other was rated as often relaxed and happy) and three of the four were rated as almost always relaxed and happy by school staff (the other was rated as often relaxed and happy). In addition, these young people were reported to show fewer manifestations of mental health difficulties in school, with three members of school staff and two parents reporting none at all. Parents and members of school staff themselves linked improving friendship patterns with the young person feeling happy in school:

For example, when asked if there were particular things that made one of the young people relaxed and happy in school, the member of staff interviewed said:

> *"In school, he's got a good social network now, he's got a few, two or three good friends, I think if he's with them and he's playing football, he's happy"* (School staff)

In contrast, one of the young people who appeared to be under significant stress in school, had not made friends so successfully. His mother appeared to be aware of the value of friendships in promoting emotional well-being:

*"I think from a personal point of view for [YP], what would make his life so much better in school would be if he had a friend who was a typically developing child who was reasonably popular so that he could help [YP] to field some of these negative comments from other kids and also to lead by example, somebody who could invite him out so that they could go out with a group of teenagers you know when they meet on a weekend and things, meet in town or whatever. That would be my magic wand. Somebody who would see [YP] for what he is accept him for what he is and still be his friend and sort of support him and guide him, you know, that's my hope for [YP] personally."* (Parent)

Despite the apparent link between having friends and emotional well-being in school, parents, teachers and young people disagreed over what schools could do to promote friendships in this group of young people. Several young people and one parent commented that this was not something that schools could help with. As one young person explained, teachers could not help:

*"It's just up to yourself to do it."* (Young person)

Other young people did not want help to make friends as they were happy with the friends they had, even though their parents and teachers thought that their friendships were inadequate. However, three of the young people said that help to make friends and deal with difficult social situations did help them to feel relaxed and happy in school and a further three said this kind of help would help them feel happy but was not available to them in school

School staff, parents and young people all mentioned support that helped the young person make friends. A variety of different kinds of support were provided by schools, including individually tailored support to help young people make and maintain friendships with particular individuals, lunchtime clubs, social skills training and peer education about autism or Asperger syndrome.

Of the different forms of support, young people spoke most positively of staff's attempts to help them become friends with particular individuals in class situations. Two of the young people (whose teachers also described supporting them to make friends) talked about an adult in school had supported their friendship with another student. When asked who had helped him make friends, one young person said:

*"Teachers, like Mrs A helped me make friends with S"* (Young person)

Another explained:

> *Mrs B has tried to encourage us to be friends…. She's just really tried to make me and K be friends, to keep friends throughout everything."* (Young person)

Parents, school staff and young people discussed the benefits of lunchtime clubs of various kinds that helped young people make friends in a more structured environment. A parent described one such club:

> "*They have what do they call it, the lunchtime club, which is a sort of invitation only place, it's in the learning support centre, and people are invited I guess, special invitations, and it's a mixture of children who are, just noted to be friendly and supportive, and children who need friendship and support. They have games and computers and things so that there is just a space for ones who can't really cope with the playground and I know they've found that what tends to happen is that when they go in Year 7 and it's an overwhelming big big place they make friendships there that they then gradually move out into the playground."* (Parent)

Social skills training was frequently discussed by parents and members of school staff, but there were differing perceptions of its usefulness. Eight parents and five of

the school staff reported that it had helped or might help the young person concerned. Many parents were very keen for their children to have social skills training and one parent described it as *'absolutely essential'* .

However another parent explained that she was unsure whether such help would be effective:

> *"His social skills, making friends, isn't as good as we'd like to see them, but whether it would help to have a teacher telling them or involving themselves with other children and and then develop it naturally"* (Parent)

Another cautioned that such training might not be useful if the young person did not recognise its value:

> *"They've tried. Again, it's an area that 's very important because he doesn't really have many social skills, but you can only do it if the person wants to learn and he doesn't see it as an issue."* (Parent)

One member of staff talked about problems with social skills training when a group was run recently in the school. The group only involved young people with autism and Asperger syndrome and there was a wide age range. As a result most of the sessions were spent trying to get the group to gel and little was achieved.

Five parents thought that work with peers to help them understand the young person's individual needs or autism / Asperger syndrome would be helpful. Most commented that they wanted general awareness raising only, not any talk of individual children's needs. One talked about its potential benefits several times during the interview:

*"I would've hoped that it wouldn't' have happened as much that they would but perhaps they don't understand. [YP]'s weird, [YP]'s freaky, [YP]'s geeky, [YP]'s whatever, but they don't really know, what it's like for him. So I think education of his peers is would be a good. Not necessarily singling a particular child with Aspergers out but saying that there are boys and girls in our, in your year who have more difficulty, you know how hard it is for you, well multiply that by whatever factor it is whatever and that's what it's like for them, and try to, for some it will won't make any difference, but hopefully for others they might just kind of think"* (Parent)

However, other parents were very opposed to this idea. In only one case did the member of staff interviewed say that the young person's form group had been spoken to and in the other cases school staff did not think it would be helpful or appropriate. Peer education was not discussed with the young people themselves.

**4.7.3b Friendship Difficulties**

Problems with friendships were frequently discussed during the interviews. Nine of the eleven parents interviewed, five members of school staff and six of the young people talked about such problems. Difficulties with both making and maintaining friendships were reported to cause the young people stress and anxiety. Four of the five reasons that young people gave for wanting to hurt others were linked to friendship difficulties. These comments were typical:

*"He gets anxious I think because he doesn't have any [friends]"* (Parent)

*"I had a best friend and now she was my best friend and now she has another friend…. And that's the kind of change that would make me feel upset."* (Young person)

One young person talked about a time he felt sad when:

*"Everyone was just leaving me. Everyone was just deserting me." (Young person)*

When asked what he would change about school, this young person explained:

*"I'd change I'd change the kids I'd change all the kids about so they're a bit more friendly to you… I'd change them to friendly kids."* (Young person)

Despite the major impact of not making friends or struggling to keep friends on the young people's emotional well-being, bullying did not appear to be a big problem for the young people in this study. Only two of the eleven young people talked about incidents of being teased and bullied and the vast majority said that either bullying was not a problem for them at all in school, or that it had been a problem, but had been dealt with effectively. One young person explained how:

*"[Bullying has been a problem] partly, but it has stopped. They were calling me annoying names, cause my names [  ], and my nicknames [  ] so they've been calling me [   ]…  They just got told off for it…. I told my mum and she rung up the teacher."* (Young person – names and nicknames have been deleted and brackets [   ] inserted to preserve anonymity).

Another said:

*"It doesn't help me as an individual, but I think staff in school do a good job dealing with bullying."* (Young person)

Four of the eleven members of school staff said that the young person was sometimes teased or 'wound up' by other students. Six parents noted that their child had been teased or bullied but almost all said that it had been dealt with very

effectively by the school and was not an ongoing problem. This comment was typical:

> *"The issues of bullying that we have come across with [YP] they've dealt with it straight away, so we were pleased with that…. and they didn't try and um deny that it was happening, there's no bullying in school or anything, they just dealt with it straightaway."* (Parent)

Only one parent thought that her child currently had a problem with being bullied and in this case neither the member of school staff interviewed nor young person supported this view.

### 4.7.4a Appropriate Support for Learning

Seven young people indicated that 'Extra help with schoolwork that you find particularly difficult' helped them to feel relaxed and happy in school and one other indicated that this would help them feel happy but they were not getting any extra help at the moment. Most of the young people were happy with the amount of support they were receiving and that it helped them. One explained that he had:

> *"It's probably the right amount of help and the way teachers act… they are nice and helpful"* (Young person)

His parent agreed:

*"I think he gets enough help…. whatever they're doing is working."* (Parent)

Nine parents and nine members of school staff thought that extra help with schoolwork was helping the young person feel more relaxed and happy. Parents and members of school staff described four key features of appropriate support for young people in school. The first was having the correct amount of support, so that the young person had enough help, but still maintained their independence and developed their independence further as they became older. One member of school staff explained:

*"It has really been with [YP] when things have already arisen, like the lunchtimes, like you know P.E., particularly were the two elements that were an issue, so we've just responded to things as they've arisen, rather than pre-empting them… you don't want to put too much in if there isn't going to be a problem. On the other hand, you will want to be aware that if there is a problem you need to deal with it quite quickly."* (School staff)

This sentiment was echoed by a parent of another young person:

*"I personally don't like the idea of him getting more help if he doesn't actually need it because he'd be separated from the other children. I don't get the impression that he is getting too much or too little help."* (Parent)

The second key feature of effective support was having some continuity, so that the young person worked with similar support assistants, many parents particularly valued this. Thirdly, some parents observed that to be effective, support had to be unobtrusive. One explained that her child:

*"Has to be able to you know have access to some trained to an adult where they can help her without making it obvious and without letting the other children see."* (Parent)

Finally, support to record written work was seen as essential for seven of the eleven young people in the study, including the three who had a diagnosis of dyspraxia. In one case such support was reported by school staff to prevent the young person from getting stressed in school:

*"His big problem is, is writing, he is extremely slow at writing. If he was going to get stressed in a lesson it would be because he can't keep up with the work."* (School staff)

## 4.7.4b Insufficient or Inappropriate Support

Many parents talked at length about how they thought the support their child was given in school could be improved. In a few cases their concerns were echoed by school staff, but the young people themselves did not often indicate that they were unhappy with the support they were receiving.

Some parents had had discussions with the school where they had requested more support. In one case the young person was not getting the support that his Statement of Special Needs set out until the parent wrote to explain this to the Headteacher. Another parent of a young person in the same school reported that her son appeared to be misbehaving because he could not understand the work in the special needs small group and needed more help:

> *"I said, 'Why were you getting angry?'*
>
> *'cause I couldn't understand what she was asking us to do.'*
>
> *Now obviously, in that situation it's like 12 of them with one teacher whereas in other subjects he has got somebody with him who probably could explain it."* (Parent)

This parent's concerns about lack of support were supported by both the member of school staff and the young person. When asked what he would like to change about school the young person wanted:

*"Teachers would come around like helping…"* (Young person)

The member of school staff in this case was quite outspoken about the need for more individual support for the young person, saying things would be improved:

*"If we had more support, more like 1 to 1 support in lessons. At the moment there are two TAs [teaching assistants] to about 10 children….So although we do give them all time he would benefit from more…. in my opinion he does need to have more TA because we are sometimes spread quite thinly"* *(School staff)*

Several parents and a member of staff, from the school where the amount of support had been highlighted as a problem, mentioned lack of continuity of support as stressful for the young people, as they had to get to know so many teaching assistants. The young people themselves did not mention continuity or having different teaching assistants as a cause of stress or difficulty for them.

It is interesting this school in which lack of support and continuity of support appeared to be a problem as perceived by parents and some staff, was the same school in which another parent had questioned the Headteacher's commitment to inclusion (see section 4.7.1b).

In two cases the member of school staff explained that the young person had difficulty recording their work but did not indicate that any help was provided, leading to stress for the young person. In a different case the young person described how he became stressed when people drew attention to his difficulty recording work:

> *"Like, in science my friend, ….. basically she just wound me up so much that I just went bang. She basically decided just decided to wander off and now she's having a right go at me, today she's having a good go at me, just because I was miles behind everybody else because my writing's so slow. I think I would rather have my writing neat than having it big and scrawly without being able to read it, she was having a go at me for not being able to catch up….I felt like just grabbing her and throwing her out of the room and locking the door"* (Young person)

Five parents discussed how not wanting to be seen as different made it difficult to for their child to access appropriate support in school. One explained how:

*"He refused any help when he first went. I think he saw it as a clean slate so he wanted to try to be like anyone else."* (Parent)

In another case a desire to fit in meant the young person went without lunch:

*"School have been, have done, you know the school have bent over backwards to try and make it better for him, they've given him a pass so he can go right to the front of the [lunch] queue if he wants, or the teachers have agreed they take they escort a group of children with similar problems, they'll escort them through the queue at the front, but he won't it take up because he doesn't want to be seen to be being different…. The answer is, you can't have your cake and eat it, he wants to be seen to be one of the others."* (Parent)

However, problems with feeling different to others when receiving support were not commonly mentioned by school staff and only two of the young people explained that feeling different from other people made them feel stressed, sad or worried in school.

**4.7.5a Adult Attention**

Having access to a key member of staff to talk to when they were feeling stressed was highly valued by several of the young people interviewed. Four explained that

talking individually to a member of staff about things which are important to you, helped them to feel relaxed and happy in school. The frequency of this ranged from each day to fortnightly.

Young people talked to a variety of school staff including their Head of Year, school SENCo, a particular teacher, learning mentor or teaching assistant or in two cases someone from outside school, a mentor and a member of staff from the Local Authority's autism outreach team. Five of the parents also talked about particular members of school staff whom the young person liked and felt able to talk to and school staff also described young people seeking out trusted adults when they were in difficulty.

Young people who appeared to be experiencing high levels of stress appeared to have more need for this kind of support. One of the parents of the two young people who frequently showed signs of stress explained how:

> *"He likes to go up to learning support. He likes a sympathetic ear and he usually gets one. Most of the TAs [teaching assistants] are brilliant with him that usually is what helps to keep him calm or calms him if he's been stressed."* (Parent)

This was echoed by the member of school staff talking about that young person:

*"When he first came in Year 7 he cried every day, he cried a lot, and he would always came down to the staff room and he would focus on one or two people he really wanted to be with all the time: adults. He's always attached himself to one specific teaching assistant really, at the moment Mrs B is the one, and he needs that person, he's very needy and he comes down…. I must have Mrs B, where's Mrs B is she here?* (School staff)

Some members of school staff drew the link between a young person being highly stressed and needing a lot of adult support and attention and young people who were feeling happier who needed rather less:

*"The fact that I don't hear from him or he doesn't come to see me as much, makes me think that things are good"* (School staff)

For some young people the support from a familiar adult was needed less frequently but still needed to be available in case it was needed:

*"He knows that I liase with his mum and dad and that if there's anything goes wrong we can sort it out. He kind of knows that I'm the one that will come if he has a problem and you know he usually knows where to find me if he needs me, but he's fairly independent"* (School staff)

Three members of school staff and one parent discussed how individual adult support for young people sometimes included anger management. This was well received by the young people themselves with five of the eleven young people reporting that someone teaching them to calm themselves down when they were stressed had helped them feel better in school. In some cases they were quite keen to stress just how helpful this was:

*"It helps…. There was a teacher in my old school that did it and I do it now in this school"* (Young person)

*"That's definitely going on to helps me feel good.. the crew from here [learning support] has helped me"* (Young person)

## 4.7.5b Insufficient Pastoral Care

There was limited evidence provided by the study that insufficient attention from school staff demoted young people's emotional well-being in school. However, three young people said that they would like to meet regularly with an adult to talk about things that were important to them, but this was not happening at the moment. Some explained that they wanted to have a regular session rather than seeking out someone when they needed to. Another two said that they would like someone to

help them learn to calm down when stressed. Parents and school staff did not comment that insufficient access to adults in school made the young people feel stressed, worried or sad.

**4.7.6a Quiet**

Quiet was a recurrent theme in the interviews with the young people. When asked what made them feel relaxed and happy in school, seven of the eleven young people interviewed selected 'When it's quiet' as important for them. Young people valued quiet in lessons with other students behaving well, and at other times during the school day including lunchtime, changing for P.E. and on the school bus. One explained:

> *"I like that when it is quiet, when everyone's being quiet…. In lessons when if everyone's running about and throwing things at each other and yelling just cause the teacher is not there or cause the teacher's out of the room, I hate that, but then when the teacher comes back in it's really nice because it's quieter."* (Young person)

The young person going to a quiet place at lunchtimes to avoid crowds and noise was mentioned by six parents and six school staff. Five young people said that having a quiet area to go to when you need to helped them feel relaxed and happy

in school. Two specifically mentioned seeking out a quiet area to go to at times when they were stressed out. One explained that he went to a particular room:

*"Not very often, it's just if I need to calm down or something."* (Young person)

His parent confirmed:

*"He knows if he is upset or anything at school he can go to like the learning miss or special needs centre, he goes there and she's got a stress ball tucked away for him and he can just sit there and calm down and chill out."* (Parent)

However, the need for a quiet place to go at lunchtime was not universal and appeared to be confined to those young people who were had negative feelings in school. In one case the young person had ceased to access a quiet environment since he became more settled. For another of the young people who still needed to access a quiet area very occasionally, this reduction in frequency, to around only once a month, was seen by school staff as a sign that the young person was feeling happier:

*"He used to spend a lot of time in the library but he doesn't do that anymore. You know, away from people, so that's why I'm saying he does seem a lot lot more content with himself really."* (School staff)

His parent confirmed this:

*"Year 7 was hard for him, and I remember in Year 7 he would just every lunchtime he would go to the homework club and he didn't need to go to the homework club but he did it because it was a quiet room and there was a teacher sitting in the room, and it was quiet nobody was there and it was just because he didn't want to go outside and interact with the other children."*
(Parent)

In four of the eleven cases the member of staff observed that the young person could access a quiet area at lunchtimes but did not choose to do so or did so extremely infrequently. In two of these cases the parents confirmed this. It is perhaps not a coincidence that these young people were the same ones who were rated as relaxed and happy almost always or often, displayed fewer behavioural difficulties and had some supportive friends in school.

### 4.7.6b Noise and Disruption

Many of the young people reported that they found noise and disruption caused by other students very stressful and parents and sometimes also school staff confirmed this. Misbehaviour in lessons and problems with noise at various throughout the

school day, including corridors, dining halls and changing for sport, as well as on the bus after school were mentioned by small numbers of parents, school staff and young people as causing stress to the young people. Two young people said that having a quiet area to go to if they needed to at lunchtime would make them feel relaxed and happy but there was nowhere to go at the moment. One young person explained that he felt like hurting other people:

> *"Most days because they like annoy me, just making stupid noises… it's the stupid noises that's mostly the real problem. "* (Young Person)

A parent of another child explained:

> *"[YP] gets very distressed If there's a lot of disruption, it other people are being naughty. He gets very distressed."* (Parent)

Although not commonly mentioned, teachers shouting in lessons was also reported to cause stress by one parent, one member of school staff and one young person, talking about three different cases. The young person said that he would change school to a place where teachers would be nicer to students and complained about teachers that were too loud:

> *"I just don't like teachers shouting at me."* (Young person)

**4.7.7a Predictability**

There was almost universal agreement between the interviewees on the value of predictability and consistent routines in school. Nine of the eleven young people interviewed said that knowing exactly where everything was in school made them feel relaxed and happy and nine said that knowing exactly what is going to happen each day and being warned of any changes made them feel relaxed and happy in school.

Similarly, all eleven parents interviewed felt that having consistent routines in school and a timetable in a planner or notebook helped their child to feel relaxed and happy. Two parents highlighted that the routine bound nature of secondary schools was perfect for their child:

*"Secondary school is fantastic for AS children – because there is a routine and every hour, we move on"* (Parent)

*"She likes things in order, and she likes routine, she likes it, I think that's why she loves school, because it's a routine. She likes even at home she likes her routine so I think that's probably what it is, she knows what's happening and she knows what's next"* (Parent)

The school staff that were interviewed were well aware of the young people's need for consistency and predictability. It was apparent that in each case, they worked hard to warn the young people of any changes, and thus pre-empted problems from arising. This comment was typical:

*"If there are any changes to be honest if I can think of and I know, I will go and talk to him and tell him… it does help if you do warn him of things like that, of any change really."* (School staff)

It appeared that having things predictable and warning of changes was working well in the schools in the study. Eight of the young people explained that this "I became upset because there was a change I wasn't expecting" had not happened within the last month. The young people seemed to value the advance warning of changes they received in schools. Some mentioned their form tutor keeping them informed of any changes and one talked about a member of staff in Learning Support who went through the timetable with him most days warning him of any changes. Another young person even explained how:

*"While I was at home [in half term] I got a phone call saying that our geography class was going to be split into loads of little groups, so I just got a week of advance warning."* (Young person)

For the big change, the transition from primary to secondary school, parents reported that most of the young people settled in more quickly than expected. Four parents from two of the different schools praised the additional transition arrangements which had significantly reduced stress for their child. When asked if the transition to secondary school had caused their child stress, parents typically responded like this:

*"Well I think it caused more stress to me than him, I think it could have done, but it was managed extremely well."* (Parent)

**4.7.7b Change**

Change in school did adversely affect the emotional well-being of some of the young people in the study, although this was surprisingly rare. When asked what caused him to feel stressed in school, one young person replied:

*"Each term having a new technology teacher…. It's because like as soon as you get along with one teacher, then you've got to get used to another one."* (Young person)

One member of school staff commented that some changes could not be avoided, for example if staff were ill, and another described how if there were changes in

classrooms it affected the young person and said that if she had a magic wand there would be no such changes because:

*"Changes in classrooms or such like, you can tell he's quite agitated and quite vocal, calling out."* (School staff)

Although three of the eleven young people, four parents and five members of school staff said that moving schools at Year 7 made the young person feel stressed, worried or sad at the time, none had ongoing concerns in this area.

### 4.7.8a Support for Organisational Skills

Throughout the interviews parents, young people and to a lesser extent, school staff, highlighted how support for the young person's organisational skills helped them feel more relaxed and happy in school.

Ten of the eleven young people interviewed, all eleven parents and ten of the school staff said that having a planner in school helped the young person feel more relaxed. However, some members of school staff were keen to make the point that the young person would often rely on the existing school routines and structures and did not need anything additional and different in this regard.

For some of the young people storing belongings safely was important to them. Six young people reported that having a safe space to put their things was something that helped them to feel relaxed and happy in school. In two cases the member of school staff explained how a place had been found for the young person's belongings to reduce their stress.

One member of school staff clearly had a strong role in supporting the young people's organisational skills, which they greatly appreciated. She provided support such as keeping completed homework so that it did not get lost, ensuring young people had a specific space to change for sport. so that they did not lose their things, reminding them to complete homework on time and warning them of changes to routine.

Homework appeared to be a key area where support for organisational skills was in place. In three cases the parent or member of school staff reported that the teaching assistant would write down the homework for the young person to ensure they had it recorded correctly. In addition, two schools ran homework clubs to help the young people complete their homework in school. In one of these schools, three of the four parents and three of the four young people interviewed commented on how helpful the homework club was in reducing stress.

**4.7.8b Difficulties with Personal Organisation**

In many of the interviews, the young person's struggles to organise him or herself was a recurrent theme which impacted on their well-being in school. Parents and school staff reported that the young people found a number of facets of organisation in school difficult, including looking after their belongings, filing handouts, dealing with homework demands, getting themselves to the right place in the school on time and changing for sports.

Three parents thought their child should be receiving more support than they were currently getting and one had recently asked for additional help to meet her child's organisational difficulties. One parent pointed out that because her child was quite bright, the teachers did not understand the difficulties he had with organisational skills.

Two of the young people talked about how they worried about forgetting or losing things that they needed in school and three said having a safe space to put their things in school wasn't available to them, but that if it was, it would help them feel more relaxed and happy. Two parents commented that their child took all their books with them each day, just to make sure they had the right ones.

Five parents and one young person commented that the size of the school or moving between lessons around the school caused anxiety. This was mainly a

problem for Year 7 students and when it was mentioned for older students it was in the context of settling into Year 7 rather than a current problem.

One young person was described thus:

*"I would say he was anxious coming [to secondary school at start of Year 7], ….the rooms, having to go to different rooms for each different lesson and you know he struggled with organisation, to get his things together and move on."* (School staff)

A different young person, who was in Year 7, explained that to help him feel better in school:

*"I would make the school like more smaller… yeah 'cause this school is massive… 'cause I don't know where anything is."* (Young person)

However, the biggest source of stress for young people's limited organisational skills appeared to be homework. Six of the eleven parents, five of the young people and three members of school staff mentioned problems with homework.

Between them, parents mentioned a number of features of homework as stressful. These included teachers not giving specific literal instructions about writing down

homework, homework taking too long and problems remembering when to hand homework in.

Young people themselves described worrying about the amount of homework they got, how long it would take them, whether they would get it done, and even forgetting to do it at all:

> *"I'm starting to get tons of homework…. I don't know if I don't know how much homework I'm going to get, so if I get like too much, how am I going to get it done?"* (Young person)

One member of school staff explained how worry about homework was something that would be guaranteed to make the young person stressed and anxious in school:

> *"If he's got homework and he hasn't actually managed to do it. And although he would sort of you know tell you it doesn't matter and it's ok, but it obviously does."* (School staff)

### 4.7.9 Non School-Based Mental Health Promoting and Demoting Factors

Participants were also asked about whether the young person well-being was currently being improved by, or might be improved by factors outside school,

principally medication and counselling. None of the young people were on medication to improve their mental health. One was receiving counselling, a form of Cognitive Behaviour Therapy and in this case both the parent and member of school staff reported that it helped the young person.

Participants were also asked about any recent life events, such as hospital stays or parental separation, that the young person had experienced which have be affected their well-being in school. Although these were mentioned by a small number of parents, teachers and young people, none of the participants placed an emphasis on life events affecting the young person's emotions in school.

**4.8.1 Differences in Views of Mental Health Promoting and Demoting Factors Held by Those in the Different Roles**

Various differences of opinion emerged between the roles of parents, school staff and young people regarding which factors promoted and demoted the well-being of the young people.

Firstly, having a caring and inclusive ethos was mentioned equally by parents and school staff but less so by the young people. Parents were most likely to stress the positive impact on the young person of school staff understanding their needs and the most likely to report school staff not understanding the young person's needs.

More parents than young people or school staff talked about the positive impact of making friendships for the young person but all three groups of participants talked about the negative impact of friendship difficulties. Several parents wanted the young people to receive structured support in school to make friends, whereas school staff and young people were less keen on this. Parents also expressed a desire for work with peers to help them understand autism much more frequently than school staff.

Parents were the most likely group to state that lack of appropriate support in school was making the young person feel stressed, sad or worried and often discussed difficulties with support in detail. However, some members of school staff supported the parents' concerns. A desire for support to remain unobtrusive was reported most often by parents.

Having access to a key member of staff was mentioned equally by parents, school staff and young people, but discussed in most detail by school staff. Quiet and the absence of disruption were mentioned more frequently and stressed as more crucial by young people and parents, than by school staff. Whereas school staff were most likely to discuss problems on starting secondary school, parents tended to praise the transition arrangements that had helped their child to settle quickly and happily. Fairly equal numbers of parents, school staff and young people talked about the

young person requiring support for their organisational skills. All three groups mentioned problems with and support for homework in roughly equal numbers.

**4.8.2 Within Case Differences in Views Regarding Mental Health Promotion or Demotion**

This section provides a summary of the level of agreement within cases concerning factors that promoted or demoted the mental health of the young person.

In almost all cases there appeared to be good agreement as to what helped the young person, and to a slightly lesser extent, agreement about what made the young person feel stressed, sad or worried.

When the participants were asked to sort strategies into piles to indicate whether or not they were helpful to the young person there was good agreement between the parents and school staff in individual cases, about what strategies helped the young person to feel relaxed and happy in school.  Parents tended to rate slightly more of the strategies as helpful to their child (a mean of 7.3) than school staff (a mean of 6 helpful strategies) but the mean number of strategies which were rated as helpful by both parents and school staff in each case was 4.9, which indicates rather good agreement between the parent and member of school staff interviewed about what helped individual young people (see Appendix 13 for full details). In fact in eight of

the eleven cases, all, or all but one, of the strategies that the member of school staff said were helpful, were also thought helpful by the parent.

Not all the strategies presented to the young people could be compared directly with those presented to parents and school staff, but for those strategies which were presented to both the young people and adults in the study, there was also good agreement between different roles within each case. For example, in seven of the eleven cases, all, or all but one of the strategies that the member of school staff thought helped the young person feel relaxed and happy, was also mentioned by the young person themselves. In nine out of the eleven cases, four or more strategies were rated as helpful by all three participants.

When the participants were asked to sort sources of stress into piles to indicate which caused the young person to feel stressed, worried or sad in school, parents and school staff often agreed on the same sources of stress. In eight of the ten cases where sources of stress were identified, more than half the sources of stress mentioned by the member of school staff were also mentioned by the parent. Again, young people were asked about slightly different sources of stress so their results cannot be directly compared but there was some, more limited, agreement between them and their parents and school staff. In each of the ten cases where the young person reported one or more of sources of stress, at least one of the sources of

stress that they identified was also identified by their parent or the member of school staff interviewed.

## 4.9 Summary of Results

Overall, a positive picture of the emotional well-being of young people with autism or Asperger syndrome in mainstream schools was reported by the participants. Most of the young people were said to be feeling relaxed and happy in school for much of the time, and sadness was rarely reported. Few manifestations of mental health difficulties were identified. A notable exception was the reports of anger and aggression, made by at least one of the people involved in the case, regarding all but one of the boys in the study. Different manifestations tended to be reported by the different groups – parents, school staff and young people – perhaps reflecting their different perspectives.

The cases can be clustered into three groups, reflecting their well-being in school. In three of the eleven cases, the young person's emotional well-being was very positive. For the majority there were occasional periods of stress and anxiety in response to specific incidents. Two of the young people exhibited high levels of stress on daily basis in school and these cases were discussed in more detail in section 4.5. There was good agreement between the different groups of participants,

young people, parents and school staff, about the young people's emotional well-being.

An interesting feature of the results which was not anticipated was the fact that in many cases the young person's well-being had varied dramatically over time. The reasons for this were not clear, although in some cases gaining friends and / or moving schools had led to an improvement, indicating possible influence of the environment. However, there was no particular pattern as regards when improvements and deterioration occurred with this varying across cases.

Eight pairs of key factors that promoted and demoted mental health of this group of young people were described. These were ethos and attitude to inclusion, understanding of the young person's needs, friendships, appropriate learning support, adult attention, noise levels, predictability and support for organisational skills. Evidence regarding each of these factors was gained from participants in each of the different roles in the study, young people, parents and school staff.

There was good agreement between those in different roles within each case about the factors that promoted the young person's emotional well-being in school, and some agreement about aspects of school life that made the young people feel stressed, sad or worried in school.

The next chapter develops further the results presented here, by discussing how they link to the literature presented in Chapter 2 and considering their implications for practice in mainstream secondary schools and for further research in the area.

# CHAPTER 5:

# CONCLUSIONS AND IMPLICATIONS

## 5.1 Introduction

As reported in section 2.9, the literature indicates that despite an increasing awareness of mental health difficulties in people with a diagnosis of autism or Asperger syndrome, this topic remains poorly researched, with an emphasis on questionnaire based studies which seek correlations between different diagnoses, leaving a lack of focus on the views and experiences of those with autism or Asperger syndrome and those who know them well. There is also little research into the impact of the school environment on the mental health of young people with autism and Asperger syndrome or mental health promotion for this group of young people generally, despite the insistence of many articulate people with autism or Asperger syndrome of the importance of the environment in the onset of their mental health difficulties.

The purpose of the research was to seek and compare the opinions and experiences of young people with autism and Asperger syndrome, their parents and school staff, regarding the young people's emotional well-being and what schools do that promotes or demotes this, as outlined in the research questions in section 1.5. These research questions were constructed to focus on a number of gaps in the literature as detailed in section 2.9 including a lack of focus on mental health

promotion for this group, limited research into the impact of different environments, including schools, on their mental health, and a lack of detailed exploration of the experiences and viewpoints of those with autism or Asperger syndrome and those around them.

The study provided evidence regarding these previously unexplored areas and answers each of the research questions, which are discussed in turn below. The strengths and limitations of the methods used to answer these are then highlighted. In the light of these, conclusions are drawn and finally the implications of the study both for practice in schools and further research in the area are noted.

## 5.2 The Young People's Feelings and Emotions

Miles and Huberman (1994) report that in a multiple case study the cases can be ordered along dimensions, often on a continuum with a few exemplars of each end. In the current study the emotional well-being of the young people appeared to follow this description. Two young people did show several signs of stress and anxiety on a daily basis. In sharp contrast, the picture for three of the eleven young people was very positive, as reported by themselves, their parents and school staff. They were reported to be relaxed and happy for most of the day in school. For the remaining young people in the study the picture was that they were mainly calm but sometimes became very stressed, quite quickly. There was no link between well-being and

school attended with the young people who were having difficulties attending two different schools and those who were doing well also attending two different schools.

Although the current study was not designed with the aim of establishing prevalence rates of mental health difficulties it is interesting to note that the overall profile of the mental health of this particular group of participants is more positive than might be expected from the literature discussed in section 2.5.1. All eleven of the young people said that most days in the previous few weeks they felt happy and in eight of the eleven parent interviews and eight of the interviews with school staff, the young person was rated as often or almost relaxed and happy. In contrast many studies, carried out outside the United Kingdom, report a higher prevalence of mental health difficulties (de Bruin et al., 2007; Gjevik et al., 2011; Mayes et al., 2011; Mazefsky et al., 2011). However, in much of this research, samples were drawn from cases where people were presenting at clinics with difficulties, whereas the current study which aimed to look at the range of presentation of emotional well-being in this group within the three designated schools. The proportion of 2 out of the 11 cases appearing to be under stress each day found in the current study is similar to the 16% figure reported by Green et al. (2005) in a large scale survey of the general population of the United Kingdom and perhaps taken together, these results suggest that relying solely on clinic based studies for this prevalence data is rather flawed. However, as no attempt was made to use strict diagnosis procedures in my study, few firm conclusions can be drawn.

In the current piece of research, anxiety was mentioned much more often than sadness. This finding supports the view of Tantam (2007) who reports that there is often a dramatic increase in anxiety around the age of 11 to 13 years (the participants in the current study were aged between 11 and 14 years) whereas the onset of depression occurs around 16 to 18 years. It also supports the view of the majority of prevalence studies which have concluded that anxiety is the most prevalent mental health difficulty for this group (de Bruin et al., 2007; Gjevik et al., 2011).

A recurring theme in the research, which was unexpected, was that several of the young people had periods of time (lasting for several years in some cases) when they were particularly stressed and needed a high degree of support and then this later lessened. These changes were most often mentioned by parents, but also on occasion by school staff. When the situation improved the impact on the young person's behaviour at home and at school was considerable, although it was not entirely clear what had led to the inconsistent profile of the young person's emotional well-being over time.  One possible explanation is that the environment may play a significant role in the young people's mental health. This certainly accords with the reports of many people with autism and Asperger syndrome (Andrews, 2002, 2006; Beardon and Edmonds, 2007; Beardon and Worton, 2011). However, in follow up questioning, most of the participants did not attribute a particular cause to the young

person becoming more or less settled and happy. On two occasions improved friendships appeared to provide at least a partial explanation (these are discussed in more detail later) and several parents mentioned how the move to secondary school had led to their child becoming less anxious as school staff appeared to understand their needs better.

Another possible explanation for these changes in well-being is a natural variation over time and with age in levels of anxiety. Davis et al. (2011) used a cross sectional study to examine how anxiety symptoms varied across the lifespan of those with autism and found a pattern in which anxiety increased from toddlerhood to childhood and then decreased again to young adulthood before a further increase. Unfortunately however, the study is weakened by the fact that it was not longitudinal in design and that the childhood age included participants from 3 – 16 years, which meant that any variations in anxiety levels at different ages between 3 and 16 years could not determined. However, it does provide an indication that changes in anxiety levels occur across the lifespan of those with autism and they could be related to some of the changes in well-being experienced by those in the current study. Further research, perhaps looking longitudinally at anxiety in those with autism throughout childhood and adolescence, would be needed to determine this.

Linked to this, the deterioration in behaviour of young people with autism or Asperger syndrome when they reach adolescence which is written about by

clinicians (e.g. Ghaziuddin, 2005a) and those with autism themselves (e.g. Grandin, 2006) did not appear to be true for all young people in the current study. At least two had significant problems in primary school with emotional and behavioural difficulties which lessened within a year of transfer to secondary school. Although the well-being of other young people in the study had worsened in recent years, in some cases significantly so, the current study indicated that the changes in emotional well-being as young people with autism or Asperger syndrome approach adolescence is not necessarily unidirectional. However, these conclusions should be interpreted with caution as the young person's emotional well-being over time was not the focus of the current study; further research using a longitudinal design may be helpful.

## 5.3 Manifestations of Mental Health Difficulties

Few manifestations of mental health difficulties were reported in most of the interviews. Some symptoms of mental health difficulties overlap with the usual profile of a person with an autism or Asperger syndrome and as such they are hard to interpret. Only two parents and one member of school staff reported that the young person was displaying an increase in the core features of autism, which is mentioned in the literature as a key indicator of mental health difficulties in people with autism or Asperger syndrome (Tantam, 2000). In addition, a change in character of special interests to dark subjects, which many have noted may be linked to mental health difficulties (Ghaziuddin et al., 2002; Ghaziuddin, 2005;

Attwood, 2006; Tyler, 2010), was reported by only one parent and one member of school staff in the current study. However, in one of the two cases where the young person was experiencing high levels of stress; the young person often withdrew from social contact at home. This is a solution to stress noted by those with autism and Asperger syndrome (Andrews, 2002; Brown, 2011) and can be important in diagnosis of mental health difficulties for this group (Ghaziuddin et al., 2005a; Tyler, 2010). This young person was also reported by school staff to make bizarre comments, and at times, appeared to be in a fantasy world, which can be part of an escalating pattern of anxiety in young people with autism and Asperger syndrome (Etherington, 2010b).

The other young person experiencing high levels of stress was reported to be very self-critical and have a low self-esteem. This can be a factor in the development of depression (Vermeulen and Vanspranghe, 2006) and in this case the young person's parent and teacher reported that it was affecting his well-being. He was working with a Clinical Psychologist tackling 'Negative Automatic Thoughts', which are associated with anxiety, behaviour problems and life interference in those with autism (Farrugia and Hudson, 2006). In many ways this young person's story is very similar to that of Lim (2011) a person with Asperger syndrome who experienced name calling from others highlighting her differences from them, was painfully aware of these differences and did not want to be the way she was, but was not able to change, with a resounding negative impact on her self-esteem.

Aggressive behaviour was commonly reported and was linked to stress and anxiety by parents, school staff and young people. The two young people experiencing high levels of stress displayed high levels of aggression, in one case predominantly at home, in the other predominantly at school. Recent studies in the United States (Kanne and Mazurek, 2010; Farmer and Aman, 2011) have found a high prevalence of aggressive behaviours in children and young people with autism but have not investigated the link between these and mental health. This is supported by a community study of adolescents and adults with high-functioning autism or Asperger syndrome in the United Kingdom, which found that 84% reported they angered easily and 31% reported they often hit people (Balfe and Tantam, 2010). Anger in adolescents with Asperger syndrome can have a significant effect on home and school life (Carter, 2010) and some writers (Kim et al., 2000; Ghazuiddin, 2005a; Farrugia and Hudson, 2006; Balfe and Tantam, 2010; Mattila et al., 2010) have linked aggression with anxiety in young people with autism and Asperger syndrome and the current study certainly supports this claim, with greater levels of stress being linked with more frequent and serious forms of aggression amongst the cases studied.

School refusal (Kurita, 1991; Madders, 2010) was not noted in the current study and although mental health difficulties can lead to out-of-authority placements for those with autism and Asperger syndrome (Jones et al., 2008) no school placements

appeared to be in jeopardy. However, the young people who were regularly stressed in school were receiving very high levels of support. The impact on their own lives and that of their family members was also adverse and significant, similar to that reported by other family members of those with autism and mental health difficulties (Kim et al., 2000; Madders, 2010).

## 5.4 Differences in Perceptions of the Young People's Mental Health

This study found good agreement between parents and school staff within each case regarding the young person's overall feelings in school, and some agreement when all three perspectives within a case were considered. Parents and school staff within each case also reported a similar number of manifestations of mental health difficulties, again perhaps indicating a similar level of concern. There was much less agreement on the precise nature of the manifestations reported, possibly due to the different perspectives of those in different roles.

This finding indicates a possible reason for the complex picture provided by other studies which have compared the reports of parents, teachers and young people with autism or Asperger syndrome regarding the young people's mental health. It is likely that the precise features used to provide indicators of mental health difficulties vary from study to study and that some of these are more likely to be reported by certain groups than others. As a result in some studies parents report more mental

health difficulties than teachers, perhaps when the 'symptoms' listed are more visible to parents (Kanne et al., 2009) and in others the reverse is true (Hurtig et al., 2009), when the focus is on other aspects of behaviour. Another possible reason for this discrepancy is the impact of environmental context in the expression of mental health difficulties, a view that would supported by many with Asperger syndrome and their advocates (Andrews, 2006; Beardon and Edmonds, 2007; Beardon and Worton, 2011).

### 5.5.1 Features that Promote and Demote the Young People's Mental Health

Considering the five main approaches that were described by the DfES (2001) as effective in working with young people who were depressed or anxious, one, medication, was not being used with any of the young people in the current study. None of the young people were receiving general counselling; however, teaching relaxation strategies, often an element of counselling and useful in tackling stress and anxiety in people with autism and Asperger syndrome (Attwood, 2003; Paxton and Estay, 2007; Etherington, 2010b) was appreciated by the young people in this study. Five of them said that someone teaching them to calm themselves down when they felt stressed helped them to feel relaxed and happy in school and a further two reporting that such support would help them if it were available. One young person was receiving CBT from the Health Service and six had had some form of social skills training, either individually or in a group. The fifth approach,

dealing with underlying school problems, was being used to a greater or lesser extent in each case and is the area which my research focuses on in most detail.

In investigating this final approach, the responses of those in this study were often similar which led to a tentative proposal of eight factors which appeared to promote emotional well-being of the young people in school. For each of these a contrasting factor which was reported to demote emotional well-being was identified (see Table 8 in section 4.7). For each pair of factors, there was support from many or all of the cases that it was important for the young person's emotional well-being. As a result of the links between these opposing factors the research questions concerning mental health promoting and demoting factors are considered together in this section.

## 5.5.2 Ethos and Attitudes

Research into mental health promotion in schools for all young people has focused heavily on the role of leadership (Weare, 2008; Roffey, 2008; Rowling, 2009; West-Burnham, 2010), the importance of whole school approaches (Rowling, 2009; Herman et al., 2009; Layard and Dunn, 2009; NICE, 2009), the need to value all in the school (Atkinson and Hornby, 2002) and have an inclusive culture (NICE, 2009). All these features were highlighted in the current study in which the ethos of the school towards inclusion of those with autism and Asperger syndrome was a key

theme. This is in line with the work of other researchers who have highlighted how the ethos of the school impacts on those with autism and Asperger syndrome (Humphrey and Lewis, 2008; Jones et al., 2008) and that young people with autism and Asperger syndrome are aware of the importance of school ethos (Williams and Hanke, 2007). Flexibility of staff to meet individual needs was particularly valued by parents as supporting their child's inclusion. In the literature this flexibility has also been viewed as promoting genuine inclusion (Connor, 1999; Whittaker, 2007; Jordan, 2008; Frederickson et al., 2010).

### 5.5.3 Understanding the Young Person's Needs

The importance of staff who are knowledgeable and understanding of the needs of those with autism in school (Jones et al., 2008; Jordan, 2008; Tobias, 2009) and who can empathise with those with autism (Barrett, 2006; Whittaker, 2007) is a key feature of the literature on autism and education. Perhaps unsurprisingly therefore, school staff understanding autism and understanding the young person's individual needs was viewed as mental health promoting by all eleven parents and in ten of the interviews with school staff. In addition, six parents, five members of school staff and three of the young people themselves commented that there were times when school staff did not understand autism or the young person's needs and this had caused them to feel stressed in school. In most cases it appeared to be just a small

minority of staff, whose lack of understanding impacted negatively on the young person's well-being.

However, for some young people lack of understanding was more widespread and in a few cases, most commonly in one particular school, the behaviours of those with autism were reported by both parents and school staff to be misunderstood by some teachers who viewed them as disrespectful rather than a product of autism. This pattern has also been recorded by others (Whittaker, 2007; Jordan, 2008; Tobias, 2009; Ashburger et al., 2010). In this school those with autism were viewed as the responsibility of the special needs department rather than the wider staff (a problem also noted by Osler and Osler, 2002 and Humphrey and Lewis, 2008) and parents identified problems in communication between the SENCo and Heads of Year (again noted by Humphrey and Lewis, 2008). Several parents from this school and some from other schools mentioned the need for more staff training to help subject teachers understand autism; mirroring the requests of those in other studies which have sought the views of parents with autism (Batten et al., 2006; Jones et al., 2008).

The daily interactions within classrooms build relationships between teachers and young people and are important in developing connectedness (O'Hanlon, 2000; McLaughlin, 2008; Roffey, 2010). Therefore it is perhaps inevitable that if a member

of teaching staff did not understand the young person's needs this connectedness is seriously affected and the young person's emotional well-being is reduced.

### 5.5.4 Friendship

A varied pattern of friendships existed across the cases studied. Four of the eleven cases appeared to have at least one good friendship; this reflects other research findings that a minority of young people with autism and Asperger syndrome do enjoy some good quality friendships (Chamberlain et al., 2007; Kasari et al., 2011; Humphrey and Symes, 2010). The other young people had difficulty maintaining friendships or were not interested in making friends. This pattern of most young people with autism or Asperger syndrome having few and poor quality friendships is a common feature of the literature on autism (Green et al., 2005; Wainscot et al., 2008; Locke et al., 2010; Mazurek and Kanne, 2010). It was also interesting that many of the young people in the current study were keen on making friends despite their difficulties with social interaction, as others have reported (Whittaker et al., 1998; Bauminger and Kasari, 2000; Howard et al., 2006). Several of the young people in the study were aware of others teasing or rejecting them (as in the study by Ochs et al., 2001) and some were aware of the negative impact their difficulties with friendships had on their well-being (as were the young people studied by Humphrey and Symes, 2010).

There appeared to be a clear link between friendship and well-being with three of the four young people who had at least one good friendship having high levels of emotional well-being and the remaining young person being mostly settled in school. The two young people with high levels of stress had problematic friendships; one appeared to have only acquaintances rather than true friends and the other wanted to be included but lacked social skills and found friendships hard to develop and maintain (as discussed by Attwood, 2006; White et al., 2009a; White et al., 2009b; White et al., 2010b). This young person's friendship difficulties were reported to be a key contributor to his anxiety and upset. The link between friendship difficulties and poor mental health in those with autism or Asperger syndrome has also been reported by Konstantareas (2004) and Whitehouse et al. (2009). Those with autism and Asperger syndrome often highlight the role of difficult social environments in the onset of mental health difficulties (Andrews, 2002, 2006; Beardon and Edmonds, 2007; Beardon and Worton, 2011) and this study provides some evidence to support these views.

There was a wide consensus, amongst participants, across cases and across roles, of the importance of friendships for promoting mental health and the role of friendship difficulties in demoting the mental health of many of the young people with autism and Asperger syndrome. In cases in which the young person had been much more frequently upset, angry or aggressive at some point in the past this often coincided with a time that they did not have many friends. Parents and school staff

reported that young people who had made friends in school had become much happier in school and friendships seemed to have a 'protective power' which helped the young person be more resilient and able to handle stresses that did occur with less support from adults. This supports the assertions of Humphrey (2008) who reports that friendships help young people with autism and Asperger syndrome to increase their resilience to mental health difficulties and maintain a positive sense of self. In addition, it supports research with young people generally which has found that friendships are a key protective factor against mental health difficulties and promoting well-being, particularly during adolescence (Duckett et al., 2008; Herman et al., 2009; McLaughlin and Clarke, 2010).

Despite the agreement on the importance of friendships, there were significant differences of opinion however, in how to promote friendships and hence emotional well-being, for these young people, which mirror disputes in the literature. Social skills training for those with autism and Asperger syndrome is a high priority for some schools (Reid and Batten, 2006; Whittaker, 2007; Frederickson et al., 2010), although evidence for the effectiveness of such programmes is by no means clear with concerns about lack of generalisation and maintenance of skills learnt (Ghaziuddin, 2005a; Cappadocia and Weiss, 2011). In the current study, many parents wanted support to develop their child's social skills, but some young people questioned the need for this and several school staff questioned the effectiveness of

social skills groups as a result of their experiences, which supports the equivocal findings in the literature.

Again work with the peers of those with Asperger syndrome divided opinion. In recent years practitioners have written about the successes of training young people to become peer supporters for young people with autism or Asperger syndrome (Whittaker et al., 1998; Gus, 2000; Etherington, 2007, 2010a) but the majority of parents and school staff in the current study did not support this. Despite evidence that disclosure of diagnosis may be beneficial in helping young people with autism or Asperger syndrome to gain support from peers (Ochs et al., 2001; Humphrey and Lewis, 2008), the vast majority of those interviewed in the current study did not view such disclosure as desirable.

In contrast to much research in the area which has reported high levels of bullying experienced by those with autism and Asperger syndrome (Reid and Batten, 2006; Tantam and Girgis, 2009; Humphrey and Symes, 2010; Cappadocia et al., 2011), in the current study, bullying was reported only rarely and when it was mentioned it was usually said to have been dealt with promptly and effectively. Schools vary in their effectiveness in tackling bullying and as only three schools participated in the study, it is possible that these three schools had good procedures in place, which reduced the exposure of young people with autism and Asperger syndrome within them to bullying.

### 5.5.5 Support for Learning

Support for learning was widespread, with nine parents, nine members of school staff and seven of the young people explaining that this helped the young person feel relaxed and happy in school. The correct amount of support in school was reported to reduce the stress felt by young people with autism. Conversely, a lack of support was blamed by some parents as causing the young person high levels of stress and leading to behavioural difficulties; supporting the findings of Osborne and Reed (2011).

Some parents and some members of school staff mentioned the need to have a careful balance of support to help promote the independence and socialisation of the young person. This has also been reported by Tobias (2009) and by Osborne and Reed (2011).

Three young people displayed regular avoidance of support in case these made them appear to be different from their peers. This hiding of differences has also been described by others studying young people with autism and Asperger syndrome (Carrington and Graham, 2001; Humphrey and Lewis, 2008). Perhaps surprisingly, given the emphasis of the literature on awareness of difference (Attwood, 2006; Meyer et al., 2006; White and Roberson-Nay, 2009; White et al., 2009b; White et al., 2010a), these feelings appeared to be restricted to a minority of the young people in the current study and many others did not appear to be concerned about their

differences. Feeling different to other people was mentioned by only two of the young people, three school staff and five parents as a potential source of stress.

## 5.5.6 Adult Attention

Many writers have stressed the importance of pastoral support for promoting mental health of all young people (Atkinson and Hornby, 2002; Duckett et al., 2008; NICE, 2009; MacLaughlin and Clarke, 2010). In the current study, four young people said that talking individually to a member of staff about things that were important to them helped them to feel relaxed and happy in school and a further three would have liked this support to be available. Such requests would perhaps be satisfied by the personal tutorials described by Christie et al. (2008) or a similar system, in which the young person's concerns are listened to in a quiet, supportive, individual meeting with a member of staff. Pastoral support can be particularly important when a young person with autism or Asperger syndrome has a stressful incident in school (Howlin, 2003; Tobias, 2009) and young people, parents and school staff in the current study all described such support as particularly valuable at times of crisis.

Both attention from adults in school and peer friendships (both of which many of the young people in the study appeared to crave) are part of the notion of connectedness discussed in section 2.3.2 (McLaughlin, 2008; Roffey, 2008, 2010; Herman et al., 2009; McLaughlin and Clarke, 2010). Feeling cared for by people at

school during adolescence promotes well-being and is a key protective factor against mental health difficulties for all young people (McLaughlin and Clarke, 2010). The young people in this study did show some awareness of this in their requests for regular adult support and the importance of friendships with peers. However, an organisational commitment is required to prioritise these areas (Christie et al., 2008).

### 5.5.7 Noise Levels

Research has reported that quietness in school is valued by young people with autism (Williams and Hanke, 2007) and can help to reduce anxiety (Humphrey and Lewis, 2008; Tobias, 2009). In the current study seven young people indicated that when it was quiet this made them feel relaxed and happy in school and five young people, six members of school staff and ten of the eleven parents interviewed thought that having a quiet area to go to helped the young person. It was also interesting that some parents and school staff reported that young people who had become more settled emotionally now needed these areas less.

Noise was by far the most commonly mentioned sensory source of stress within the study, confirming the literature which reports how noisy schools and classrooms can lead to anxiety (Attwood, 2006; Humphrey and Lewis, 2008; Tobias, 2009) and aggression (Mesibov and Shea, 1996) in those with autism or Asperger syndrome. Indeed one of the young people in the current study who was regularly stressed

made the link between noisy disruption and feeling aggressive. Disruption caused by other students could cause them considerable stress, in a similar way to the young people in Humphrey and Lewis' (2008) study.

**5.5.8 Predictability**

Predictability was mentioned as a key factor in promoting the mental health of almost all the young people in the study, both in terms of the consistency of daily life and preparation for changes large and small, including the transition to secondary school. Many have commented on how even small changes can lead to crises for those with autism and Asperger syndrome (Tantam, 2007; Turk, 2008) and the literature on autism and Asperger syndrome (for example Attwood, 2006) places a large emphasis on managing change. It was perhaps not surprising therefore, that participants often reported that the schools appeared to be meeting this need well for the young people in the study and as such were very mental health promoting. The structure, routine, order and predictability present in all the schools in the study appeared to make the young people feel more secure, mirroring the results found by Humphrey and Lewis (2008). However, change did cause stress for some young people on occasions.

High levels of support to enable the transition to secondary school to progress smoothly had been provided to young people in all three schools in the study as

advised by Watson et al. (2006) and Tobias (2009). This support did appear to have been effective in reducing anxiety. Therefore this study supports the work of Parsons et al. (2009) who reported that although the transition to secondary school for young people with autism or Asperger syndrome was stressful prior to the change and initially following it, most of the young people settled more quickly and easily than predicted.

**5.5.9 Organisational Skills**

In contrast to the emphasis on predictability and managing change, the need for support with organisational skills is a less prominent feature in the literature on autism and Asperger syndrome (Tobias, 2009, is a notable exception), although it was equally prominent in the current piece of research. Perhaps as a result of this lack of emphasis, the current study found that support to promote the organisational skills of young people with autism or Asperger syndrome was not as widespread as the level of need appeared to indicate. When support was provided it was highly valued by the young people themselves and helped them feel calmer in school. In other cases, disorganisation, in terms of struggling to find their way around the school, have correct belongings at the correct time and complete the correct homework on time, caused significant stress and anxiety for many of the young people in the study.

**5.6 Differences in Views Regarding Mental Health Promotion and Demotion**

The promoting and demoting factors listed above were each mentioned by parents, school staff and young people in the study, to varying degrees. Differences in the reporting of individual factors by those in different roles are described in some detail in sections 4.8.1 and 4.8.2. In a similar vein to the reporting of the manifestations of mental health difficulties, the reporting of promoting and demoting factors appeared to be influenced to some extent by role. However, there were more similarities than differences between the accounts given by the different participants with many explaining the key factors in detail from their own perspective. Within cases there was good agreement, particularly on which factors promoted the young person's emotional well-being in school, and also some agreement within cases on which factors led to the young person feeling stressed in school.

Parents rated slightly more factors as stressful than school staff; explanations for this may include the possibility that young people complain more readily about their difficulties in school to their parents than school staff and the possibility that school staff may be more likely to want to present the school in a good light, and hence omit mention of aspects of school life which were causing young people stress.

### 5.7.1 The Value of the Research

This research provides some pointers towards a greater understanding in the poorly researched area of mental health promotion in schools for young people with autism, and addresses some of the gaps in the literature identified in section 2.9. Lengthy interviews were a strength of the study, in that they allowed an in-depth insight into the participants' views and experiences and areas that emerged that may not have been expected. Such detail and richness may have been lost in a larger study. However, alongside this detail, several participants from a variety of schools were involved, allowing the opportunity for comparison between cases.

Another strength of the research is its preventative focus. This was achieved in a number of ways. Firstly, by focusing on young people aged 11 to 14 years, it highlighted the age just before mental health problems become much more prevalent both in young people with autism and Asperger syndrome (Tantam, 2007). By focusing on what supports young people's well-being at this particular stage in their life, it may prevent further problems developing in adolescence and early adulthood. Secondly, this study focuses on the mental health of the full range of young people with autism or Asperger syndrome within particular settings. Much research in this area only considers cases where the young person has a diagnosis of a mental health difficulty, but in the current study, there was the opportunity to examine cases in which the young person's emotional well-being was good, in order to see what could be promoting this.

Finally, this study moves on from previous research which has sought to establish prevalence rates of mental health difficulties or evaluate structured intervention packages for those having difficulties. Instead it focuses on mental health promotion more widely, on the impact of the school environment on young people's experiences, in line with a settings approach to health promotion. With this focus on the environment, it is supportive of the opinions of many clinicians and those with autism or Asperger syndrome themselves who report the key role of the environment in the development of mental health difficulties in this group.

## 5. 7.2 Limitations of the Study

Discussion of limitations is important in any research, because as Glesne and Peshkin (1992, p.147) write "Limitations are consistent with the always partial state of knowing in social research, and elucidating them helps readers to know how they should read and interpret your work."

A number of limitations of the study's methods are explained below, both to qualify the results obtained and conclusions drawn and to provide pointers for improvements when further research is carried out. The limitations relate to the research design, interview schedule, participant selection and the analysis of the data.

The lack of triangulation through the use of a variety of different methods is a limitation of the research design. Many authors including Gillham, (2000), Walford (2001) and Richards (2009) caution against relying solely on interviews in research due to the discrepancy between what people say in interviews and what actually occurs. Documentary analysis is often considered useful for providing triangulation and a richer picture of the situation (Glesne and Peshkin, 1994; Robson, 2002). However, as Yin (2009) notes, documentary evidence can be deliberately withheld which leads to bias in selection of data. I had intended to obtain policy documents from schools regarding areas that impacted on the well-being of the young people but was unable to obtain sufficient documents for analysis. Diaries kept by the young people about their emotions and the impact of school on their well-being was a further method that had initially been considered as part of the design of the study and would have provided further triangulation of the data. Unfortunately, time constraints made it difficult to include them within the study, but could strengthen the validity of further studies of this type.

Another limitation of the study was the lack of opportunity for participants to comment on the data obtained and conclusions drawn, as advised by Pring (2003), which would have improved the validity of the study. This process can be complex and time consuming and the feedback given would need to have been handled as

new data (Richards, 2009). Unfortunately, due to a period of leave of absence, the time between data collection and analysis meant that this was impractical.

There were two main concerns about the interview schedules. One possible criticism is that much of each interview schedules may not have been sufficiently open ended enough, so that the ideas of the researcher (albeit gleamed from relevant research in the area) were planted in the minds of participants. To counteract the effects of this, each interview did start off with open ended questions which covered the main research questions and opportunities for closed responses came later. Analysis of the data focused heavily on which areas the participants talked about at length and expanded on. However, there were also advantages to the use of closed questions within the interviews. Closed questions allowed participants to comment directly on aspects of the literature such as manifestations of mental health difficulties, strategies to promote well-being and stressors in school and they also permitted comparisons to be made more easily between participants' responses. Also, the young people appeared to be very comfortable responding to such questions, especially when they involved practical, visual sorting tasks.

Another concern about the interview schedules was that young people were asked different questions from their parents and school staff so it was not possible to compare directly the manifestations of mental health difficulties, strategies deemed helpful in promoting well-being or sources of stress reported by young people with

those reported by their parents and school staff on their behalf. This was partly because the interviews had to be appropriate to the young people's age and level of understanding but also because they had insight into different aspects. For example the young people could talk about their internal feelings more directly, such as 'I felt panicky' whereas the parents and school staff could only reliably report observable behaviours or what the young person had said about their thoughts and feelings. However, the lack of ability to compare the responses of the three participants within each case was a weakness of the study and for further research in this area, care should be taken to have 'matched' questions wherever possible.

It is quite possible that the policies and practices of the three schools which the young people in this study attended may be better or worse than other schools in meeting the emotional needs of those with autism or Asperger syndrome. Indeed, the schools who volunteered to participate in the study could have been better organised, more open to outside agencies and also more confident in meeting the needs of young people with autism and Asperger syndrome than those who did not choose to volunteer. Hence it could be argued that the experiences of the young people in the study were more positive than for the population overall and, as a result, fewer of the young people were stressed than would be expected. To improve the validity of the study it would have been helpful therefore to gain participants from a wider range of schools but time constraints and problems recruiting schools precluded this. However, as this study does not seek to produce generalisations

regarding the population of young people with autism or Asperger syndrome in other mainstream schools and other Local Authorities, but simply to describe a situation in a local context and provide a rich picture of the experiences of those interviewed this is less of a limitation than it appears. This limitation however, needs to be remembered when drawing conclusions from the study.

One potential problem with interviewing whoever the school SENCo thought knew the child best was that the people interviewed were of very different status. As a result their responses to the interview questions had different emphases. This made comparison between them less reliable, although it did add to the richness of the study due to the different perspectives held. For example, SENCos had a broader knowledge of policies and procedures but teaching assistants were generally less concerned about presenting a positive view of the school's work and tended to mention practices or staff which had a detrimental effect on the young persons' well-being.

Finally, a further weakness of the study lies within the analysis. Categories and the data extracts that were sifted into them were not tested for inter-rater reliability as advised by many authors including Edwards and Talbot (1999) and Richards (2009). Although they were checked to ensure that data extracts were appropriately placed in each one, this was all completed by myself.

## 5.8 Conclusions

As noted above, this is a multiple case study, reporting on specific cases and therefore, the results reported and conclusions drawn cannot be said to be true of all young people with autism or Asperger syndrome and must be considered in context.

In this study, several of the young people had a positive experience of school promoting their emotional well-being and as a result were mainly or almost always, calm, relaxed and happy in school. This is in contrast to the literature in the area of autism and mental health which focuses on mental ill-health and the difficulties faced by young people who have a diagnosis of autism or Asperger syndrome in educational settings. This piece of research hints that although they are widespread, mental health difficulties for this population are not inevitable. However, when they do occur, as in the case of two of the young people in the study, these difficulties have a large impact on the young person themselves, their family, their school and their education. There appeared to be significant variations in well-being over time in many of the cases but because this was reported retrospectively, this is a very tentative finding, with further research needed.

There was reasonably good agreement between the three different roles within each case regarding the overall well-being of the young person and their emotions in school, although, in many cases, those in the three different roles reported different

manifestations of mental health difficulties. However, when taken together as a whole, the three interviews about each case did not appear to provide dramatically contradictory information about the young person concerned. Instead they tended to provide complementary information, as the manifestations reported reflected the perspective of the person being interviewed. This has implications for both further research work in this area and clinical work, as it may be that only by interviewing the young person themselves and people who know them in at least two different settings such as home and school, that a full picture of any manifestations of mental health difficulties is provided.

Within cases there was good agreement on factors that promoted and demoted mental health for the young person. Overall eight pairs of factors were identified which promoted or demoted emotional well-being across the cases. These related to ethos and attitudes to inclusion, understanding of the young person's needs, friendships, appropriate learning support, adult attention, noise levels, predictability and support for organisational skills. The identification of these eight pairs of factors supports the views of many with autism and Asperger syndrome who have focused on the importance of the environment when considering the causes and treatment of their mental health difficulties.

Finally, by identifying key areas that promoted and demoted emotional well-being across cases, this study supports the notion that an effective approach may be for

secondary schools to view themselves as 'mental health promoting settings' for young people with autism or Asperger syndrome as well as their neurotypical peers.

### 5.9.1 Implications for Practice in Mainstream Secondary Schools

Oakley (2000) notes that interpretivist research stresses the meaningfulness of research findings to the user community as well as the research community. This is an area about which I am passionate; I would like to see young people with autism and Asperger syndrome free of anxiety, to improve their enjoyment of, and achievement in, school.

The pairs of promoting or demoting factors can be used to provide a list of eight pointers for school staff to be aware of when considering how their school as a setting promotes the emotional well-being of young people with autism and Asperger syndrome. These are as follows:

1. Have a caring ethos and a positive attitude towards inclusion, with young people with autism and Asperger syndrome viewed as the responsibility of the whole school.
2.  Ensure that all staff are aware of and understand the young person's individual needs and are prepared to be flexible in order to meet them.

3. Help the young person to develop peer friendships, following a discussion between the young person, his / her parents and school staff to ensure that support benefits the young person as an individual and takes account of their opinions regarding what is most likely to help.

4. Provide appropriately targeted support that is flexible, consistent and unobtrusive.

5. Enable the young person to access a key member of staff when needed urgently if possible and for regular sessions at other times, if they wish.

6. Minimise noise and disruption within and outside lessons, and provide access to a quiet area for the young person to visit when stressed.

7. Prepare the young person for changes, however minor.

8. Provide a very high level of practical support to help the young person organise him/herself and his or her belongings, homework and clothing when changing, if required.

Due to the absence of children who do not have autism or Asperger syndrome in the study, it is not possible to determine to what extent these recommendations might apply to groups of young people without a diagnosis of autism or Asperger syndrome including those with other disabilities. At present, based on the research conducted, recommendations for practice in schools can only be made regarding young people with autism or Asperger syndrome and dissemination of the study's findings should not imply that other young people would necessarily benefit from such an approach. However, it seems plausible that many of the eight points listed

above, such as understanding the young person's individual needs and having a positive attitude towards inclusion will apply to a much wider group of young people. In contrast, other recommendations are more linked to the nature of autism itself; therefore support in areas such as reducing noise and preparation for change may be particularly relevant to young people with autism. In conclusion, although there may be many common approaches that would benefit children with disabilities generally, and many of the eight key factors may relate to these, young people with autism may also require specific support related to their areas of difference.

### 5.9.2 Implications for Educational Psychologists

Educational Psychologists could play a key role in ensuring these recommendations are adopted by schools. One approach could be to expand the eight pointers listed above into a school evaluation checklist, which may include many areas which will apply to all young people, not just those with this particular diagnosis. Educational Psychologists, or other support staff, such as those from an Autism Outreach Service, could use this with school staff to evaluate the strengths and weaknesses of their provision for young people with autism and Asperger syndrome.

The study has other implications for Educational Psychology practice. In particular it demonstrates the value of obtaining the viewpoints of young people with autism and Asperger syndrome in mainstream schools. Educational Psychologists are well

positioned to carry out this work, as they are well known to gatekeepers and adept at building rapport with young people.

In seeking the opinions of young people with autism, either for research or practice purposes, Educational Psychologists may benefit from using a number of techniques adopted in this study, such as the use of closed tasks, such as rating scales or sorting cards onto different options, followed up by more open-ended questions about their choices. Alongside this, the use of an "I don't know / I don't understand" card could be helpful to Educational Psychologists when interviewing any young person, as it reduces the pressure to produce a correct response immediately and allows the young person to ask for clarification in a simple, non-verbal, manner. Finally, a solution focused approach involving the use of rating scales, followed by questions about which factors would lead to movement up and down these scales proved an effective method of exploring the viewpoints of parents and school staff in this study, and could be used by Educational Psychologists in both practice and research.

### 5.9.3 Implications for Further Research

This study investigates a topic area which has not been well researched to date and provides a number of pointers towards possible future research.

As previously noted the picture was more positive than might be expected with only two of the young people stressed and anxious for much of the time in school. Further research could be carried out to ascertain if indeed the population of young people who have good mental health in mainstream secondary schools is as large as this study suggests. Case studies are not the best method for assessing the prevalence of phenomena and in the future survey research could be carried out. To be effective this would require careful sampling and work to avoid response bias. The checklists devised by Leyfer et al. (2006) and Helverschou et al. (2009) to assess comorbid mental health difficulties in those with autism may be more effective than the use of instruments not standardised on those with autism (see section 2.5.2) and could be of particular help in designing an effective study to consider prevalence rates.

An interesting area for further research could be the fact that parents and school staff and the young people often reported periods of extreme stress and unhappiness for the young person involving difficulties with the young person's behaviour at school and at home, interspersed by periods of relative calm. Longitudinal case study research focusing on young people's well-being over a period of several years and the presence of other factors, such as friendships, over this period would be very useful.

The link between aggression and feelings of anxiety or stress found for many of the young people in this study may also be a fruitful area for further research, as

reducing aggression in young people with autism and Asperger syndrome would have a positive impact for them and those around them and may help reduce their exclusion from mainstream schools.

Finally, research could be carried out to ascertain whether or not the eight factors that appeared to promote and demote the emotional well-being of the young people in this study have the same impact on other young people with an autism or Asperger syndrome in other secondary schools in different local authorities. At present these factors are presented tentatively, as the design of the study means that results cannot be generalised to a wider group of young people. However, with greater research evidence to support them, and refinement if necessary, they could be a useful pointer to schools working with those with autism and Asperger syndrome.

Clearly, more research is needed to support schools to become mental health promoting settings for young people with autism and Asperger syndrome but such research would be very worthwhile. The outcomes of future successful research in this area could include improved well-being for young people with autism and Asperger syndrome, leading to a reduction in stress for families, better learning outcomes in school and their increased inclusion in mainstream settings.

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# APPENDIX 1:
## EXAMPLE LETTER SENT TO HEADTEACHERS REQUESTING INVOLVEMENT IN THE STUDY

**Your ref:**

**Our ref:**

**Contact: Louise Meehan**

22<sup>nd</sup> April 2008

Mrs X
X School
XXXX
XXXX

Dear Mrs X

**The emotional well-being and mental health of young people with high-functioning autism / Asperger Syndrome**

I am writing to ask if you would agree to a small number of students, teachers and parents participating in a research project. This research is part of my work as Specialist Senior Educational Psychologist (Autism) for X County Council and contributes to my doctorate course at the University of Birmingham.

As you will be aware, schools nowadays are expected to play an increasingly important role in the emotional development of their students and promoting their mental health. Recent research has shown that people with high-functioning autism or Asperger Syndrome are particularly at risk of developing problems in these areas.

In order to investigate how schools can help promote mental health and emotional well-being in young people with high-functioning autism or Asperger Syndrome I am intending to interview a number of such young people in Key Stage 3 across various schools. I will also ask them to record a diary about their feelings over a period of a week. For each young

person who participates I will also interview a parent and key member of teaching staff (such as a form tutor or the Senco) to get a wider perspective.

The interviews will last a maximum of one hour. They will focus on any stresses or anxieties perceived by the students, or those reported on their behalf by their parents / teachers. I will also discuss with interviewees how the young person's school is supporting him or her in this area. For students who report good mental health the interviews will have a positive focus and be helpful in providing information about how schools are promoting success. The aim of the research is to gather information in this sometimes very challenging area so that good practice can be shared.

I am aware that this is a difficult topic and I would like to assure that the subject matter will be handled sensitively, both during the interviews and afterwards. When reporting the results of the study, I will take care not to provide any information which allows individual schools, children, parents or teachers to be identified. With the exception of illegal or harmful behaviour, information disclosed in the interview will remain confidential.

My plan is to carry out the interviews in the Summer Term 2008, at a time convenient to school staff. A quiet, private room will be required in school for the duration of the interviews.

Following the interviews, I will provide a short written summary of the research findings to yourself and all participants, alongside the opportunity to speak with me about the research if required.

I hope you will agree that this research is worthwhile and will allow your students and staff to participate. To confirm whether or not your school is able to participate in the study, or if you have any questions, please contact me on _____ or louise.meehan@X.gov.uk. If your school is able to participate I will then approach parents, teachers and students to seek their consent to participate in the research.


Yours sincerely


Louise Meehan
Specialist Senior Educational Psychologist (Autism)

**Your ref:**

**Our ref:**

**Contact:  Louise Meehan**

11<sup>th</sup> June 2008

Mrs XXX
XXXXXX
XXXXXX
XXXXXX

Dear Mrs X,

Thank you for agreeing to participate in my research project. I am writing to confirm our meeting on 25<sup>th</sup> June at your home, as we discussed on the telephone.

I am also writing to explain a little more about the research project. The project is part of my work as Specialist Senior Educational Psychologist (Autism) for XX County Council and contributes to my doctorate course at the University of Birmingham.

Recent research has shown that young people with high-functioning autism or Asperger Syndrome are at increased risk of emotional difficulties and stress. Schools are now expected to support the emotional development of all children but little is known about how they can help those with autism or Asperger Syndrome. My research aims to consider what schools can do to help these students.

I am planning to interview some young people in secondary schools and also for each young person, a parent and a teacher who knows them well. If the student is willing and able to do so, I will also ask them to keep a very short, structured diary for five days, in which they will record their feelings (in very simple terms) and a little what has been happening at school, good and bad. If a student is not able to complete the diary, the interview will still be very useful.

The parent and teacher interviews will last a maximum of one hour and the interviews with the young person a maximum of forty minutes. Some questions will focus on any stresses or anxieties perceived by the young person, or those reported on their behalf by their parents / teachers and how the young person's school is supporting him or her with these. For students who are settled and happy the interviews will not try to find problems or dwell on negatives but discuss what helps them enjoy and succeed in school. This is also very helpful information.

I am aware that this is a sensitive topic and that young people with autism or Asperger Syndrome may find the interviews difficult. I aim to ensure that they are not made to feel uncomfortable and their interviews will involve practical activities (for example sorting cards into categories of things that do and don't help them in school). In your interview we will talk about things that will help to put X at ease during her interview.

When I have completed all the interviews, I will provide a short written summary of the general research findings to all people who were interviewed. I will also report back to the schools involved, and hopefully, wider across X county. I will take care not to provide any information which allows individual schools, children, parents or teachers to be identified.

Information disclosed in the interview will remain confidential (unless any illegal or harmful behaviour is disclosed, which I would be obliged to report). You and X have the right to withdraw from the interview at any time if you wish to do so. Throughout the interview, you will not be obliged to answer any questions if you do not wish to do so. Obviously I will make this clear to X as well when I meet with her.

I plan to tape record the interviews to help me. I will follow appropriate procedures about this. This means that I will keep these recordings in a locked cabinet and will destroy them five years after the completion of the research.

I am interested in gathering a wide variety of views and experiences about this topic, so whatever your opinions, and X's, it will be good to hear them.

If you have any further questions, or need to rearrange our appointment for any reason, then please contact me on _____ or louise.meehan@X.gov.uk.


Yours sincerely


Louise Meehan
Specialist Senior Educational Psychologist

**APPENDIX 3:**
**LETTER DRAFTED FOR YOUNG PEOPLE REQUESTING PARTICIPATION IN THE STUDY (USED AS THE BASIS FOR DISCUSSIONS)**

Dear (insert name of young person)

Hello! I am writing to ask you if you can help me. I am carrying out some research. This is part of my job and is also for a course I am doing at the University of Birmingham.

If you agree to help me then the following will happen:

❑ I will meet with you in school.

❑ I will ask you questions about how you are doing at school. I will ask you about things in school which help you and things which don't help you.

❑ If you don't want to answer a question you do not have to. If you decide that you do not want to continue with our meeting for any reason, you can tell me.

❑ The meeting will last around 45 minutes. I will make sure that your teachers know where you are and that you are excused from your lesson.

❑ I will then ask you to fill in a short diary, each day for one week. I will show you it and explain exactly what to do when we meet.

There are no right or wrong answers to the questions that I will ask you or the questions in the diary. I want to speak to people who have many different opinions, so whatever you think about school, I would like to talk to you about it.

I will keep your answers private unless I am concerned about your safety. If I am going to talk to someone about what you have said, I will talk to you about it first.

I will tape record our conversation as this will help me with my work. My memory is not perfect! I will keep the tapes locked away when I am not using them. I will destroy the tapes after the work is finished.

I will write about what people have said once I have met with lots of students and their parents and teachers. When I am writing about what people said, I will make sure that people reading what I have written cannot tell which teacher, parent or student said those things, or even what school they go to.

I will write to tell you what I have found out about how schools help people do well and enjoy school.

If you do want to meet with me you can sign the form that your parent or carer has to say that you are happy to help me with my research.

If you have any questions about this you can ask your parent or carer or you can ask me at the start of our meeting.

Thank you for reading this letter, I hope you can help me.

With best wishes,


Louise Meehan

# APPENDIX 4:
## INTERVIEW SCHEDULE FOR PARENTS

**Interviewee Code:**

**Introduction to Interviews**
My name is Louise Meehan and I am the Specialist Senior Educational Psychologist for Autism for X County Council. As I said in my letter, these interviews are part of a project I am carrying out which contributes to my doctorate course at the University of Birmingham.

The interviews are about any stresses or worried that young people with autism or Asperger Syndrome may feel in school and how schools help them with these. If the young person is settled and happy in school the interviews will not try to find problems but instead focus on how the school his supporting him / her successfully.

This interview will last around forty five minutes to one hour. You have the right to withdraw from the interview if you wish to or to decline to answer any question that you do not wish to answer.

The interviews carried out with the young people will be different from those carried out with adults with more practical activities and I aim to ensure that they are not made to feel uncomfortable. Again he/she will be able to withdraw from the interview or refuse to answer any questions that he / she does not wish to.

I will be tape recording this interview and will follow appropriate procedures about this. This means that I will keep these recordings in a locked cabinet and will destroy them five years after the completion of the research.

With the exception of illegal or harmful behaviour, information disclosed in the interview will remain confidential.

Following the interviews, I will provide a short written summary of the general research findings to all participants, alongside the opportunity to speak with me about the research if required. I will take care not to provide any information which allows individual schools, children, parents or teachers to be identified.

There are no right or wrong answers to the questions I am going to ask. I am not looking for particular answers but genuinely interested in what different people's opinions and experiences are. Don't worry if you think that your child / school is not typical, I hoping to find a real range of situations to explore.

**Tell me a bit about _____ .**

**How old is he / she?**

**What year group is he / she in?**

**How long has he / she been at _____ school?**

**Does he/she have a diagnosis of autism or Asperger Syndrome?**

**Tell me a bit about your son / daughter that might help me interview him / her. What is s/he interested in? What kind of things will make him/ her more relaxed when I am talking to him/her? Is there anything I should avoid doing or saying?**

**Does he / she know that he / she is autistic / has Asperger Syndrome? Is he / she happy with the label or would he / she prefer it not to be used?**

**1a) Is _____ relaxed and happy in school?**

(alternative answers displayed on card)

| | |
|---|---|
| Almost never | (less than once a week) |
| occasionally | (at least once a week) |
| often | (at least once most days) |
| almost always | (most of the time during each day) |

**1b) How does _____ show that she/he is relaxed and happy?**

Prompts:
Non-verbal communication – face and body
Speech
Behaviour

**1c) What makes _____ relaxed and happy in school?**

Prompts:
Activities
People (adults, peers)
Places in the school
Sensory issues
Times of day

**2a) Is _____ often stressed or anxious in school?**

(alternative answers displayed on card)

Almost never          (less than once a week)
occasionally          (at least once a week)
often                 (at least once most days)
almost always         (most of the time during each day)

Which?

**2b) People with autism / AS often don't show their stresses or anxiety in the same way as others. How does _____ show that s/he is stressed or anxious?**

Prompts:
Non-verbal communication – face and body
Physical / physiological
Speech
Behaviour
Use cue cards if struggling.

**2c)  What makes _____ feel stressed or anxious in school?**

Prompts:
Activities
People (peers and adults)
Places in the school
Sensory issues
Times of day

**3a) Is _____ often sad in school?**

(alternative answers displayed on card)

| | |
|---|---|
| Almost never | (less than once a week) |
| occasionally | (at least once a week) |
| often | (at least once most days) |
| almost always | (most of the time during each day) |

Which?

**3b) People with autism / AS often don't show their sadness in the same way as others. How does _____ show that s/he is sad?**

Prompts:
Non-verbal communication – face and body
Physical / physiological
Speech
Behaviour
Use cue cards if struggling.

**3c) What makes ____ feel sad in school?**

Prompts:
Activities
People (peers and adults)
Places in the school
Sensory issues
Times of day

4) Pick one of the above to explore in more detail. One which seems most valid and relevant to interviewee and elicits most information.

**In an ideal world, if anything was possible, what could be done to alter one position on the scale up / down as appropriate to make _____ more relaxed and happy, or less often stressed, worried or sad? Think about things that are being done at the moment and also things that could be done in the future.**

Prompts:
What can school staff do?
What can parents do?
What can peers do?
What can the young person do?
Changes to the school environment?

5) Together look at framework for promoting mental health in schools from Atkinson and Hornby (2002) / Hornby and Atkinson (2003).

Talk through each section in turn. Fill in the ideas that the parent has.

**Are there things in each section which are helping your child at present? What are they?**

**Are there any areas which are not being covered successfully?**

**6a) Cue Cards– symptoms of stress, worry or sadness – sort onto 'yes' card if true of
___ in the last 3 months or 'no' card if not.**

Crying

Focuses on the negative in each situation

Change in special interest to morbid or dark topics

Appears to be becoming more autistic – e.g. more and more focus on high interest activities
to the exclusion of others, less and less social contact, more and more repetitive behaviours

Not motivated by activities he/she previously enjoyed

More stressed than usual when change occurs

More easily distracted than usual

School work has deteriorated

Fidgeting or pacing around more than normal

Friendship changes, not interested in 'old' friends

Decrease in levels of self-care and hygiene

Risk taking, e.g. drugs, alcohol

Much more sensitive or irritable than usual

Apathy- everything seems an effort

Talk or attempts of self-injury or suicide

Says things are hopeless

Change in eating or sleeping patterns

Unexplained stomach aches, headaches or tiredness

Often looks very pale or very flushed

**6b) Discuss the 'yes' responses. When have they occurred? In response to what event?
Tell me a bit more about what happened?**

**7a) These are some things that can make some young people in school feel stressed, worried or sad. Have any of these made _____ feel stressed, worried or sad?**

**Change in school at Year 7**

**Friendship difficulties**

**Increasing awareness that s/he is different to other people**

**Sensory sensitivities, e.g. lights, sounds or smells becoming overwhelming**

**Bullying**

**Feeling that s/he is not as good as other young people in their class / school**

**Teaching staff not understanding autism / AS or _____'s individual needs**

**_____ tending to see things only in black or white**

**Any major life events (serious accident or illness, death of a close friend or family member, family separation, new baby in the house)**

**Anything else that may have made _____ feel stressed worried or sad?**

**7b) If so, can you explain in more detail what happened? Can you give me an example? Has anything helped _____ to feel better about them?**

**8a) These are some things that can help young people with autism / AS to feel more relaxed and happy in school. Have any of these helped _____? Or do you think they might help if they haven't been tried? Or wouldn't it help at all?**

**Consistent routines in school**

**A clearly defined area for _____'s personal belongings**

**Extra help with schoolwork that _____ finds difficult**

**Visual timetables on the wall or in a planner or notebook**

**Reducing bullying**

**Work to help peers understand ____'s needs and autism / AS**

**Avoiding crowds and noise, e.g. by coming out of lessons early or eating lunch somewhere different**

**Avoiding other sensory difficulties (e.g. smells, lighting)**

**Having a quiet area that _____ can go to**

**Social skills training**

**Counselling or therapy**

**Medication**

**Helping ___ to understand autism / Asperger Syndrome**

**School staff understanding _____'s individual needs and autism/ AS**

**Anything else that has helped?**


**8b) Tell me a bit about how they have helped. Can you give me an example? Who is involved? What do they do? Why do you think it helps?**


**8c) This is nearly the end of the interview. Is there anything else you wish to tell me about ____?**

**Thank you for your time.**

**Consent form**

I am happy for my child to participate in an interview about how schools can help young people with autism or Asperger Syndrome deal with stresses and anxieties.


Signed ………..…………………………….………


Name of Parent / Carer……………………………


Name of Child…………………………...................

**Interviewee Code:** _____

**Introduction                               to                              Interviews**
My name is Louise Meehan and I am the Specialist Senior Educational Psychologist for Autism for X County Council. As I said in my letter, these interviews are part of a project I am carrying out which contributes to my doctorate course at the University of Birmingham.

The interviews are about any stresses or worried that young people with autism or Asperger Syndrome may feel in school and how schools help them with these. If the young person is settled and happy in school the interviews will not try to find problems but instead focus on how the school his supporting him / her successfully.

This interview will last around forty five minutes to one hour. You have the right to withdraw from the interview if you wish to or to decline to answer any question that you do not wish to answer.

The interviews carried out with the young people will be different from those carried out with adults with more practical activities and I aim to ensure that they are not made to feel uncomfortable. Again he/she will be able to withdraw from the interview or refuse to answer any questions that he / she does not wish to.

I will be tape recording this interview and will follow appropriate procedures about this. This means that I will keep these recordings in a locked cabinet and will destroy them five years after the completion of the research.

With the exception of illegal or harmful behaviour, information disclosed in the interview will remain confidential.

Following the interviews, I will provide a short written summary of the general research findings to all participants, alongside the opportunity to speak with me about the research if required. I will take care not to provide any information which allows individual schools, children, parents or teachers to be identified.

There are no right or wrong answers to the questions I am going to ask. I am not looking for particular answers but genuinely interested in what different people's opinions and experiences are. Don't worry if you think that your child / school is not typical, I hoping to find a real range of situations to explore.

**Tell me a bit about _____ .**

**What year group is he / she in?**

**How long has he / she been at _____ school?**

**Does he/she have a diagnosis of autism or Asperger Syndrome?**

**Tell me some more that might help me interview him / her? What is s/he interested in? What kind of things will make him/ her more relaxed when I am talking to him/her? Is there anything I should avoid doing or saying?**

**Does he / she know that he / she is autistic / has Asperger Syndrome? Is he / she happy with the label or would he / she prefer it not to be used?**

**1a) Is _____ relaxed and happy in school?**

(alternatives displayed on card)

Almost never        (less than once a week)
occasionally         (at least once a week)
often                (at least once most days)
almost always      (most of the time during each day)

**1b) How does _____ show that she/he is relaxed and happy?**

Prompts:
Non-verbal communication – face and body
Speech
Behaviour

**1c) What makes _____ relaxed and happy in school?**

Prompts:
Activities
People (adults, peers)
Places in the school
Sensory issues
Times of day

**2a) Is _____ often stressed or anxious in school?**

(alternatives displayed on card)

Almost never          (less than once a week)
occasionally          (at least once a week)
often                 (at least once most days)
almost always         (most of the time during each day)

Which?

**2b) People with autism / AS often don't show their stresses or anxiety in the same way as others. How does _____ show that s/he is stressed or anxious?**

Prompts:
Non-verbal communication – face and body
Physical / physiological
Speech
Behaviour
Use cue cards if struggling.

**2c)  What makes ____ feel stressed or anxious in school?**

Prompts:
Activities
People (peers and adults)
Places in the school
Sensory issues
Times of day

**3a) Is _____ often sad in school?**

(alternatives written on card)

| | |
|---|---|
| Almost never | (less than once a week) |
| occasionally | (at least once a week) |
| often | (at least once most days) |
| almost always | (most of the time during each day) |

Which?

**3b) People with autism / AS often don't show their sadness in the same way as others. How does _____ show that s/he is sad?**

Prompts:
Non-verbal communication – face and body
Physical / physiological
Speech
Behaviour
Use cue cards if struggling.

**3c)  What makes ____ feel sad in school?**

Prompts:
Activities
People (peers and adults)
Places in the school
Sensory issues
Times of day

**4)** Pick one of the above to explore in more detail. The one which seems most valid and relevant to interviewee and elicits most information.

**In an ideal world, if anything was possible, what could be done to alter one position on the scale up / down as appropriate to make _____ more relaxed and happy, or less often stressed, worried or sad? Think about things that are being done at the moment and also things that could be done in the future.**

Prompts:
What can school staff do?
What can parents do?
What can peers do?
What can the young person do?
Changes to the school environment?

**5)** Together look at framework for promoting mental health in schools from Atkinson and Hornby (2002) / Hornby and Atkinson (2003).

Talk through each section in turn. Fill in the ideas that the teacher has.

**Are there things in each section which are helping this child at present? What are they?**

**Are there any areas which are not being covered successfully?**

**6a) Cue Cards– symptoms of stress, worry or sadness – sort onto 'yes' card if true of ___ in the last 3 months or 'no' card if not.**

Crying

Focuses on the negative in each situation

Change in special interest to morbid or dark topics

Appears to be becoming more autistic – e.g. more and more focus on high interest activities to the exclusion of others, less and less social contact, more and more repetitive behaviours

Not motivated by activities he/she previously enjoyed

More stressed than usual when change occurs

More easily distracted than usual

School work has deteriorated

Fidgeting or pacing around more than normal

Friendship changes, not interested in 'old' friends

Decrease in levels of self-care and hygiene

Risk taking, e.g. drugs, alcohol

Much more sensitive or irritable than usual

Apathy- everything seems an effort

Talk or attempts of self-injury or suicide

Says things are hopeless

Change in eating or sleeping patterns

Unexplained stomach aches, headaches or tiredness

Often looks very pale or very flushed

**6b) Discuss the 'yes' responses. When have they occurred? In response to what event? Tell me a bit more about what happened?**

**7a) These are some things that can make some young people in school feel stressed, worried or sad. Have any of these made ____ feel stressed, worried or sad?**

**Change in school at Year 7**

**Friendship difficulties**

**Increasing awareness that s/he is different to other people**

**Sensory sensitivities, e.g. lights, sounds or smells becoming overwhelming**

**Bullying**

**Feeling that s/he is not as good as other young people in their class / school**

**Teaching staff not understanding autism / AS or ____'s individual needs**

**____ tending to see things only in black or white**

**Any major life events (serious accident or illness, death of a close friend or family member, family separation, new baby in the house)**

**Anything else that may have made ____ feel stressed worried or sad?**

**7b) If so, can you explain in more detail what happened? Can you give me an example? Has anything helped ____ to feel better about them?**

**8a) These are some things that can help young people with autism / AS to feel more relaxed and happy in school. Have any of these helped _____? Or do you think they might help if they haven't been tried? Or wouldn't it help at all**

**Consistent routines in school**

**A clearly defined area for _____'s personal belongings**

**Extra help with schoolwork that _____ finds difficult**

**Visual timetables on the wall or in a planner or notebook**

**Reducing bullying**

**Work to help peers understand _____'s needs and autism / AS**

**Avoiding crowds and noise, e.g. by coming out of lessons early or eating lunch somewhere different**

**Avoiding other sensory difficulties (e.g. smells, lighting)**

**Having a quiet area that _____ can go to**

**Social skills training**

**Counselling or therapy**

**Medication**

**Helping ___ to understand autism / Asperger Syndrome**

**School staff understanding _____'s individual needs and autism/ AS**

**Anything else that has helped?**


**8b) Tell me a bit about how they have helped. Can you give me an example? Who is involved? What do they do? Why do you think it helps?**


**8c) This is nearly the end of the interview. Is there anything else you wish to tell me about ____?**

**Thank you for your time.**

**Interviewee Code:** _____

**Introduction**             **to**             **Interviews**

My name is Louise Meehan. These interviews are part of a project I am carrying out which contributes to my course at the University of Birmingham. I also work for X County Council and visit schools as part of my work.

Thank you for agreeing to meet with me in school today. As I said in my letter, I am going to ask you some questions and we are going to do some activities.

Our meeting will take around half an hour. I have made sure that your teacher knows you are here. You will not miss any break / lunchtime. If you don't want to answer a question you do not have to, just tell me. If you decide that you do not want to continue with our meeting for any reason, you can tell me and go back to your lesson.

There are no right or wrong answers to the questions that I will ask you. I want to speak to people who have many different opinions about school, so do not worry that other people may tell me something different. I want to hear your answers as I don't know what you think about things.

Introduce the "I don't understand" card. If you do not understand the question you can point to the card or if you have something to do that you do not understand you can put it on the card – like this. Don't guess the answer or make one up if you do not understand.

I will not tell anyone else your answers. I will keep them private. However, if I am concerned about your safety, I will talk to someone about this to try to help you. If I am going to do this, I will talk to you about it first.

I will tape record our meeting as this will help me with my work (my memory if not perfect!). I will keep the tapes locked away when I am not using them. I will destroy the tapes after the work is finished.

I will write about what people have said once I have met with lots of students and their parents and teachers. When I am writing about what people said, I will make sure that people reading what I have written cannot tell which teacher, parent or student said those things, or even what school I am writing about.

**TELL ME A BIT ABOUT YOURSELF**

**What year group are you in?**


**How long have you been at this school?**



**Do you like this school?**




**What do you like doing after school or at weekends?**

**HOW DO YOU FEEL?**

**1a) How do you feel in school today**

(alternatives displayed on card with happy / sad faces to annotate descriptions)

Very stressed, sad or worried
a little stressed, sad, or worried
a little relaxed and happy
very relaxed and happy


**1b) How did you feel in school last week?**

Very stressed, sad or worried
a little stressed, sad or worried
a little relaxed and happy
very relaxed and happy


**1c) What could make you move one point up the scale or what could help to keep you 'very relaxed and happy?** (for those at the top of the scale)  **In an ideal world, if you could wave a magic wand and change anything about school – the building, the people, what would you like to change to help you move up the scale?**

## DEALING WITH FEELINGS

**2a)** Complete chart with the young person, or if they prefer, allow them to do it independently.

| Feeling | Most days in the last few weeks | At least once in the last month | Not in the last month or never | I don't know / don't understand |
|---|---|---|---|---|
| I felt happy | | | | |
| I didn't feel like eating any food all day | | | | |
| I felt panicky | | | | |
| I couldn't concentrate on something that I used to be able to concentrate on | | | | |
| My heart was racing | | | | |
| I became very upset when there was a change I wasn't expecting | | | | |
| I couldn't stop thinking about something bad that had happened in school or something bad that might happen | | | | |
| I slept very well | | | | |
| I felt things were hopeless | | | | |
| I was successful in what I was asked to do | | | | |
| I felt like hurting other people | | | | |
| Everything seemed too much effort | | | | |
| I deliberately hurt myself | | | | |
| I enjoyed myself at school | | | | |
| I had a bad tummy ache or headache | | | | |
| I disliked myself | | | | |

**2b)** Investigate those feelings which are most commonly experienced by that young person.




**Tell me a bit more about a time when this has happened? What time of day? What did you do? How did your face / body show your feelings? Had anything made you feel this way?**

**THINGS THAT HELP YOU IN SCHOOL**

**3a) What helps you feel relaxed and happy in school or what helps you feel less stressed, worried or sad in school?**

Explain that what helps one person in school, another person might find really unhelpful, or even annoying. Or what parents and teachers think are helpful may not be what students really want. So I want to know your opinion. Series of cards to sort –

**Knowing exactly where everything is in school**

**Having labels on rooms and cupboards**

**Having a safe space to put your own things**

**Help to make friends or deal with difficult social situations**

**Having a timetable, planner or notebook**

**When it is quiet**

**Staff in school dealing with bullying**

**Extra help with schoolwork that you find particularly difficult**

**Someone teaching you how to calm yourself down when you are stressed**

**Having a quiet area to go to when you need to**

**Help to avoid crowded or noisy places, e.g. coming out of lessons early to avoid busy corridors, eating lunch somewhere different**

**Knowing exactly what is going to happen each day in school and being warned of any changes**

**Help to avoid annoying lights, sounds or smells**

**Talking individually to a member of staff each day or each week about things that are important to you**

**Taking medication**

**School staff (teachers and other adults) understanding what helps you to do well in school**

One large sheet of paper which says "helps me feel good" with a smiley face, "might help me but isn't happening at the moment", "doesn't help me" and also the "I don't understand' card. Young people to place on the "helps me feel good" paper the cards which describes things that help them personally.

**3b) What else makes you feel relaxed and happy in school?**
**What else makes you feel less stressed, worried or sad in school?**

Blank cards for young person to fill in themselves (drawing or writing) and then place on the 'helps me' paper.

**3c) Consider some of the items that the young person says has helped them and investigate these in more detail. Tell me more about this. Can you give me an example of when this happened? How did it help? What did you do? What did other people do?**

**THINGS THAT CAN MAKE SCHOOL MORE DIFFICULT FOR YOU**

**4a) These are some things that can make people feel stressed, worried or sad. Which, if any, make you feel stressed, worried or sad in school?**

Explain that what makes one person feel very bad, may not bother someone else. So I want to know what bothers them in school. Series of cards to sort –

**Moving schools**

**Having to meet new people (students and teachers) at secondary school**

**Problems with lighting, noises or smells that you really can't stand**

**Finding it difficult to make or keep friends**

**Feeling different from other people**

**Being bullied or being afraid of bullies**

**Feeling that you can't solve the problems you need to in school**

**Feeling that you are not as good as others in your class**

**Teachers or other adults in school not understanding what helps you**

**A big change outside school (for example, being in an accident, being ill in hospital, someone in my family dying or being very ill, parents splitting up, new baby in the house, new step-parent / siblings).**

One large sheet of paper which says "makes me feel stressed, worried or sad" with a sad face and another one which says "doesn't bother me" and a third which says "hasn't happened to me recently" and also the "I don't understand" card. Young people to place on the "makes me feel stressed, worried or sad" card the cards which describe things that make them feel bad in school at the moment.

**4b) What else makes you feel stressed, worried or sad in school?**

**4c) Consider one or more of the items that the young person says stresses them in school and explore in more detail. Tell me more about this? When has it happened to you? What did you do? What did other people do?**

**Thank you for coming to this interview and answering my questions. Do you have anything else you want to tell me about?**

# APPENDIX 7:
## EVIDENCE FOR EACH RESEARCH QUESTION PROVIDED BY THE INTERVIEW SCHEDULES

i) Which emotions do young people with autism or Asperger syndrome commonly feel in school?

ii) Do young people with autism and Asperger syndrome show any manifestations of mental health difficulties in school or home contexts?

iii) How do the young people concerned, their parents and school staff, differ in their perceptions regarding the young people's mental health?

iv) What factors lead to stress and mental health demotion for young people with autism and Asperger syndrome and are any of these affected by the school environment?

v) What are mainstream secondary schools doing that successfully promotes the mental health of this group of young people?

vi) How do the young people themselves, their parents and school staff differ in their views and perceptions regarding which school based factors promote and demote the young people's mental health?

The table below indicates the question numbers within each interview that tackle the research questions.

| Research Question | Parent Interview | Teacher Interview | Young Person Interview |
|---|---|---|---|
| i | 1a 2a 3a 6a | 1a 2a 3a 6a | 1a 1b 2a |
| ii | 2b 3b 6a 6b | 2b 3b 6a 6b | 2a 2b |
| iii | 1a 1b 2a 2b 3a 3b 6a 6b | 1a 1b 2a 2b 3a 3b 6a 6b | 1a 1b 2a 2b |
| iv | 2c 3c 5 6b 7a 7b | 2c 3c 5 6b 7a 7b | 4a 4b 4c |
| v | 1c 4 5 8a 8b | 1c 4 5 8a 8b | 1c 3a 3b 3c |
| vi | 1c 2c 3c 4 5 6b 7a 7b 8a 8b | 1c 2c 3c 4 5 6b 7a 7b 8a 8b | 1c 3a 3b 3c 4a 4b 4c |

**Code 1 - Not wanting to be seen as different**

**Code 2 - Having Friends or A friend / group of friends helping the young person to settle in school**

**Code 3 - Feeling relaxed and happy**

**Code 4 - Feeling stressed and anxious**

**Code 5 - Feeling sad**

**Code 6 - Not showing problems on face or through body language**

**Code 7 - Would like social skills group or support to make friends**

**Code 8 - Don't want / need social skills group or support to make friends**

**Code 9 - Aggression and anger towards others**

**Code 10 - Misbehaviour of other students in lessons**

**Code 11 - Individual teachers not understanding autism**

**Code 12 - Teachers in the school understanding autism (on the whole)**

**Code 13 - Caring Ethos**

**Code 14 - Negative attitudes towards inclusion**

**Code 15 - Positive attitudes towards inclusion**

**Code 16 - Not sure whether diagnosis is accurate**

**Code 17 - Not all staff know about diagnosis**

**Code 18 - Staff are not sure whether young person knows about the diagnosis / labelling issues generally**

**Code 19 - Teachers need mandatory training**

**Code 20 - Bright children with Asperger's or Autism not understood**

**Code 21 - Communication within school**

**Code 22 - Poor communication with home**

**Code 23 - Good communication with home**

**Code 24 - Noise outside lessons**

**Code 25 - Teachers shouting**

**Code 26 - Queues at lunchtime**

**Code 27 - Benefit of special arrangements for Year 7**

**Code 28 - Tests / Exam Stress / Grades and Deadlines**

**Code 29- Setting**

**Code 30 - Organisational Skills requiring support**

**Code 31 - Writing skills requiring support / dyspraxia additional needs**

**Code 32 - Time in the past when things were much worse**

**Code 33- Likes consistency / predictability / structure**

**Code 34 - School making changes to fit around the child's needs or wishes**

**Code 35 - Leap from Year 7 to Year 8**

**Code 36 - Parents don't feel that they know what is going on in school**

**Code 37 - Nothing seems to stress him / her out in school**

**Code 38 - Others worry about young person's difficulties but they are unaware**

**Code 39 - Not understanding / recording / remembering what to do for homework**

**Code 40 - Talking with young person about the diagnosis**

**Code 41 - Named teacher who understands / cares for / talks to the child or a desire for this**

**Code 42 - Transition arrangements that helped**

**Code 43 - Calm environment within school**

**Code 44 - Extra Help with Learning (learning difficulties / academic)**

**Code 45 - School not noticing if there are problems and parents drawing attention to it**

**Code 46 - School are supporting the young person socially**

**Code 47 - Avoiding crowds and noise / quiet area to go to**

**Code 48 - Letting out aggression on the return home from school**

**Code 49 - Being teased or bullied by peers**

**Code 50 - Homework**

**Code 51 - Finding certain subjects boring**

**Code 51 - Fear of the transition to secondary school being worse than the reality**

**Code 52 - Problems with getting changed for PE**

**Code 53 - Work with peers to help them understand autism**

**Code 54 - Staff dealing with bullying**

**Code 55 - Anger / Stress Management**

**Code 56 - Moving between lessons / size of the school**

**Code 57 - Having a space to put your things**

**Code 58 - Low self-esteem / School raising self-esteem**

**Code 59 - Likes to work on own**

**Code 60 - Not getting the support he needs / specified on statement of SEN / consistent support**

**Code 61 - Dispute about whether behaviour is 'naughty' or underneath related to autism**

**Code 62 - Not understanding what being asked to do (sometimes leading to poor behaviour)**

**Code 63 - Sensory Sensitivities - lights, sounds, smells**

**Code 64 - Problems with transition at year 7**

**Code 65 - Behaviour Policies or Practice Not Appropriate for ASC pupils**

**Code 66 - Curriculum**

**Code 67- Friendship difficulties**

**Code 68 - Being in a group with just special needs children doesn't help**

**Code 69 - It's not fair!  and black and white thinking.**

**Code 70 - Doesn't want to be told what to do**

**Code 71 - Support with Homework / Homework Club**

**Code 72 -  Different Subjects**

**Code 73 - Deteriorating Schoolwork / Attitude to Schoolwork / Concentration on Schoolwork**

**Code 74 - Fostering Independence**

**Code 75 - Apathy**

**Code 76 - Can't see the point**

**Code 77 - School start to do something and then it tails off**

**Code 78 - Having a sibling with autism / other stresses outside school**

**Code 79 - Day going up and down**

**Code 80 – Dwelling on things  / retreating into thoughts / can't sleep**

**Code 81 – Further discussion of symptoms of mental health difficulties not already covered**

**Code 82  - Self- Harm**

**Code 83 – Appears to be becoming more autistic**

**Misc / Comments on the process**

**Code 67- Friendship difficulties**

**Parent**
**XX** friend has called her this 13, 0m30, talks not about those that are bullying her but about those who she is trying to make friends with. ends up looking for a girl all lunchtime and not finding her, spending lunchtime and playtime on her own. 13, 1m30.

Not friends with any of the children in her form, class 4m20.Friend she thought she had was taking advantage of her, using E's dinner money to pay for her dinners 9,40 check through print outs from school – 2 main courses etc. interactions with other young people mainly 10m20

Friendship difficulties.

Finding something to do if on your own at breaktime 37m

if friends with parents – you can't force the other child to be friends with E 22m15

**XX** Friendship difficulties a big issue 14m

**XX**  Because he is in his special needs group there is other children. incident with another boy with AS who has been a problem 11m40 sometimes if people wind him up the wrong way he can lash out at them really.

Problems with friendships 4230

**XX** Some things have proved more difficult, like understanding team games has always been a challenge for him 7m50 working out what other people are going to do and working with other people's agendas has always been difficult. 8m15

**XX** he doesn't really have any friends as such but he does hang round with a couple of boys that are really good for him at the moment. 2m10 R doesn't make friends like everybody else.

Friendship difficulties – gets anxious because he doesn't have any. 16m20

**XX** Year 5,6,7 were probably the worst [for friendship] 8m

**XX** Particular people, he has trouble, I wouldn't' say he has any friends in school. He never really has had, he has at best acquaintances, and a lot of them from what I can gather tend to be children like himself. They tend to sort of cling, be attracted to one another I think. Children with some special needs. And of course have their own needs and they have their own often volatile personalities so if one goes off, they can spark against each other sometimes. So sometimes he can get on quite well with some of the people and other times they will spark him off. 12m

Social skills - It seems to be throw him in with the tutor group but they have to and this comes back to teaching peers about aspergers, they have to meet him far more than halfway and they don't. I've said it to his year head because b wanted to change tutor groups, you know form groups and me and the year head were of the opinion that the grass is always greener and he wouldn't be any better in another one. they've got to talk to him and nobody will talk to him,

He also feels, they have to talk in groups and he's not included . he tries conversation and says oh they talk about sport and I hate football and we don't' have sky telly so I can't talk about so and so and so and so. he said they don't include him so  He would rather go up on a 1-1 basis to talk to a member of learning support staff, but it's not encouraged. 49m

He's desperate for friendships, but he hasn't got the skills to create friendships. 15m30 if he's upset it' usually to do with friends 16m

friendship difficulties – yes 39m

**XX** Friendship difficulties I think they do worry him but he doesn't really say too much about it 17m20

I don't know whether he feels that he's got the friendships that he needs and he doesn't' want to take them any further or he feels that he would like to take them further but he just hasn't go the confidence I'm not completely clear on that 18m

He says that he likes his friends, but I do think his friendship groups are limited but that's my perception  and the depth of his friendships are limited but he's happy with it1m45 and 2m05

I would like H to have more friends and I'm sure that there are kids in the same position, you know that have got the same disability and find it very hard to communicate, it would have been nice if I could have linked up with some of their parents maybe and … because H wont' organise any out of school activities for himself . maybe if there'd been some link where I could have contacted some parents. maybe linking up with other parents who have children with similar problems 12m30

**XX** I don't think he's got as a social network of friends as he could have or I'd like him to 13m30

Mentions a couple of other children 4m has got into arguments with them 16m

**Teacher**

**XX** Re peers – obviously we have tried but you can't force people to be friends with somebody that they don't understand or relate to , I think that's going to be an ongoing problem10m45

Friendship difficulties 23m15, making and maintaining

Arguments with peers 24m40

Understanding why people she has been friends with have fallen out with her 19m0

Why don't people like me? 21m20

Apathetic – there's nothing I can do, when talking to staff about friendship issues21m20 Its how she sees herself 22m15, for someone who has AS she is quite self aware – leads to depression type symptoms

usually do with peers friendships, no one walks to school with her.

Activities around break and lunchtimes, difficult to find other people who are willing to do that.

peer pressure  (causes stress) 5m35

**XX** Another student who winds him up 6m we tell him to ignore him but he just

cannot ignore him.
Move certain pupils out of his way 11m15.
Friendship difficulties, - one minute they're best friends, the next minute they're enemies 27,20 he always has at least one friend in the group.
Falls out with people but it doesn't seem to bother him. 28,30
**XX** He wasn't' very sociable in year 7 22m
In year 7 it probably did but now he seems to be very happy with his friendship groups. 22m30
**XX** Relationships is his problem as you'd expect.  15m
Friendship difficulties 23m
Falling out with people he's got one or two specific friends and if they fall out with each other that stresses him out. 6m
Probably his best friend is also Aspergers. She has different social issues from him, so it's quite easy for them to fall out 8m20
He does like to be in control he's quite bossy. He likes to be in charge of something and if somebody else challenges that then there could be an argument 8m30.
**XX** In the PE department I did go along and ensure he had a space for his things 32.30 he gets bothered by certain people so he needs to be in a spot. The first couple of times after I set it up I did check and it was working ok.
If he takes a dislike to a child they've had it….. he cannot abide the poor lad and the minute he's with him there's problems . if he's with somebody he really can't cope with it bothers him so therefore he wont' get anything done 6m10
He can't see that he's the person that's causing the problem, because if he can't stand somebody he'll call names at them and create a noise. he can't seem to be quiet and you know leave them alone, and if the teacher told that child off he'd be like 'yeah' which would wind them up even more… it sort of escalates 8m
He had a problem with bullying and he still now doesn't realise that what he's saying can upset somebody. 14m30 he will think that he's the one that's being victimised.

**Young Person**
**XX** Feeling that you can't solve all the problems you need to in school 12m50 I'm stuck between (names 3 friends) each one of them hates each other and they all want to be my friend.
I had a friend now she isn't my friend that's a change and now I'm upset20m30
Finding it difficult to make or keep friends 12m05 Would like help to make friends.
Want to have more friends,
**XX** some people didn't like me at first, nobody liked me, at least I've got some friends now.
Finding it difficult to make friends or keep friends 23m
**XX** Finding it difficult to make or keep friends doesn't bother me but it has happened 10m
**XX** It took me a while to fit in 17m
**XX** I'd change the kids I'd change all the kids about so they're a bit more friendly to you 5,15 I'd change them to friendly kids 6m

Talking to me everyone just decides to skiddoodle and won't talk to me, they just leg it  6m30

Finding it difficult to make or keep friends – yeah that really is annoying – I can't ever keep friends for some reason they all leg it. 27m40 it's as if I'm like a bomb that's about to go off, they stay with me for a while and then they all like, after about a day or so they go right I'm off neeeow, out the door. I used to have friends at primary school. I had a lot in Year 6. 28m

I've got friends. All my friends are kind of like me, kind of got problems. I've got a friend called D who's he's got severe learning difficulties and he's always like really loud and noisy and stuff it's not his fault but …I don't mind being friends with him, easier, but the thing is, it makes me unpopular with all the others because I don't actually bully him . everyone else just laughs and bullies him. I got to admit I've laughed and bullied him along with my mates before or along with a friend before. But then after I realised what we were actually laughing about I decided that I wasn't going to bother. And the other friend I was with has decided to skidoodle because she's not happy that I actually stopped it. She always wants to laugh at D 28m10

Harder to make or keep friends in secondary school. I've got quite a few in train club. This club that Mr X (headteacher) organised where you can go and play with model railways, but it's turned into a bit of a funny club now it's turned into a bit of a fun club. 29m

The thing is with my form I just don't like my form at all. We're all like, in the mornings like, I come in and I sit down ready for registration, he says everyone go off and chat, so everyone goes off for a chat, if I try and join in they say, oh sorry, do you mind just going over there? Sorry, no you can' t come and join us, no it's none of your business, go away…. I just feel like saying to the teacher right I'm off see you later and going upstairs to the library. I never do that because he won't let me 40,30 Stressed about it.

All weekend people had been sending me weird messages on my MSN for example, 'hi I'm a banana'. So I sent back 'hi I'm not a banana'
35m50

I've just chosen to leave it… Because it's quite funny when everyone writes to you. It means that I'm a bit more socially social and can talk to people over the internet. 36m30 I just sort them out nonsense messages as well. I just send them back something friendly.

Other lessons that stress me out. Like, in science my friend, ….. basically she just wound me up so much that I just went bang. She just decided to wander off and now she's having a right go at me, today she's having a good go at me, just because I was miles behind everyone else because my writing's so slow. I think I would rather have my writing neat than having it big and scrawly and not being able to read it, she was having a go at me for not being able to catch up. 38m30

I felt like just grabbing her and throwing her out of the room and locking the door. 'so you did get quite angry?' yeah but I don't. at times I just I never would actually throw anyone out the door. The thing is I felt  like just standing up about that thing and

saying to them, look, if you've got a problem take it to someone else, take it to Ms C (senco) or something. 39m

It was an issue with everyone just leaving me alone, everyone just deserting me. It was about two or months or so ago  34m30

The form tutor he was another thing stressing me out yesterday. He wont' let me come up to the library to let me go on the computer… make me go down to registration. I hate it because if no one talks to you there's no point in actually going other than to register and disappear. 'and you'd rather be in the library?' yeah some mornings 8,45

**XX** Finding it difficult to make or keep friends hasn't happened 14m10

**XX** I felt like hurting other people – once – if they annoy me, other students, like, they keep on winding me up and grassing me on for whatever I do? 26m all the time they try and dob me in for whatever I do. If I'm like on the computers they try and get me into trouble. 27m

(N.B. In each instance the initials of the young person in the case were used to identify and cross reference across roles but for the purposes of anonymity these have been removed and placed with 'XX'. It should also be noted that other topic areas related to friendship difficulties were placed in other codes relating to social skills training, bullying and so on).

**APPENDIX 10:**
**EXAMPLE OF TABLE CREATED DURING DATA ANALYSIS –**
**COMPARSON BETWEEN PARENT AND TEACHER RATINGS OF FEELINGS**
**ACROSS EACH CASE**

This table considers the similarities and differences in ratings given by parents and teachers regarding how often the young person had different feelings in school, across each case. These results are discussed in section 4.6.

On a small number of occasions, parents did not feel they knew the situation well enough to complete the question.

| Case | How often feeling relaxed and happy? | How often feeling stressed and anxious? | How often feeling sad? |
|------|---------------------------------------|------------------------------------------|-------------------------|
| 1 | Same rating | Same rating | One rating away |
| 2 | Same rating | Same rating | Same rating |
| 3 | One rating away | Same rating | Same rating |
| 4 | Same rating | Same rating | Same rating |
| 5 | One rating away | Same rating | Same rating |
| 6 | Question not completed | Question not completed | Question not completed |
| 7 | Opposite ends of scale | Two ratings away | One rating away |
| 8 | One rating away | One rating away | One rating away |
| 9 | One rating away | One rating away | Question not completed |
| 10 | Same rating | One rating away | Same rating |
| 11 | One rating away | One rating away | Question not completed |
| **Totals** | 4 pairs gave same rating, 5 one rating away, 1 opposite ends of scale | 5 pairs gave same rating, 4 gave one rating way, 1 gave two away | 5 gave the same rating, 3 gave one rating away |

**APPENDIX 11:**
**EXAMPLE OF TABLE CREATED DURING DATA ANALYSIS-**
**FEATURES THAT YOUNG PEOPLE REPORT HELP OR MIGHT HELP THEM**
**FEEL GOOD IN SCHOOL**

This table was created from the results of the sorting task in Question 3 of the interviews with the young people (see Appendix 6 for the interview schedule). These figures were considered alongside the other data gained in the interviews and are reported and discussed in sections 4.7 and 5.5.

| | No. of young people who indicated that this helped them feel good in school | No. of young people who indicated that this might help them but was not happening |
|---|---|---|
| Having a timetable in a planner or notebook | 10 | 0 |
| Knowing exactly what is going to happen each day in school and being warned of any changes | 9 | 1 |
| Knowing exactly where everything is in school | 9 | 0 |
| Having labels on rooms or cupboards | 8 | 0 |
| School staff understanding what helps you do well in school | 7 | 2 |
| When it is quiet | 7 | 1 |
| Extra help with schoolwork that you find particularly difficult | 7 | 1 |
| Having a safe space to put your own things | 6 | 3 |
| Someone teaching you to calm yourself down when you are stressed | 5 | 2 |
| Having a quiet area to go to when you need to | 5 | 2 |
| Talking individually to a member of staff each day or each week about things that are important to you | 4 | 3 |
| Help to avoid annoying lights, sounds or smells | 4 | 1 |
| Help to make friends or deal with difficult social situations | 3 | 3 |
| Staff in school dealing with bullying | 3 | 0 |
| Help to avoid crowded or noisy places, e.g. by coming out of lessons early or eating lunch somewhere different | 1 | 2 |
| Counselling | 0 | 0 |
| Medication | 0 | 0 |

**APPENDIX 12:**
**EXAMPLE OF TABLE THAT WAS CREATED DURING DATA ANALYSIS-FEATURES THAT PARENTS AND SCHOOL STAFF REPORT HELP THE YOUNG PERSON FEEL RELAXED AND HAPPY IN SCHOOL**

This table was created from the results of the sorting task in Question 8 of the interviews with the parents and school staff (see Appendices 4 and 5 for the interview schedules). These figures were considered alongside the other data gained in the interviews and are reported and discussed in sections 4.7 and 5.5.

| Things that do or might help the young person feel more relaxed and happy in school | Number of parents who thought this would help | Number of school staff who thought this would help |
|---|---|---|
| Having consistent routines in school | 11 | 9 |
| School staff understanding the young person's individual needs and autism / Asperger Syndrome | 11 | 10 |
| Having a timetable in a planner or notebook | 11 | 10 |
| Having a quiet area that the young person can go to | 10 | 6 |
| Extra help with schoolwork that the young person finds difficult | 9 | 9 |
| Social Skills Training | 8 | 5 |
| Work to help peers understand the young person's individual needs and autism / Asperger Syndrome | 5 | 1 |
| Avoiding crowds and noise, e.g. by coming out of lessons early or eating lunch somewhere different | 4 | 2 |
| Avoiding other sensory difficulties (e.g. smells, lighting) | 1 | 2 |
| Helping the young person to understand autism / Asperger Syndrome | 1 | 2 |
| Reducing bullying | 4 | 1 |
| Having a clearly defined area for the young person's belongings | 1 | 4 |
| Counselling or therapy | 1 | 1 |
| Medication | 0 | 0 |

**APPENDIX 13-**
**EXAMPLE OF TABLE THAT WAS CREATED DURING DATA ANALYSIS**
**COMPARISON ACROSS ROLES WITHIN A CASE REGARDING STRATEGIES**
**THAT MAKE THE YOUNG PERSON FEEL RELAXED AND HAPPY**

This table displays the number of strategies that parents, school staff and young people rated as helpful or might help, in answer to question 8 in the interviews with parents and school staff (see Appendices 4 and 5) and question 4 in the young people's interviews (see Appendix 6). It also compares the number of strategies within each case that two or more participants agreed on. So for example in case 1, there were six strategies mentioned by all three participants as helpful to the young person. The final row presents the mean figures across the cases which have been been rounded up or down to the nearest 0.5 as appropriate. It should be noted that the young people were asked about a slightly different list of strategies so this affects comparison of results. These results are discussed in sections 4.8.2 and 5.6.

| Young person | Parent – no. of helpful strategies | School staff – no. of helpful strategies | Young person (YP) – no. of helpful strategies | YP – no. of strategies that might help but not happening | Parent – school staff matches | Young person – parent matches | School staff - young person matches | No. of 3 – way matches |
|---|---|---|---|---|---|---|---|---|
| 1 | 10 | 10 | 8 | 5 | 7 | 7 | 9 | 6 |
| 2 | 6 | 4 | 7 | 2 | 4 | 4 | 4 | 4 |
| 3 | 8 | 3 | 9 | 2 | 3 | 6 | 3 | 3 |
| 4 | 7 | 8 | 10 | 1 | 7 | 5 | 6 | 5 |
| 5 | 9 | 5 | 6 | 4 | 5 | 5 | 4 | 4 |
| 6 | 9 | 5 | 6 | 2 | 5 | 6 | 4 | 4 |
| 7 | 7 | 7 | 9 | 1 | 6 | 5 | 4 | 4 |
| 8 | 5 | 5 | 4 | 0 | 4 | 2 | 2 | 2 |
| 9 | 9 | 10 | 12 | 1 | 6 | 7 | 7 | 5 |
| 10 | 6 | 4 | 8 | 2 | 4 | 4 | 4 | 4 |
| 11 | 4 | 5 | 10 | 1 | 3 | 4 | 5 | 4 |
| Mean | 7.5 | 6 | 8 | 2 | 5 | 5 | 5 | 4 |

## APPENDIX 14 -
## SCHOOL CHARACTERISTICS

| School Characteristics | School I | School II | School III |
|---|---|---|---|
| **Number on roll** | 1833 | 1332 | 1704 |
| **Age range** | 11-18 years | 11-18years | 11-18years |
| **Description** | Comprehensive Mixed CE (Aided) | Comprehensive Mixed Community | Comprehensive Mixed Community |
| **Catchment** | Urban and rural | Urban and rural | Urban and rural |
| **% Free School Meals (Nat. average 14%)** | 1% | 6% | 4% |
| **% English not first language (Nat. average 11%)** | 1% | 5% | 7% |
| **Ofsted Category** | Outstanding | Satisfactory | Good |