

This is a repository copy of *Mental health difficulties among young people on the autistic spectrum in mainstream secondary schools: A comparative study.*

White Rose Research Online URL for this paper: http://eprints.whiterose.ac.uk/119967/

Version: Accepted Version

Article:

Hebron, J and Humphrey, N (2014) Mental health difficulties among young people on the autistic spectrum in mainstream secondary schools: A comparative study. Journal of Research in Special Educational Needs, 14 (1). pp. 22-32. ISSN 1471-3802

https://doi.org/10.1111/j.1471-3802.2012.01246.x

Reuse

Items deposited in White Rose Research Online are protected by copyright, with all rights reserved unless indicated otherwise. They may be downloaded and/or printed for private study, or other acts as permitted by national copyright laws. The publisher or other rights holders may allow further reproduction and re-use of the full text version. This is indicated by the licence information on the White Rose Research Online record for the item.

Takedown

If you consider content in White Rose Research Online to be in breach of UK law, please notify us by emailing eprints@whiterose.ac.uk including the URL of the record and the reason for the withdrawal request.



Mental health difficulties among young people on the autistic spectrum in mainstream secondary schools: a comparative study

Judith Hebron & Neil Humphrey

Educational Support and Inclusion School of Education University of Manchester Oxford Road Manchester M13 9PL

Tel: 0161 275 3404

Email: neil.humphrey@manchester.ac.uk

Mental health difficulties among young people on the autistic spectrum in mainstream secondary schools: a comparative study

Abstract

Young people on the autistic spectrum (AS) may be at an increased risk of developing mental health difficulties, but to date research evidence has been equivocal and/or inadequate. The aim of the current study was to document the mental health profiles of adolescents on the AS, and to identify factors that contribute to difficulties in this area. Mental health profiles of a group of adolescents on the AS (N=22) were compared to age, gender and SENprovision-matched control groups of adolescents with dyslexia (N=21) and with no special educational needs (N=23) using the Beck Youth Inventories. Additionally, five participants on the AS participated in semi-structured interviews about their experience of school. Quantitative analysis demonstrated that adolescents on the AS experienced significantly greater anxiety, depression, anger and lower self-concept than those with no special educational needs. They also experienced significantly greater anxiety and anger than those with dyslexia. Qualitative analysis revealed that problems in social relationships, understanding the nature of the AS, and disruptions to routine were common contributory factors to the mental health difficulties of participants. However, interview data also revealed key coping strategies implemented by participants to help them overcome their difficulties. The implications of these findings are discussed, and methodological limitations are noted.

Keywords: mental health, autism, Asperger syndrome, inclusive education,

secondary school

Introduction

Recent research has pointed to a substantial increase in adolescent mental health problems in the last 30 years (Collishaw, Goodman,& Pickles, 2004). Current estimates suggest that 11.5% of 11-16 year olds have clinically recognisable mental health difficulties (compared to 7.7% of 5-10 year olds) (Green,McGinnity, Meltzer, Ford, & Goodman, 2005). The longer term consequences of such difficulties can include an increased risk of leaving school without qualifications (Colman et al., 2009), unemployment (Healey, Knapp, & Farrington, 2004), family and relationship problems (Colman et al., 2009), mental health problems in adulthood (Hofstra, Van Der Ende, & Verhulst, 2002) and increased financial costs to society (Scott, Knapp, Henderson, & Maughan, 2001).

Several risk factors for adolescent mental health problems have already been established. Youth who are from poorer backgrounds, black and ethnic minority groups, experiencing familial discord (Green et al., 2005), whose parents have mental health problems (British Medical Association, 2006) and/or are in the care of the state (Meltzer, Corbin, Gatward, Goodman, & Ford, 2003) are all more likely to experience difficulties. Being identified as having special educational needs can also put young people at increased risk (Rose, Howley, Fergusson, & Jament, 2009; Office for National Statistics, 2008). For example, Green et al.'s (2005) survey indicated that being identified as having SEN doubled the likelihood of experiencing emotional disorders in children and young people. In particular, it has been suggested

that individuals on the autistic spectrum (AS) may be the most vulnerable group in this regard (Ghaziuddin, Weidmer-Mikhail, & Ghaziuddin, 1998), with up to 30% reported to experience clinically recognisable disorders (Green et al., 2005). However, as outlined in the following section, research to date in this area has been equivocal and/or methodologically flawed.

Mental health of children and young people on the AS

Children and young people on the AS experience difficulties in social and emotional understanding, language and communication, and imagination/flexibility of thought (Frith, 2003). Concerns around their mental health have been reported for a number of years (e.g. Baron-Cohen, 1989; Tantam, 1991), but it is only in the last decade or so that systematic research examining incidence,prevalence rates and etiological factors have begun to emerge. Before reviewing and discussing this evidence, it is important to first briefly establish *why* children and young people on the AS may be more likely to experience mental health problems than others.

The nature of the AS may promote endogenous factors that lead to an increased risk of mental health difficulties. The difficulties individuals on the AS experience affect the way they process, experience, and ultimately make sense of the world around them, and each may feasibly contribute to mental health difficulties. Taking, for example, difficulties with social and emotional understanding, the well-established problems individuals on the AS experience in relation to adopting the perspective of others ('theory of mind'

or 'mentalising') (Baron-Cohen, 2005) have been linked to maladaptive social attribution processes (for example, the tendency to infer hostile intention from the behaviour of others), which in turn have been associated with internalising symptoms (e.g. anxiety, depression) (Meyer, Mundy, Vaughan Van Hecke, & Durocher, 2006). Similarly, the desire for routine, predictability and 'sameness' caused by difficulties in understanding what is happening in the environment can mean that changes and disruptions to routine – which are inevitable in an unpredictable world – can trigger increased anxiety (Gillott, Furniss, & Walter, 2001). Finally, the sense of 'difference' experienced in particular by those with high-functioning autism or Asperger syndrome may trigger emotional distress (Bolman, 2008; Portway & Johnson, 2003).

However, there are also exogenous factors that may lead to an increased risk of mental health difficulties among children and young people on the AS, particularly in relation to the school environment. In particular, peers are more likely to reject and bully them, and they report receiving less social support from classmates, friends and parents than do other children (Humphrey & Symes, 2010; Symes & Humphrey, 2010). This victimisation is proposed to stem from a lack of awareness and understanding among peers; without an appropriate explanation for their behaviour, other children may simply view those on the AS as 'odd', 'strange' or 'weird', and therefore prime candidates for bullying and teasing (Humphrey and Symes, 2011). Furthermore, teachers report tensions when dealing with the difficulties in social and emotional understanding associated with AS. These tensions can determine the quality of teacher-student interactions (Emam and Farrell,

2009), and teachers are less likely to report having positive relationships with those on the AS as a result (Robertson, Chamberlain, & Kasari, 2003).

Research in this area has tended to demonstrate high levels of mental health difficulties among children and young people on the AS. As previously noted, Green et al.'s (2005) survey indicated that up to 30% have a clinically recognisable disorder. In terms of anxiety, prevalence estimates vary wildly. For example, White, Oswald, Ollendick and Scahill's (2009) recent review of research suggested figures ranging from 11% to 84%. It is also of note that anxiety appears to increase during adolescence in AS, with the opposite trend in typically developing teenagers (Kuusikko et al., 2008). In relation to depression, reported prevalence rates are again varied – whilst Ghaziuddin, Weidmer-Mikhail and Ghaziuddin (1998) reported rates of up to 30% in those on the AS, Kim, Szatmari, Bryson, Streiner and Wilson (2000) reported just under 17%; in all cases though, rates are typically significantly higher than in analogue samples.

Although less common, some research has also focused on the prevalence of externalising difficulties, such as disruptive behaviour, among children and young people on the AS. As with internalising problems, these estimates vary greatly. So, whilst, the aforementioned study by Kim et al (2000) reported prevalence rates of 8.5%, Breverton, Tonge and Einfield (2006) reported that nearly 74% of their sample score above the clinical case cut-off score for behaviour problems. It is, of course, recognised that internalising and externalising problems can co-vary with one another to a significant degree in

AS. For example, Carrington and Graham (2001) suggest that aggressive behaviour in young people on the AS can "surface as a result of stress and the overwhelming panic that individuals may feel when events in their social world become unintelligible and unpredictable" (p. 46). Thus, it is important for research to provide a comprehensive view of mental health difficulties in such individuals.

Limitations of the extant evidence base

Our understanding of the nature and prevalence of mental health difficulties among children and young people on the AS is currently limited by a number of associated factors evident in the current literature. First, several studies have used extremely small samples (e.g. 15 in Gillott, Furniss, & Walter, 2001), causing problems in relation to statistical power and generalisability of findings. Although some studies have used larger samples (e.g. Gadow, De Vincent, & Schneider, 2008), this has tended to be the exception. Secondly, some studies have not included a comparison group (e.g. Barnhill, 2001), and those that have often only use typically developing peers (e.g. Meyer et al, 2006). Given the general increased risk of mental health disorders among children and young people with SEN (Green et al., 2005; Rose, Howley, Fergusson, & Jament, 2009; Office for National Statistics, 2008), it is important for studies to utilise an additional SEN comparison group (as in Evans, Canavera, Kleinpeter, Maccubin, & Taga, 2005) in order to more clearly establish whether certain difficulties are specific to the AS. Thirdly, many studies have focused only on a single aspect of mental health (e.g.

anxiety in Gillott et al., 2001); studies which provide a more comprehensive view of the mental health of children and young people on the AS are needed. Fourthly, recruitment of participants in some studies may lead to skewed/unrepresentative samples and make comparison between studies potentially unreliable (e.g. children attending medical clinics in Ghaziuddin et al., 1998); more community and/or school samples are therefore needed. Fifthly, there has been something of an over-reliance on third-party report in studies (e.g. in Stewart, Barnard, Pearson, Hasan, & O'Brien's (2006) review of the presentation of depression in those on the AS, only one of 27 studies used self-report). This is particularly relevant given that some informants such as parents - can over-report symptom prevalence (Butzer & Konstantareas, 2003). Finally, given that seeking the views of individuals with disabilities is thought to empower them and enable them to feel part of the research process (Minkes, Robinson, & Weston, 1994), it is surprising to note the enduring paucity of qualitative studies. While they tend to have much smaller sample sizes, and cannot be generalised in the same way as quantitative studies, they are nevertheless able to generate data that is extremely rich, offering an insight into the experiential world of those on the AS (see, for example, Humphrey & Lewis, 2008).

Rationale for the current study

The research reported in this article was designed to address several of the limitations reported above. Specifically, we sought to collect data using a research design which incorporated: (i) a sample size which would be

sufficient to confer the statistical power to detect estimated effect sizes, (ii) two comparison groups – children with other (dyslexia) and no (typically developing) SEN, (iii) a comprehensive profile of mental health, including anxiety, depression, anger, disruptive behaviour and self-concept, (iv) a sample drawn from mainstream schools as opposed to clinics, (v) use of self-report, and (vi) collection of qualitative data to increase explanatory power and offer insights into the experiential world of young people on the AS.

The current study is significant in that it is the first to incorporate the characteristics outlined above, increasing rigour and the potential contribution to knowledge in this important area of research. The setting of the study – mainstream school – is also noteworthy, in that it aligns with a growing body of research that has begun to examine the effectiveness of inclusive education for young people on the AS (e.g. Humphrey & Lewis, 2008; Humphrey & Symes, 2010, 2011). In particular, this research has focused on their experiences in secondary school; this is particularly pertinent in relation to issues of mental health in those on the AS because adolescence is a time of greater social demands, and so awareness of social difficulties is likely to be extremely stressful (Barnhill, 2001).

In light of the above, the aims of our study were to (i) compare the mental health profiles of adolescents on the AS, those with dyslexia and those with no special educational needs attending mainstream secondary schools, and (ii) identify influences on and responses to mental health difficulties of adolescents on the AS from their perspective. In relation to (i) above, we

predicted that adolescents on the AS would exhibit significantly worse mental health profiles than either comparison group, both in terms of mean scores and probability (odds ratio) of attaining clinically significant ratings.

Method

Design

The research reported in this article utilised a *causal comparative* framework. The independent (explanatory) variable was the group to which each participant belonged – autistic spectrum (AS), dyslexia (DYS) or no special educational needs (CON). The dependent (response) variable was selfreported mental health in the following domains: anxiety, depression, anger, disruptive behaviour and self-concept.

Participants

An a priori power analysis indicated that 21 participants per group would be sufficient to detect a large effect size (which one could reasonably surmise from the preceding literature) at *Power = 0.80* and α = 0.05 (Cohen, 1992), and so this was set as the minimum group size.

The sample was recruited from 17 mainstream secondary schools in north Wales and the north-west of England. Letters were sent to head teachers and/or SENCOs, who acted as gatekeepers and forwarded information and

consent sheets to parents of prospective participants. 22 participants were recruited to the AS group (19 male, 3 female; mean age: 14y2m), 21 participants were recruited to the DYS group (17 male, 4 female; mean age: 14y1m), and 23 participants were recruited to the CON group (19 male, 4 female; mean age 14y7m). Inclusion criteria for all three groups comprised of school and parental consent (written), pupil assent (verbal)¹, aged 11-17, and no co-morbid difficulties. Failure to meet these criteria resulted in exclusion from the study. Three students in the AS group were subsequently discovered to also have a diagnosis of dyslexia and were excluded from the analysis. All participants' academic achievement levels in core subjects (e.g. Maths, English) fell within the normal range that would be expected in large, diverse secondary mainstream schools in England

A matched-triad process was undertaken to ensure that the groups were matched as closely as possible by age and gender. A one-way ANOVA confirmed no statistically significant differences between the groups in age (p>.05). Furthermore, a Chi-Square test confirmed no statistically significant association between group and gender (p>.05). Students in the AS and DYS groups all had relevant confirmed diagnoses and were on their schools' SEN registers. A matched-pairs process was undertaken in an attempt to ensure that these two groups were matched by stage of SEN provision from the national code of practice (DfES, 2001)². A Chi-square test confirmed no

¹ Student assent was facilitated by an information sheet written at an appropriate reading level so as to be accessible to all participants, in addition to being 'AS friendly' (e.g. using clear, direct language and avoiding figures of speech and metaphors).

² Students identified as having special educational needs in schools in England are classified according to the nature and level of additional provision they receive as a result of their difficulties. Thus, they can be at School Action (SA), School Action Plus (SAP) or in receipt of

statistically significant association between group and SEN stage (p>.05). Thus, participants in the three groups were considered to be adequately matched in relation to age, gender and (for the AS and DYS groups) SEN provision.

Materials

Beck Youth Inventories (2nd Edition)

A range of self-report measures of mental health for young people were considered. Selection criteria included theoretical grounding, psychometric properties, use in similar or related research, brevity and ease of use (particularly in relation to participant groups in the current study) and scope (e.g. range of mental health difficulties assess within a given measure). The measure used in the study was the *Beck Youth Inventories (2nd Edition)* (BYI-II) (Beck, Beck, Jolly, & Steer, 2005).

The BYI-II is a self-report measure of mental health for children and young people. It provides ratings of their anxiety, depression, anger, disruptive behaviour and self-concept. The measure comprises of 100 statements (20 for each domain of mental health) to which the respondent provides an agreement rating (Never, Sometimes, Often, Always). An example item is, "I

a Statement of SEN (SSEN). Students at School Action have their special needs met within the schools' normal resources. Those at School Action Plus are likely to have additional support from an external agency (e.g. educational psychologist). Finally, students whose needs have not been met at either SA or SAP will typically undergo a full statutory assessment of their needs, resulting in the production of an SSEN which legally secures a particular level of resources that can be used to support the student.

work hard". A total raw score for each domain is calculated before being converted to a standardised *T* score.

In relation to the selection criteria outlined above, the BYI-II has a strong theoretical and empirical base (Bose-Deakins & Floyd, 2004). It also has strong psychometric properties, with internal reliability co-efficients above 0.86 for each domain, test-retest reliability co-efficients above 0.74 for each domain, and demonstrable factorial and convergent validity (Beck, Beck, Jolly, & Steer, 2005). The BYI-II is amongst the most widely used screening measures in child and adolescent mental health (Johnston & Gowers, 2005), and benefits from simple and unambiguous items (written at US second grade level; approximate reading age of 7-8) that enable the participation of those with literacy difficulties (e.g. the DYS group) and those who find abstract language difficult to process (e.g. the AS group). Finally, the BYI-II covers a wide range of mental health difficulties, distinguishing not just between internalising and externalising symptoms, but discrete disorders within these broad domains (e.g. anxiety and depression within the internalising domain).

Semi-structured interviews

Semi-structured interviews were conducted with a sub-sample of the AS group. The aim of these interviews was to identify influences on and responses to mental health difficulties of adolescents on the AS from their perspective. Semi-structured interviews are a widely used method to obtain rich qualitative data, as they allow the viewpoints of interviewees to be

expressed in more detail than in a wholly structured interview or questionnaire (Flick, 1998). Smith and Osborn (2008) summarise the advantages of the semi-structured interview succinctly, stating that, "it facilitates rapport/empathy, allows a greater flexibility of coverage and allows the interview to go into novel areas, and it tends to produce richer data" (p. 59).

Procedure

All participants were tested individually by the first author in a quiet withdrawal area in their school. Following completion of the BYI-II questionnaires, 5 participants from the AS group ('Daniel', 'Joanne', 'Oliver', 'Simon', and 'James')³ took part in follow-up interviews. Interview questions were devised to be used as a guide by the researcher and expanded upon themes addressed in the five sections of the BYI-II. Following guidelines suggested by Smith and Osborn (2008), questions were initially fairly concrete and pragmatic, but were gradually funnelled into more focused experiential questions. The questions were open-ended and allowed the interviewees to speak freely. The areas covered were the same for all participants, although the order of the questions was flexible. Additional probing questions were added ad hoc where appropriate. Interviews were recorded using a Olympus DS-30 .mp3 voice recorder. This avoided the need to take notes and allowed the researcher to focus on the flow of the interview, making the interaction more natural and informal.

³ All names were changed to protect anonymity.

Ethical considerations

Standard ethical procedures for educational (British Educational Research Association, 2004) and psychological research (British Psychological Society, 2004) were followed throughout the study. As mentioned above, consent was sought and received from each school, from each pupil's parents and from the pupils themselves. Participating pupils were given a clear explanation of the purpose of the study, and informed that their data would be treated in confidence and that they would remain anonymous. Their right to withdraw at any point was also made clear. The school special educational needs co-ordinator (SENCO) confirmed consent at all three levels before the first author was introduced to participants.

Results

Quantitative analysis

Alpha (α) was set at 0.05 for all quantitative analyses. In view of the inflated family-wise error rates associated with multiple comparisons, a multi-variate analysis of variance (MANOVA) was utilised as the primary analytical technique.

Descriptive statistics (means and standard deviations) pertaining to the mental health profiles of participants in the current study are presented in Table 1. As can be seen, there is a clear trend towards greater mental health

difficulties in the AS group, relative to both the DYS and CON groups. However, the magnitude of this trend appears to vary as a function of the mental health domain in question (for instance, greater differences apparent for anxiety and anger).

<<TABLE 1 HERE>>

Error charts with clinical cut-off thresholds super-imposed for each domain of mental health are presented in Figures 1-5. Amongst the more striking trends here are that the AS group mean scores fall close to or within the clinical range for all domains of mental health except for disruptive behaviour. Furthermore, comparison of the confidence intervals around the group means of the AS and CON group reveals little or no overlap (although again, disruptive behaviour is an exception here). This would seem to indicate that the differences outlined in the above analysis are likely to be reflected in the population from which the group samples were drawn.

<<FIGURES 1-5 HERE>>

As predicted, the MANOVA revealed a significant main effect of group, $[F(2,116) = 2.915, p<.01, \eta^2 = 0.20]$. Analysis by domain of mental health revealed significant group effects in relation to anxiety $[F(2,63) = 8.450, p<.01, \eta^2 = 0.212]$, anger $[F(2,63) = 7.332, p<.01, \eta^2 = 0.19]$ and depression $[F(2,63) = 3.249, p<.05, \eta^2 = 0.09]$, and a marginal, non-significant trend for selfconcept $[F(2,63) = 3.128, p=.051, \eta^2 = 0.09]$. There was no statistically

significant group effect in relation to disruptive behaviour [F(2,63) = 2.105, p>.05].

Table 2 provides post-hoc Tukey's HSD and Cohen's *d* effect size analyses by group. With the exception of the disruptive behaviour domain, the AS group display significantly worse mental health scores than the CON group, with effect sizes varying from medium to large. In the cases of anxiety and anger, the AS group also displayed significantly worse scores than the DYS group, with effect sizes ranging from small to large.

<<TABLE 2 HERE>>

The prevalence of clinically significant difficulties in the AS group was very high. 36.4% scored at or below the clinical cut-off for *self-concept*, compared to 21.7% in the CON group, with an associated odds-ratio of 2.06. 59.1% scored at or above the clinical cut-off for *anxiety*, compared to 8.7% in the CON group, with an associated odds-ratio of 15.17. 36.4% scored at or above the clinical cut-off for *anxiety*, in the CON group, with an associated odds-ratio of 8.7% in the CON group, with an associated odds-ratio of 15.17. 36.4% scored at or above the clinical cut-off for *depression*, compared to 8.7% in the CON group, with an associated odds-ratio of 6. 40.9% scored at or above the clinical cut-off for *anger*, compared to 4.3% in the CON group, with an associated odds-ratio of 15.23. Finally, 31.8% scored at or above the clinical cut-off for *disruptive behaviour*, compared to 0% in the CON group (this meant that an odds-ratio could not be calculated).

Qualitative analysis

Interview data was transcribed verbatim, and analysed thematically using NVivo 7 in accordance with Interpretative Phenomenological Analysis (IPA), with the aim of exploring inner experiences and their meanings (Smith & Osborn, 2008). The mechanics of this followed the six stages of thematic coding described by Braun and Clarke (2006). The themes are presented as a visual model in Figure 6 in order to give a concise overview, and also to illustrate possible relationships between them (Bazeley, 2007).

<< FIGURE 6 HERE >>

Feelings of anxiety were expressed clearly by all of the participants interviewed, and appeared to play a significant part in their lives. Social contexts were a recurring cause of anxiety for all participants, with issues such as self-consciousness (e.g. *Joanne: "I always think that everyone's going to stare at me"*), worries about the perceptions of others (e.g. *Simon: "I find it quite distressing if the teacher gets annoyed with me"*), and unstructured social situations (e.g. *Oliver: "There's like a mad rush, people running "awol"*) causing concern. This anxiety was closely allied to anger, with worry frequently leading to frustration, usually in response to other people or difficulties. Daniel recognised that his anxiety in lessons could easily escalate into very public outbursts over which he had little control: *"Sometimes I cry... I go "ughhr!" and then "warrr!" I have this stupid anger and I say stuff like "I wish I was dead", which I don't mean. Sometimes, I just say it because I'm worried about my body and the situation. [...] If I get angry, it's*

like I'm not controlling myself. Someone else is. So I'm being controlled by a remote". In contrast, Joanne felt guilt over external manifestations of her anger, and as such tried very hard to internalise it: *"I feel like I want to break stuff, but I never do it... I feel like I want to run away, but I never, you don't do it... I feel silly, I feel confused".*

Related to such attempts to internalise anger, a significant discovery in the interviews was the range of coping strategies used by the young people. There was a keen sense of self-reliance in addressing emotional distress, as explained by Oliver: "I don't really talk to anyone. I keep to myself and try to sort it out in my own way, which is often why I often say certain things, I don't want to say now". The interviewees were very candid in talking about the extent to which they actively tried to hide their anger and anxiety (e.g. Joanne: "Sometimes I scream into a pillow, or sometimes I just get all my colouring pencils and just start scraping paper, just draw some mad stuff, even if it's scribbles"). This may also explain why some young people on the AS appear to explode with emotion, perhaps over something apparently trivial, when in fact tension has been rising unnoticed within them for some time. Nevertheless, these outbursts can bring considerable relief, as Joanne explained: "It just makes me feel relieved to get it out, 'cause with me I always used to hold in emotions. I always hold in my emotion until after the end, and now I feel better when I get it out. But it's hard to get it out, 'cause I leave it in so long".

The social relationships of the young people were amongst the most significant influences on their mental health. Friendships, isolation, bullying and interpreting social situations were particularly pertinent. Participants identified key qualities they desired in friends such as support, a sense of equality (James), trustworthiness (Oliver), and acceptance (Simon). Nevertheless, the guality and number of friends each of the interviewees had seemed to vary considerably. Oliver spoke only about people he chatted to on Xbox Live, rather than school friends, and while Daniel had some friends mainly drawn from his Social Skills lessons, he professed a strong desire for more friendship. On a related note, a sense of isolation also emerged, but this did not always have negative connotations. In some cases, such as Joanne, there was a sense of satisfaction in solitude: "I like being on my own. Sometimes I won't hang out with Jenny and Sarah. I'll just walk on my own and think about the things that have happened. It's kind of like a conversation with a mirror of myself". With James, it was simply accepted as a solution to other problems: "I've been staying in every day, the last year. Not the best solution, but one I'm happy with".

Bullying was a key concern for all participants, although it varied in its form, severity and frequency. Each demonstrated a clear conceptual understanding of what constituted bullying (e.g. *James: "It's either abusive names or physical abuse"*) and the purpose it served (e.g. *James: "It's a show of dominance… it could also be entertainment* [for the bully]"). As above, the participants had learned to be self-reliant in dealing with their experiences of bullying, for example, Oliver: *"I have a little secret method… there's this guy*

called Martin who's using a friend of mine called Adam to bully me and two friends. So basically, I've been trying to get through to him like a double agent. He pretends to hurt me and he gives me information about stuff happening in the future". They were reluctant to report incidents to teachers, who were generally seen as unhelpful (e.g. Daniel: "They won't listen to me"; James: "They never took it seriously, and then it got worse").

Participants were also acutely aware of their difficulties in interpreting social situations. There was unease expressed in social contexts, particularly during unstructured periods of the school day, such as immediately before and after school, break and lunchtime. For example, Joanne experienced concern going into a busy school corridor first thing in the morning because she felt other young people would stare at her. When James was asked why he felt uneasy in the playground, he answered: "*Maybe because I felt vulnerable*". This appears linked to a difficulty in understanding and managing social situations, resulting in anxiety and self-blame, as expressed by Joanne: "*I always think everyone's angry with me for some reason, like I've done something wrong*". In some instances, misinterpretations of social situations had negative consequences, for example, Daniel: "*I want to help people, but when I try to help them, it always ends up in fights*".

In dealing with the complex and often chaotic social and school environments they found themselves in, participants reported relying on predictability and routine to provide comfort and help them make sense of their experiences. Daniel, for example, demonstrated a strong preference for subjects with

strong systemising elements such as maths ("you can figure out equations") and technology ("you can figure out what you want"). Similarly, Simon enjoyed science: "I like chemistry and physics because it talks about laws and how things work". In all of these cases, the ability to work within safe and predictable parameters generated a sense of satisfaction in the students, and also a feeling of calmness. This can be contrasted with the anxiety experienced in less predictable, unstructured social situations. However, disruptions to these routines were themselves sources of anxiety.

Participants' understanding of their AS varied, but the utility of the diagnostic label was clear, especially to Joanne, who said: *"This Asperger's has helped... the books about Asperger's, they tell more about me than I know about myself. Every time I used to do something I used to think, 'Oh weirdo, what're you doing?', and then when I read it in a book, I'm just like, 'Well I'm not a weirdo if it's in a book". There was a clear sense of feeling different from other people (e.g. Joanne: <i>"To me this Asperger's is like a horoscope, you know, with your star sign... I do understand that I'm different"*), and this was sometimes expressed negatively, but also factually and without judgement, suggesting that it was accepted much of the time by Daniel, James and Oliver. There was a strong indication of not wanting to be treated differently from others though (e.g. *Joanne: "I wouldn't want them to* [treat me differently]... *I'm happy that they're treating me like an ordinary schoolgirl"*; *James: "I can't stand people who blame, if they have ADHD, who blame it for their actions"*).

Discussion

This study uncovered worrying mental health profiles among adolescents on the AS in mainstream secondary schools. Compared to those with no special educational needs, they experienced significantly greater anxiety, depression, anger and lower self-concept. In the cases of anxiety and anger, young people on the AS also scored significantly worse than those with other SEN (dyslexia). Prevalence rates for clinically significant problems were very high, ranging from 31.8% (disruptive behaviour) to 59.1% (anxiety) - in all cases, calculated odds-ratios were indicative of greatly increased risk compared to young people with no special educational needs. For instance, those in the AS group were more than 15 times more likely to experience clinically significant anxiety problems than those in the CON group. Analysis of qualitative interview data from a sub-sample of the AS group yielded explanatory insights into the aspects of the young people's lives affecting their mental health, including their understanding of AS and their social relationships, in addition to strategies used to cope with their frequent feelings of anxiety and anger.

In terms of anxiety, results here are concordant with White et al. (2009), who reported high prevalence rates in those on the AS. The use of an additional comparison group (as in Evans et al., 2005, and Gillott et al., 2001), reinforces the notion of severe anxiety as an issue specific to those on the AS rather than young people with SEN more generally. The findings in relation to anger support research that anger and frustration are commonly found among young people on the AS (e.g. Kim et al., 2000). The co-occurrence of high

levels of anger alongside anxiety (and, to a lesser extent, depression) lends support to Farrugia and Hudson's (2006) proposal that internalising and externalising disorders are linked in THOSE ON THE AS (indeed, this also emerged from the interview data), and that there is a different anger profile compared with that of typically developing young people. The findings also support claims that young people on the AS can acknowledge and disclose difficulties in anger management (Knott, Dunlop, & Mackay, 2006).

Given these elevated levels of anger, it is of note that no significant group differences were found for disruptive behaviour (although, as with other domains, there was a clear trend towards worse outcomes for the AS group). Anger and disruptive behaviour are rarely measured separately, and the BYI-II is one of the few instruments to differentiate between them (Beck et al., 2005). Therefore it is of great interest that anger features more prominently than disruptive behaviour in this study. Although being on the AS has been associated with conduct problems and ADHD (e.g. Macintosh & Dissanayake, 2006; Carrington & Graham, 2001), the current findings suggest that the challenging behaviour seen in those on the AS may be more closely related to anger rooted in anxiety and frustration (Carrington & Graham, 2001) than to the behaviour patterns at the core of conduct disorders, even though the outcomes - as witnessed by peers, parents and teachers - may not be differentiated easily.

The findings in relation to depression were equivocal, with significant differences found between the AS and the CON groups but not between the

AS and DYS groups. Nevertheless, the data confirmed themes in the extant literature, which suggest that prevalence is high among those on the AS, but potentially not as high as for anxiety (Green et al., 2005; Ghaziuddin et al, 1998). Support here is also given to research indicating that depression and anxiety often co-occur in individuals on the AS (Matson & Nebel-Schwalm, 2007). The lack of a significant difference between the AS and the DYS groups suggests that depression could be an issue for young people with dyslexia, although research findings on this subject have not been consistent (e.g. Miller, Hynd, & Miller, 2005). A similar pattern emerged for self-concept (albeit with a marginal group effect), with significant differences found between the AS and the CON groups but not between the AS and DYS groups. Although further inspection of the literature supports the proposition of negative self-perceptions among children with dyslexia (e.g. Humphrey & Mullins, 2002), this has typically been demonstrated in specific domains (e.g. academic self-concept) rather than at the global level (as found here). Taken together, the depression and self-concept results are consistent with social comparison theory (SCT) (e.g. Festinger, 1954) as applied to special educational needs. According to SCT, individuals make self-appraisals by comparing their performance with that of others around them. It is notable that the two domains in which adolescents on the AS and those with dyslexia would yield unfavourable comparisons with their peers (social and academic skills, respectively) are also particularly salient to adaptive functioning in the mainstream secondary school environment, perhaps explaining the negative affect exhibited.

The qualitative findings yielded insights into the influences on, experiences of, and responses to, mental health difficulties among adolescents on the AS, and added to a growing body of research that has begun to explore the experiential world of those attending mainstream schools (e.g. Carrington & Graham, 2001; Humphrey & Lewis, 2008). It is perhaps significant that two key themes which have been reported in such research – social relationships and understanding/conceptualisation of the AS - also emerged here. In relation to the former, our findings validate calls for more to be done in schools to raise peer awareness and understanding of AS (e.g. Humphrey & Symes, 2010). In relation to the latter, our findings add to a somewhat mixed picture that is emerging in relation to young people's understanding and conceptualisation of the AS. Like Humphrey and Lewis (2008), our data suggested a clear sense of feeling different, whilst also not wanting to be treated differently. The interviewees in this study reported fewer difficulties in 'feeling different' than others, such as Portway and Johnson (2003) and Bolman (2008). Perhaps the key here is the level of acceptance of difference, both in the young people themselves amongst those around them. Research conducted in relation to other special educational needs (ironically, dyslexia -Armstrong & Humphrey, 2009) has suggested that emotional wellbeing may be linked to the extent to which young people resist or accommodate their sense of difference. Further research is needed, but this does provide some indication that young people on the AS who struggle to understand or accept their differences from other people may benefit from therapeutic support in this regard.

The findings of the current study have potential clinical and educational implications. Given the high prevalence of anxiety (and to a lesser extent depression), routine assessment for co-morbid internalising problems may play a valuable part in the diagnosis and treatment of children and young people on the AS. This study, using a non-clinical sample, supports findings (e.g. Ghaziuddin et al., 2002) that these mental health difficulties may be under-reported and therefore undiagnosed. If routine assessment included screening for a range of mental health difficulties, earlier targeted intervention could be implemented (although we note that this would be best supported by universal preventive strategies - see Weare & Nind, 2011). Added to this, symptoms of mental health difficulties may be confused with behaviour associated on the AS (Rose et al., 2009), so early professional identification of these difficulties would be of particular value to parents and schools. Furthermore, although young people on the AS may not spontaneously disclose feelings of distress (Russell & Sofronoff, 2005), this study indicates that they are willing to do so if asked.

In educational terms, these findings have several implications. Many mainstream schools are doing excellent work in supporting and including young people on the AS (see Morewood, Humphrey, & Symes, in press). Nevertheless, this study may be able to offer support for existing strategies and provide exploratory ideas for new ones. First of all, awareness needs to be raised of the prevalence of internalising problems in secondary school students on the AS, especially in relation to social deficits that are likely to act as triggers (Tantam, 2000). The fact that these students are (typically) high-

functioning enables them to conceal some of their anxiety, and could lead to the impression that they are coping adequately, when in fact the opposite may be true. Secondly, as the profile of behavioural difficulties among young people on the AS may be different to other adolescents (Farrugia & Hudson, 2006), better understanding of triggers and responses could help to inform specific strategies for assessing and managing difficult behaviour. Thirdly, bullying is a major issue for young people on the AS in mainstream schools (Humphrey & Symes, 2010). While schools have robust procedures for dealing with it, these young people are especially prone to bullying and peer rejection, making them vulnerable individuals who may require additional monitoring and support. Fourthly, the toxic combination of social difficulties, anxiety and bullying is likely to lead to poor educational outcomes. While many schools have excellent strategies in place to support young people on the AS, there is still a need for greater awareness among all teachers - not just SEN specialists - of the potential challenges these young people encounter. Finally, although those on the AS may not report their difficulties unprompted (Russell & Sofronoff, 2005), this study demonstrates that they are able to do so when asked, making regular dialogue a useful collaborative strategy.

It is important, as in any research, to note the inherent limitations of the current study. The sample size, whilst larger than in some published research, was still relatively small. However, it is important to note that despite this, minimum power requirements were met, and the substantial differences found between those on the AS and those with no SEN in relation

to anxiety, depression and anger are likely to generalise to the wider population from which they were drawn (as indicated by the lack of overlap in confidence intervals – see Figures 2, 3 and 4 respectively). Our study also made no distinction between sub-types of AS (e.g. Asperger's syndrome vs. high-functioning autism), limiting the precision of our analyses. However, previous research has suggested that such distinctions may not be relevant to mental health outcomes (e.g. Kim et al., 2000). Finally, in relation to the qualitative sample, since the young people were essentially self-selecting (inasmuch as informed consent and the capacity to talk candidly about mental health were apriori requirements for the interviews), their experiences may not reflect those of adolescents on the AS in mainstream schools more generally. However, the concordance of the qualitative findings with other, similar research in this area (e.g. Carrington & Graham, 2001; Humphrey & Lewis, 2008) strengthens their credibility and validity.

- Armstrong, D., & Humphrey, N. (2009). Reactions to a diagnosis of dyslexia among students entering further education: development of the "resistance-accommodation" model. *British Journal of Special Education*, 36, 95-102.
- Baron-Cohen, S. (1989). Do autistic children have obsessions and compulsions? *British Journal of Clinical Psychology*, 28, 193-200.
- Baron-Cohen, S. (2005). Theory of mind and autism: a fifteen year review. In
 Baron-Cohen, S., Tager-Flusberg, H. & Cohen, D. J. (Eds.),
 Understanding other minds: Perspectives from developmental cognitive neuroscience (2nd ed.), pp. 3-20. New York, NY: Oxford University Press.
- Barnhill, G. P. (2001). Social attributions and depression in adolescents with Asperger syndrome. *Focus on Autism and Other Developmental Disabilities*, 16, 46-53.
- Bazeley, P. (2007). *Qualitative data analysis with NVivo.* London: Sage Publications Ltd.
- Beck, J. S., Beck, A. T., Jolly, J. B. & Steer, R. A. (2005). *Beck youth inventories*, 2nd Edition. Texas: Psychological Corporation.

- Bolman, W. M. (2008). Brief report: 25-year follow-up of a high-functioning autistic child. *Journal of Autism and Developmental Disorders*, 38, 181-183.
- Bose-Deakins, J. E., & Floyd, R. G. (2004). A review of the Beck Youth inventories of emotional and social impairment. *Journal of School Psychology*, 42, 333-340.
- Braun, V., & Clarke, V. (2006). Using thematic analysis in psychology. *Qualitative Research in Psychology*, 3, 77-101.
- British Educational Research Association (2004). *Revised ethical guidelines for educational research*. Southwell, Notts: BERA.
- British Medical Association (2006). *Child and adolescent mental health: a guide for professionals*. London: BMA.
- British Psychological Society (2004). Code of conduct, ethical principles and guidelines. Leicester: BPS.
- Butzer, B. & Konstanareas, M. M. (2003). Depression, temperament and their relationship to other characteristics in children with Asperger's disorder. *Journal on Developmental Disabilities*, 10, 67-72.

- Carrington, S., & Graham, L. (2001). Perceptions of school by two teenage boys with Asperger syndrome and their mothers: a qualitative study. *Autism*, 5, 37-48.
- Collishaw, S., Maughan, B., Goodman, R. & Pickles, A. (2004). Time trends in adolescent mental health. *Journal of Child Psychology and Psychiatry*, 45, 1350-1362.

Cohen, J. (1992). A power primer. *Psychological Bulletin*, 112, 155-159.

- Colman, I., Murray, J., Abbott, R. A., Maughan, B., Kuh, D., Croudace, T. J. & Jones, P. B. (2009). Outcomes of conduct problems in adolescence: 40 year follow-up of national cohort. *British Medical Journal*, 338, 2981-2989.
- Department for Education and Skills (2001). *Special educational needs: code of practice*. Nottingham: DfES.
- Emam, M. & Farrell, P. (2009). Tensions experienced by teachers and their views of support for pupils with ASD in mainstream schools. *European Journal of Special Needs Education*, 24, 407-422.
- Evans, D. W., Canavera, K., Kleinpeter, F. L., Maccubbin, E., & Taga, K. (2005). The fears, phobias and anxieties of children with autism spectrum disorders and Down syndrome: comparisons with developmentally and

chronologically age matched children. *Child Psychiatry and Human Development*, 36, 3-26.

- Farrugia, S., & Hudson, J. (2006). Anxiety in adolescents with Asperger syndrome: negative thoughts, behavioural problems, and life interference. *Focus on Autism and Other Developmental Disabilities*, 21, 25-35.
- Festinger, L. (1954), A theory of social comparison processes. *Human Relations*, 7, 117-40.
- Flick, U. (1998). An introduction to qualitative research. London: Sage Publications Ltd.
- Frith, U. (2003). Autism: explaining the enigma, 2nd Edition. Oxford: Blackwell.
- Gadow, K. D., De Vincent, C., & Schneider, J. (2008). Predictors of psychiatric symptoms in children with an autism spectrum disorder. *Journal of Autism and Developmental Disorders*, 38, 1710-1720.
- Ghaziuddin E., Weidmer-Mikhail E. and Ghaziuddin N. (1998) Comorbidity of Asperger syndrome: a preliminary report. *Journal of Intellectual Disability Research*, 42, 279-283.
- Gillott, A., Furniss, F. & Walter, A. (2001). Anxiety in high-functioning children with autism. *Autism*, 5, 277-286.

- Green, H., McGinnity, A., Meltzer, H., Ford, T. & Goodman, R. (2005). *Mental health of children and young people in Great Britain, 2004.* Newport: Office for National Statistics.
- Healey, A., Knapp, M. & Farrington, D. P. (2004). Adult labour market implications of antisocial behaviour in childhood and adolescence: findings from a UK longitudinal study. *Applied Economics*, 35, 93-105.
- Hofstra, M.B., Van Der Ende, J. & Verhulst, F. C. (2002). Child and adolescent problems predict DSM-IV disorders in adulthood: 14-year follow up of a Dutch epidemiological sample. *Journal of the American Academy of Child and Adolescent Psychiatry*, 41, 182-189.
- Humphrey, N., & Lewis, S. (2008). "Make me normal": the views and experiences of pupils on the autistic spectrum in mainstream secondary schools. *Autism*, 12, 23-46.
- Humphrey, N. & Mullins, P. (2002). Self-concept and self-esteem in developmental dyslexia. *Journal of Research in Special Educational Needs*, 2, 1-12.
- Humphrey, N. & Symes, W. (2010). Perceptions of social support and bullying among pupils with ASD in mainstream secondary schools. *European Journal of Special Needs Education*, 25, 77-91.

- Humphrey, N. & Symes, W. (2011). Peer interaction patterns among pupils with ASD in mainstream school settings. *Autism*, 15, 397-419.
- Johnston, C. & Gowers, S. (2005). Routine outcome measurement: a survey of UK child and adolescent mental health services. *Child and Adoelscent Mental Health*, 10, 133-139.
- Kim, J. A., Szatmari, P., Bryson, S. E., Streiner, D. L. & Wilson, F. J. (2000). The prevalence of anxiety and mood problems among children with autism and Asperger syndrome. *Autism*, 4, 117-132.
- Knott, F., Dunlop, A.W., & Mackay, T. (2006). Living with ASD: how do children and their parents assess their difficulties with social interaction and understanding? *Autism*, 10, 609-617.
- Kuusikko, S., Pollock-Wurman, R., Jussila, K., Carter, A. S., Mattila, M.-L.,
 Ebeling, H., Pauls, D. L. & Moilanen, I. (2008). Social anxiety in highfunctioning children and adolescents with autism and Asperger syndrome. *Journal of Autism and Developmental Disorders*, 38, 1697-1709.
- Macintosh, K., & Dissanayake, C. (2006). Social skills and problem behaviours in school aged children with high-functioning autism and Asperger's disorder. *Journal of Autism and Developmental Disorders*, 36, 1065-1076.

- Matson, J. L., & Nebel-Schwalm, M. S. (2007). Comorbid psychopathology with autism spectrum disorder in children: an overview. *Research in Developmental Disabilities*, 28, 341-352.
- Meltzer, H., Corbin, T., Gatward, R., Goodman, R., Ford, T. (2003). *The* mental health of young people looked after by local authorities in England.
 Newport: Office for National Statistics.
- Meyer, J. A., Mundy, P. C., Vaughan Van Hecke, A. & Durcoher, J. S. (2006). Social attribution processes and comorbid psychiatric symptoms in children with Asperger syndrome. *Autism*, 10, 383-402.
- Miller, C. J., Hynd, G. W. & Miller, S. R. (2005). Children with dyslexia: not necessarily at risk for elevated internalising symptoms. *Reading and Writing*, 18, 425-436.
- Minkes, J., Robinson, C., & Weston, C. (1994). Consulting the children: interviews with children using residential respite care services. *Disability and Society*, 9, 47-57.
- Morewood, G., Humphrey, N. & Symes, W. (in press). Mainstreaming autism: making it work. *Good Autism Practice.*

- Office for National Statistics (2008). Three years on: survey of the development and emotional well-being of children and young people. Cardiff, ONS.
- Portway, S., & Johnson, B. (2003). Asperger syndrome and the children who "don't quite fit." *Early Child Development and Care*, 173, 435-443.
- Robertson, K., Chamberlain, B., & Kasari, C. (2003). General education teachers' relationships with included students with autism. *Journal of Autism and Developmental Disorders*, 33, 123-130.
- Rose, R. Howley, M., Fergusson, A. & Jament, J. (2009). Mental health and special educational needs: exploring a complex relationship. *British Journal of Special Education*, 36, 3-8.
- Russell, E., & Sofronoff, K. (2005). Anxiety and social worries in children with Asperger syndrome. *Australia and New Zealand Journal of Psychiatry*, 39, 633-638.
- Scott, S., Knapp, M., Henderson, J. & Maughan, B. (2001). Financial cost of social exclusion: follow-up study of anti-social children into adulthood. *British Medical Journal*, 323, 191-196.

- Smith, J. A., & Osborn, M. (2008). Interpretative phenomenological analysis.
 In Smith, J. A. (Ed.), *Qualitative psychology: a practical guide to research methods*, 2nd Edition. London: Sage Publications Ltd.
- Stewart, M. E., Barnard, L., Pearson, J., Hasan, R., & O'Brien, G. (2006). Presentation of depression in autism and Asperger syndrome. *Autism*, 10, 103-116.
- Symes, W. & Humphrey, N. (2010). Peer group indicators of inclusion among pupils with autistic spectrum disorders in mainstream secondary schools: a comparative study. *School Psychology International*, 31, 478-494.
- Tantam, D. (1991). Asperger syndrome in adulthood. In U. Frith (ed.), *Autism and Asperger syndrome*, pp.147-183. Cambridge: CUP.

Tantam, D. (2000). Psychological disorder in adolescents with Asperger syndrome. *Autism*, 4, 47-62.

- Weare, K. & Nind, M. (2011). Mental health promotion and problem prevention in schools: what does the evidence say? *Health Promotion International*, 26, 29-69
- White, S. W., Oswald, D., Ollendick, T., & Scahill, L. (2009). Anxiety in children and adults with autism spectrum disorder. *Clinical Psychology Review*, 29, 216-229.

Tables and Figures

	AS	DYS	CON
Self-concept	44.81 (8.06)	45.32 (7.80)	49.68 (9.23)
Anxiety	56.15 (10.53)	47.16 (11.67)	46.53 (6.70)
Depression	52.88 (9.66)	46.63 (12.20)	47.00 (7.14)
Anger	53.15 (11.09)	45.63 (8.93)	43.74 (7.19)
Disruptive	48.81 (9.50)	45.37 (6.65)	44.68 (5.76)
behaviour			. ,

Table 1. Mean (and standard deviation) mental health profile scores for
participants in the current study.

Domain	Comparison	р	Cohen's <i>d</i>
Self-concept	AS vs DYS	n.s.	0.04
	AS vs CON	<.05	0.65 (medium)
	DYS vs CON	<.05	0.62 (medium)
Anxiety	AS vs DYS	<.05	0.8 (large)
	AS vs CON	<.001	1.36 (large)
	DYS vs CON	n.s.	0.23 (small)
Depression	AS vs DYS	n.s.	0.47 (small)
	AS vs CON	<.05	0.88 (large)
	DYS vs CON	n.s.	0.19
Anger	AS vs DYS	<.05	0.40 (small)
	AS vs CON	<.05	0.74 (medium)
	DYS vs CON	n.s.	0.56 (medium)
Disruptive behaviour	AS vs DYS	n.s.	0.37 (small)
	AS vs CON	n.s.	0.55 (medium)
	DYS vs CON	n.s.	0.21 (small)

Table 2. Post-hoc Tukey's comparisons with accompanying Cohen's *d* effect sizes.

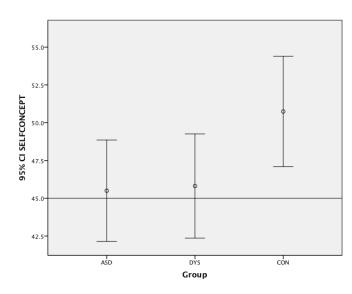


Figure 1. Error bar chart displaying mean self-concept scores with 95% confidence intervals for young people in the AS, DYS and CON groups (NB: y-axis reference line is clinical cut-off).

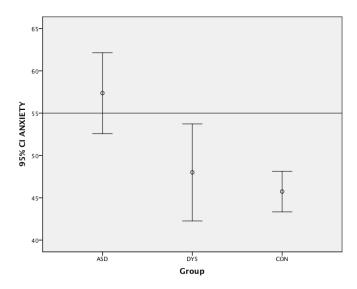


Figure 2. Error bar chart displaying mean anxiety scores with 95% confidence intervals for young people in the AS, DYS and CON groups (NB: y-axis reference line is clinical cut-off).

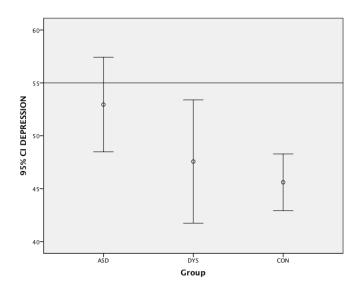


Figure 3. Error bar chart displaying mean depression scores with 95% confidence intervals for young people in the AS, DYS and CON groups (NB: y-axis reference line is clinical cut-off).

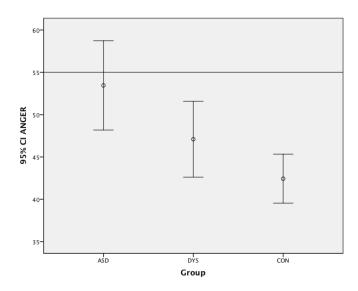


Figure 4. Error bar chart displaying mean anger scores with 95% confidence intervals for young people in the AS, DYS and CON groups (NB: y-axis reference line is clinical cut-off).

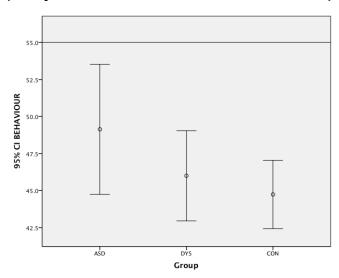


Figure 5. Error bar chart displaying mean disruptive behaviour scores with 95% confidence intervals for young people in the AS, DYS and CON groups (NB: y-axis reference line is clinical cut-off).



Figure 6. Qualitative model of influences on, experiences of, and responses to mental health difficulties among adolescents on the AS.