

VOLUME I  
RESEARCH COMPONENT

**MEMORIES OF SCHOOL TRANSITION IN YOUNG PEOPLE WITH  
ASPERGER SYNDROME AND COGNITIVE SIMILARITIES AND  
DIFFERENCES WITH SCHIZOPHRENIA; UNDERSTANDING  
DIAGNOSTIC UNCERTAINTY**

BY  
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A Thesis submitted to  
The University of Birmingham  
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Doctorate of Clinical Psychology (Clin.Psy.D)

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## **Overview**

This Thesis comprises a clinical and a research volume. It is submitted in partial fulfilment of the requirements for the degree of Doctorate of Clinical Psychology (Clin.Psy.D) at the University of Birmingham.

### **Volume 1**

Volume I, the research component, comprises a systematic literature review, an empirical paper and a public domain briefing paper. The systematic literature review examines the similarities and differences between attributes and symptoms of individuals with schizophrenia and individuals with Asperger Syndrome. The empirical paper explores the subjective experiences of moving from primary to secondary school for young people with Asperger Syndrome. The public domain briefing paper provides an accessible summary of both the literature review and empirical paper.

### **Volume II**

Volume II, the clinical component, consists of five clinical practice reports. These reports approach clinical work from a range of different perspectives in individuals of different ages, abilities and cultural backgrounds. The first report details a 44 year old women experiencing recurrent episodes of low mood whose difficulties are formulated from both a cognitive behavioural and psychodynamic perspective. The second report presents a single case experimental design which was used to evaluate the effectiveness of anxiety management versus psychodynamic approaches to obsessive behaviours in a 52 year old lady. The third report details a referrer satisfaction survey carried out within a specialist learning disabilities service. The fourth report considers a cognitive behavioural approach to low self esteem in a 73 year old lady. Finally the abstract of an oral presentation is included which explores the role of low self esteem in a 24 year old lady with a history of psychosis.

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## LITERATURE REVIEW:

### **Similarities and differences between attributes and symptoms of individuals with schizophrenia and individuals with Asperger Syndrome: A systematic review**



## **Abstract**

### *Introduction*

The degree of overlap in profiles of strengths and difficulties between individuals who have been given a diagnosis of Asperger Syndrome and those who have been given a diagnosis of Schizophrenia has led to interest into how best to separate these two groups of individuals to inform intervention. The utility of classifying individuals through the use of diagnostic categories has also been challenged with the suggestion of a formulation based approach to individual difficulties

### *Aims*

This article aims to critically review the research around the similarities and differences between the cognitive abilities of individuals with the diagnostic label of Asperger Syndrome and individuals with the diagnostic label of Schizophrenia. The utility of the current diagnostic system for these individuals is then be considered.

### *Method*

A systematic search of PsycINFO, and Medline was carried out. Following the application of inclusion and exclusion criteria 16 articles were selected. The quality of these articles was assessed using a quality framework and their findings reviewed accordingly.

### *Results*

Significant similarities between the two groups were observed, especially in terms of understanding of, and behaviour around, others. There was emerging evidence of differences in deception abilities, attribution styles and IQ profiles.

### *Discussion*

Despite some emerging differences between these two groups the degree of overlap in patterns of difficulties has created difficulties clearly defining them. There is evidence to

suggest that a formulation based approach to understanding individual strengths and difficulties may provide clearer goals for intervention which could be beneficial for both services and service users.

Keywords: Asperger Syndrome, Schizophrenia, cognitive, differences

## Introduction

Autism spectrum disorders (ASDs) are characterised by a triad of impairments in socialising, communication, and repetitive or stereotyped behaviours (Wing, 1981; Gould, 1982).

Individuals diagnosed with an ASD vary in their presentation depending on where they fall on the spectrum, from those with low functioning autism who might find it difficult to understand the world and communicate basic needs, to those whose difficulties are more subtle and may only be identified in complex situations which challenge them. This may result in some children remaining undiagnosed until their teenage years when social demands on them increase (Howlin & Asgharian, 1999).

Since the identification of ASDs by Leo Kanner and Hans Asperger in 1929 there has been confusion and debate about the symptom overlap with affective disorders such as anxiety, depression and schizophrenia (Stahlberg, Soderstrom, Rastam & Gillberg, 2004; Stewart, Barnard, Pearson, Hasan & O'Brien, 2006; White, Oswald, Ollendick & Scahill, 2009). The overlap in symptoms creates particular difficulties in distinguishing Asperger's syndrome (AS) or high functioning autism (HFA), which are often not detected until adolescence, from other mental health problems with an onset in adolescence such as psychosis or schizophrenia. HFA and AS have been used interchangeably in this article as there is a consensus that there is little or no difference between the two diagnoses (e.g. Gillberg, 1998). Schizophrenia is defined in DSM-IV\* (APA, 2000) as the presence of two of the following for a significant portion of a month; hallucinations, delusions, disorganised speech, disorganised or catatonic behaviour or negative symptoms (anhedonia, alogia, avolition).

\*DSM-IV criteria have been described as these are used by the articles reviewed. In addition some authors have raised concerns that the changes made in DSM-V may have a significant effect on the difficulties an individual would need to display to qualify for a diagnosis (McPartland, Reichow & Volkmar, 2012).

For a diagnosis to be made these must result in social or occupational dysfunction (see Appendix A).

Thus, AS/HFA and schizophrenia diagnostic criteria show a significant overlap. Individuals with AS/HFA are likely to report unusual beliefs which do not fit with social norms, they may have significant social and occupational dysfunction and they often demonstrate unusual behaviours and communication styles (see Appendix A). Furthermore, they may also display negative symptoms such as alogia or present with low mood. This has led some researchers and clinicians to question the validity and utility of the current diagnostic system (Wing, Gould & Gillberg, 2011; Sharp & Lewis, 2013; DCP, 2013). Many have suggested moving from a bio-medical diagnostic model to a bio-psycho-social model, focusing on developing a greater understanding of different belief systems and how these may shift (e.g. Read, Bentall & Fosse, 2009). They argued that this could lead to a better understanding of individuals with a range of different diagnoses (Punshon, Skirrow & Murphy, 2009), and has been adopted internationally by the Early Intervention in Psychosis service model (Schizophrenia Commission, 2012).

A recent position statement released by the Division of Clinical Psychology (DCP, 2013) reinforces this trend suggesting the need for 'an approach that fully acknowledges the growing amount of evidence for psychosocial causal factors'. It recognises a role for psychological assessment, formulation and intervention rather than a psychiatric diagnosis to address limitations in validity and reliability of diagnosis in addition to reducing stigmatisation and disempowerment (DCP, 2013). The recent publication of DSM-V has raised additional concerns that as the 'classification' of difficulties has changed through its revisions, experiences which many typically developing individuals have are included in the criteria and thus 'pathologised'. This has resulted in a lower threshold for diagnosis and

makes diagnosis more likely (BPS, 2012). Furthermore there have been concerns raised that the criteria in DSM-V may substantially change the makeup of some disorders such as ASD (McPartland, Reichow & Volkmar 2012), raising the question of their validity or usefulness. An approach which formulates individual differences to provide a client centred approach to wellbeing rather than a medical diagnostic approach (Robbins, 2013) would address these difficulties.

Despite the growing concerns with the use of categorical diagnoses, this approach is currently widely used within the NHS to commission and fund services. Furthermore the majority of published literature uses diagnostic criteria to inform evidenced based interventions within clinical settings. In recognition of this, this systematic review will consider the similarities and differences between individuals who have been given a diagnosis of AS/HFA and those who have been given a diagnosis of schizophrenia. The reader is asked to keep these diagnostic concerns in mind for consideration within the discussion.

There are a plethora of case reports of individuals who have been diagnosed with schizophrenia and admitted to psychiatric hospitals who have shown minimal response to psychotropic medications (Altas & Gerbino, 1995; Clarke, Baxter, Perry & Prasher, 1999; Dossetor, 2007). On review many of these individuals have been re-diagnosed as having ASD (Perlman, 2000; Dossetor, 2007). They are described as high functioning prior to the diagnosis, and appeared to develop normally until their teens when they began to withdraw from their peers, display increased levels of unusual behaviours and appeared to develop paranoia (Larsen & Mouridsen, 1997). Sporn et al (2004) and Perlman (2000) commented on how the different ways in which children with ASD experience the world can lead to social isolation, depression, and paranoid or unusual behaviours. These are suggested to be the

result of misinterpretation of social cues rather than the result of delusions or hallucinations. They commented on the effect of acute stress on the presentation of an individual with AS and how this may appear similar to an individual who is vulnerable to psychosis where the onset is caused by acute stress (Strauss & Carpenter, 1981).

In addition to the misdiagnosis of some individuals with ASD as psychotic, there are also challenges around differential diagnosis. Many studies have found a higher incidence of psychosis in individuals with ASD than in the general population (Atlas & Gerbino-Rosen, 1995; Clarke et al, 1999; Sporn et al, 2004). Clarke et al (1999) reported a series of seven cases in which individuals had been given a diagnosis of ASD, and were subsequently given a diagnosis of bipolar, psychotic depression or schizophrenia. The majority of these clients responded well to medication, a finding reinforced by other case studies (Atlas & Gerbino-Rosen, 1995). However psychotherapeutic work had to be adjusted for these individuals to be successful; with shorter sessions and support recognising and labelling thoughts and emotions (Atlas & Gerbino-Rosen, 1995; Perlman, 2000). Sporn and colleagues (2004) concluded that the individuals with comorbid autism or pervasive developmental disorder (PDD) and childhood onset schizophrenia (COS) were showing the same clinical patterns as those with a diagnosis of COS, but that there were additional confounding factors such as abnormal interests, poor cooperative play, and difficulties with reciprocal communication.

## **Aims**

The current paper will systematically review the evidence to further our understanding of the difficulties that arise with differential diagnosis. It will do this by asking three key questions of the current evidence;

- What are the similarities and differences between the neuropsychological presentation of individuals with the diagnostic label of AS and individuals with the diagnostic label of Schizophrenia?
- Is the level of similarity between individuals with the diagnostic label of AS and individuals with the diagnostic label of Schizophrenia dependant on the relative levels of positive and negative symptoms?
- What is the evidence for similarities in social functioning between the two groups and how does the literature explain this?

The research literature on psychosocial functioning of individuals with the diagnostic label of AS and individuals with the diagnostic label of Schizophrenia will be scrutinised in order to answer these questions. Throughout the review diagnostic categories will be used due to the reliance on these within the published literature; however the validity of these criteria will be reconsidered during the discussion. In acknowledgement of the imperfections and subjectivity of the diagnostic criteria individuals with the diagnostic label AS/HFA will be referred to as the 'AS group' whilst individuals with the diagnostic label schizophrenia will be referred to as the 'S group' within this review. Thus this review may increase our understanding of the specific differences between the two 'diagnoses' as they are currently used, and help to inform whether the current diagnostic process is conceptually and clinically valid for individuals with these patterns of difficulties. It may also suggest improvements for assessment and intervention services which are currently received by individuals who present with these types of experiences in addition to identifying areas which require further research.

## Method

A literature search was run in PsycINFO, and Medline 1946- 20<sup>th</sup> April 2013 containing the terms Asperger Syndrome OR Aspergers Syndrome OR Asperger's Syndrome AND psychosis OR schizophrenia, all terms expanded (See table 1). This elicited 214 articles.

Search Terms: Combining	And
Asperger Syndrome	Psychosis
Aspergers Syndrome	Psychosis
Asperger's Syndrome	Psychosis
Asperger Syndrome	Schizophrenia
Aspergers Syndrome	Schizophrenia
Asperger's Syndrome	Schizophrenia

*Table 1:* The search terms used to search for articles

These 214 articles were then subjected to the following criteria (see Table 2 and Figure 1).

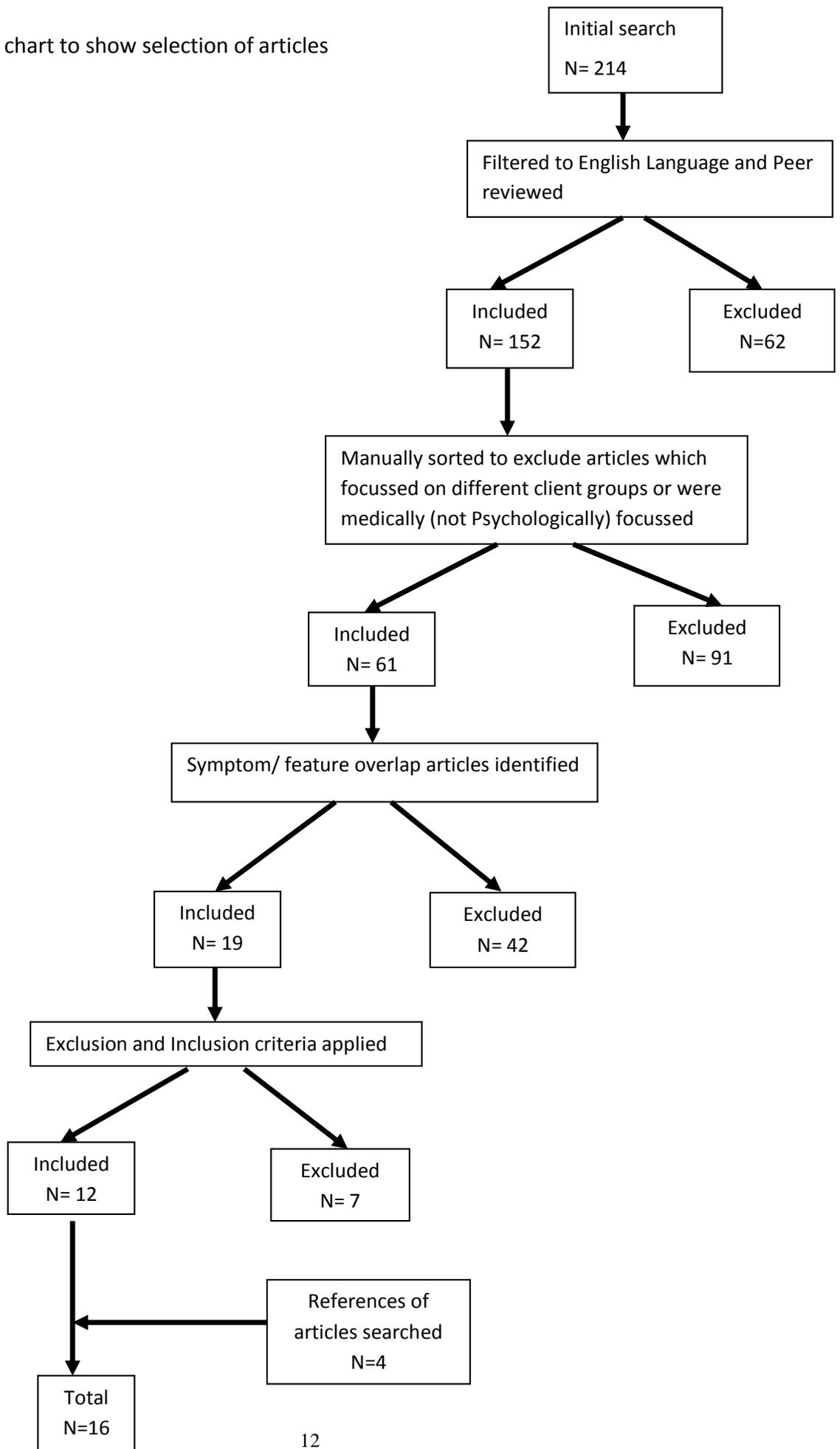
The results were filtered to only include English language articles, and those from peer reviewed journals. This left 152 articles. These were then sorted by hand to exclude any articles which did not address the correct client groups or were medically (rather than psychologically) focused. This left 61 articles. These articles were then sorted into those which addressed the issue of differential diagnosis, those focusing on bipolar syndrome, those which considered treatment options, and those considering symptom/feature overlap. There were 19 articles considering feature overlap of which 7 were case study articles. Case study articles were excluded from the analysis, and only studies which directly compare two groups of participants using neuropsychological assessments or interviews were included within the review. The majority of studies directly compare individuals with a

diagnosis of ‘schizophrenia’ or ‘schizotypal personality disorder’ with individuals with ‘AS’ or ‘HFA’. A small number of studies which focused solely on either ‘individuals with schizophrenia’ or ‘individuals with AS or HFA’ were also included as they made clear reference to the other group of individuals as part of the analysis or conclusions. The remaining 12 articles were reviewed and careful consideration of their reference lists elicited a further 4 relevant articles. These 16 articles are included within this review and described in Table 3.

	<b>Inclusion criteria</b>	<b>Exclusion criteria</b>
Language	English	Not written in English
Journal type	Peer reviewed	Non peer reviewed or review articles
Stance	Psychological	Medical
Focus	Symptom or feature overlap considered	No comparison of symptoms or features
Number of participants	More than 2	Only one individuals described
Types of participants included	Individuals with AS/HFA and/or schizophrenia considered. If only either or then clear reference to the other group must be made	Only individuals with AS/HFA or schizophrenia considered with no reference to the other group, or similarities in attributes. Articles focusing on bipolar syndrome were also excluded.
Study type	Direct comparison of individuals using neuropsychological assessment or interview	Individual cases described but not compared

*Table 2:* Inclusion and Exclusion criteria for studies

Figure 1: Flow chart to show selection of articles



Study number	Article	Aims	Participants	Method type	Measures used	Analysis; what used?	Findings
1	Abell & Hare 2005	Explore the nature and prevalence of delusional beliefs within AS group	N=46 adults with AS.	Interview	Peters' Delusions Inventory, WASI, Self Consciousness Scale, HADS, Strange Stories Test, Hayling Sentence Completion Test, Autobiographical incident schedule of the Autobiographical Memory Interview	Mean and range reported for all measures.	AS group had relatively high levels of grandiose and persecutory ideas. These were associated with anxiety, social anxiety and self consciousness.
2	Blackshaw, Kinderman, Hare & Hatton 2001	Explore the levels of paranoid ideation, self consciousness and causal attribution in the AS group	N=43 25 with AS 18 TD Not age, sex or IQ matched	1-2 hour interview plus completion of measures	Paranoia Scale, Internal, Personal and Situational Attributions Questionnaire, Projective Imagination Test, Stroop task, HADS, National Adult Reading Test, Self Discrepancies Questionnaire, Self-Consciousness Scale	Parametric; T tests, Levene's test for equal variance, Kolmogoroff-Smirnoff tests, MANCOVA and Regression analyses	AS group scored higher on paranoia measures, higher on private self consciousness and lower on theory of mind. There were no differences found in attribution style.
3	Bolte & Poustka 2003	Examine capacity to detect facially expressed emotion in ASD* and S groups	N=226 adults and children. Not sex matched 82 parents of ASD, 20 siblings of ASD, 35 with ASD. 35 Parents of S, 11 siblings of S, 21 with S, 22 TD.	Computer based assessment	Raven's coloured or Standard Progressive Matrices, Test for recognition of facial affect	Parametric; two way ANCOVA	Emotional detection deficits evident in ASD group, and some weaknesses in family, but S group were not significantly different from controls.

Study number	Article	Aims	Participants	Method type	Measures used	Analysis; what used?	Findings
4	Bowler 1992	Explore the relationship between social impairment and theory of mind difficulties in AS, S and TD groups	N= 45 adults. Not age or sex matched 15 with AS 15 with S 15 TD	Neuropsychological assessment. Then participants were read scenarios then asked to answer questions	WAIS Second order theory of mind tasks	WAIS analysed with t-tests, percentages given for story responses.	AS group were able to solve second order theory of mind tasks but not explain their solutions in terms of mental states. They scored at a similar level to the S and TD groups.
5	Couture, Penn, Losh, Adolphs, Hurley & Piven 2010	Examine social cognitive abilities of S and HFA groups	N=121 adults. Not age or sex matched 36 with HFA 44 with S, 41 TD	Neuropsychological assessment and computerised assessment	SCID-P for Sch, ADI-R for HFA, WASI, Point-Light motion displays, Movie Stills, Abbreviated Trustworthiness task, Eyes task	Parametric; ANCOVA, Bonferroni post hoc.	HFA and S groups were impaired relative to TD but not significantly different from one another.
6	Craig, Hatton, Craig & Bentall 2004	To compare theory of mind abilities and attributional style in AS group and S group	N=49 adults, age and IQ matched 16 with paranoid S 17 with AS 16 TD	Questionnaire measures, Structured Interview	Paranoia Scale, Attributional Style Structured Interview, Hints task, the 'Reading the Mind in the Eyes' test, National Adult Reading Test	F values and p values given, Pearson Correlation also used	S group scored highest on the paranoia scale, with more external-personal attributions. AS group also scored higher than TD group on the paranoia scale. Both the S and AS groups showed poorer theory of mind.
7	Esterberg, Trotman, Brasfield, Compton & Walker 2008	Consider rate of autistic traits in SPD, and investigate relationship with development of psychosis on 3 year follow up	N=121 adolescents Age and sex matched. 35 SPD, 48 TD, 38 other PD	Telephone screening, videotaped baseline interview, annual follow up interviews	SIDP-IV, SCID-I, SIPS, ADI-R,	Parametric; T-Tests, MANCOVA, Linear and logistic regression	SPD group showed significantly more autistic features, especially social impairments and unusual behaviours, than TD or other PD groups.

Study number	Article	Aims	Participants	Method type	Measures used	Analysis; what used?	Findings
8	Hirao et al 2008	Consider theory of mind impairments and brain areas affected in S group	N=40 adults 20 with S 20 TD	Neuropsychological assessment followed by an MRI scan	Japanese National Adult Reading Test, 'Vocabulary' and 'Block Design' subtest of the WAIS-R, Benton Facial Recognition Test, 'Reading the Mind in the Eyes' test.	Parametric; Independent sample t-tests and ANCOVA	S group showed poorer response on the Reading the Mind in the Eyes test, which was associated with a reduction in ventrolateral prefrontal cortex grey matter.
9	Irani et al 2006	To explore the relationship between theory of mind and self face recognition in S group	N=30 adults 10 with S, 10 of their first degree relatives 10 TD	Computerised assessment	SPQ Computerised Revised Mind in the Eyes Test Self-face recognition task	Parametric; Paired sample t-tests, MANCOVA and ANCOVA	S group show both face recognition and theory of mind deficits relative to TD. Relatives show some deficits but these are not as pronounced.
10	Konstantareas & Hewitt 2001	Assess similarities and differences in presenting characteristics of S and HFA groups	N=28 adult males 14 with S 14 with HFA	Interviews, observational data, psychometric evaluation and medical records	SCID SAPS SANS CARS Leiter IQ	Pearson Correlation T-tests with Bonferroni correction	None of the S group met criteria for autism but 7 of the HFA group met criteria for Schizophrenia
11	Lugnegård, Hallerbäck, Hjärthag & Gillberg, 2013	Compare social cognition abilities in AS and S groups	N= 139 53 with AS 36 with S 50 TD	Interviews and psychometric assessment	SCID, DISCD Vocabulary subtest (WAIS-III), Reading the Mind in the Eyes Test, Animations Task.	Parametric and non parametric, ANOVA, Chi-squared Kruskal-Wallis test, Mann-Whitney U-test, Holm-Bonferroni test	S group showed greatest difficulty with theory of mind tasks, whilst AS group scored relatively better but still significantly poorer than TD.

Study number	Article	Aims	Participants	Method type	Measures used	Analysis; what used?	Findings
12	Murphy 2006	Compare theory of mind in AS and S groups	N=39 adult males, age matched 13 with AS 13 with S 13 with PD. Forensic setting	One off individual assessment	WAIS-R, Revised eyes task, Modified advanced theory of mind test	Non-Parametric; Kruskal Wallis	Theory of mind difficulties present in both AS and S groups but not PD.
13	Ozguven, Oner, Baskak, Oktem, Olmez & Munir 2010	Compare theory of mind performance across AS, S and TD groups	N= 55 adults, age gender and IQ matched 14 with AS 20 with S 21 TD	Interview and neuropsychological assessment. Number or length of sessions not reported.	SCID-I, CGI, SAPS, SANS, First and second order false belief tasks (stories task) WAIS-R	Non-parametric; Kruskal-Wallis and Mann-Whitney U with Bonferroni correction	S group show similar theory of mind impairments to AS group. Those with high numbers of negative symptoms show greatest similarities.
14	Pilowsky, Yirmiya, Arbel & Mozes 2000	Examine theory of mind and cognitive abilities in S and HFA groups	N=36 children 12 with HFA 12 with S 12 TD	Seen individually for a minimum of 3 90 minute sessions. At least a week break between sessions.	Checklist of DSM IV criteria for Sch & Kiddie-SADS for Sch only, Checklist of DSM-IV criteria for HFA, ADI-R and ABC for HFA only,. WISC-R or WISC III 'Fact and Value Belief' task, 'Deception' test and 'False Belief' task	Mixed Non-Parametric and parametric; MANOVA, Kruskal-Wallis and Scheffé post hoc analysis	HFA group scored poorly on 'Fact and Value Belief' and 'Deception' tasks relative to TD and S groups, but both HFA and S groups scored more poorly than TD on the 'False Belief' task
15	Sasson et al 2007	Compare visual scanning and emotional judgements in ASD* and S groups	N=30 10 with ASD 10 with S 10 TD	Computerised assessment	For ASD only ADOS and ADI-R For Sch only SCID-P WASI 12 images from the 'Social Scenes' task	Parametric; paired t-test, ANOVA and Pearson correlation	Both ASD and S groups fixated faces less than controls, with ASD group being slower at this process than S group

Study number	Article	Aims	Participants	Method type	Measures used	Analysis; what used?	Findings
16	Van Lancker, Cornelius & Kreiman 1989	Compare AS, S, TD understanding of linguistic vs emotional meanings in speech.	N = 80 children, not age or sex matched. 28 with AS 19 with S 33 TD	Two individual assessments	Merrill-Palmer test, WPPSI, Emotionally neutral sentences read in an emotional manner	Parametric; T-tests, Correlation analysis	AS group scored poorly when asked to identify the emotional meanings of speech; S group scored at the same level as TD.

AS=Asperger Syndrome, HFA=High Functioning Autism, ASD=Autism Spectrum Disorder, S=Schizophrenia, SPD = Schizotypal Personality Disorder, PD = Personality Disorder, TD= Typically developing

\*Although this article does not specify where on the spectrum it's participants with ASD fall, the average non verbal IQ is 103 suggesting these are high functioning individuals.

*Table 3: A description of the studies included in this review*

The articles were then evaluated using a quality framework. A range of different quality frameworks have been used by different authors (Caldwell, Henshaw & Taylor, 2005; CASP, 2011; Sale & Brazil, 2004; Salter, Hellings, Foley & Teasell, 2008), however, there is no consensus regarding which frameworks are most reliable (Katrak, Bialocerkowski, Massy-Westropp, Kumar & Grimmer, 2004). There are a range of general methods suggested which allow the reviewer to consider broad areas such as methods, recruitment of participants, data collection, analysis, findings and value of research but these do not provide clear criteria which can be used to distinguish between similar articles (CASP 2006). In this review a method suggested by Caldwell et al (2005) has been selected as it allows the author to apply clear criteria to each article, standardising the process by applying clear questions (see Appendix B) and reducing the impact of personal biases and simplifying the process for the novice reviewer. The current review uses a version of the framework developed by Tolley (2012) who operationalised the framework to ensure consistency in rating. This framework has then been adapted to produce a numerical rating of quality to allow the reader to make rapid judgments on the efficacy of each article. The decision making process for the quality rating system is show in Table 4 below.

*Table 4: Quality rating system*

Quality rating	Definition
2	All or most of the criteria have been met. Criteria that have not been met are very unlikely to impact on the quality or conclusions of the study.
1	Some of the criteria have been met. Criteria that have not been met or described in sufficient detail are <b>unlikely</b> to impact on the quality or conclusions of the study.
0	Few or no criteria met. The unmet criteria are <b>likely</b> to have an impact on the quality or conclusions of the study.

Table 5: Framework describing the quality of the studies included (B=Bronze, S=Silver, G=Gold)

Study number	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16	Mean
Rationale Clearly described	2	2	2	1	2	1	2	2	2	2	2	2	2	2	2	2	1.87
Research aims stated	2	1	2	1	2	0	2	2	0	1	2	2	2	2	2	1	1.50
Ethical issues addressed	2	0	0	0	2	0	0	2	2	0	2	2	2	2	2	0	1.13
Method appropriate to question	1	2	2	1	2	2	2	2	2	2	2	2	2	2	2	2	1.87
Design identified and rationale evident	2	2	0	1	1	1	2	2	1	1	1	2	1	1	2	2	1.38
Hypothesis stated	0	2	0	0	2	0	0	2	2	2	0	2	2	2	2	1	1.19
Key variables identified	0	2	1	1	2	1	1	1	1	2	1	2	1	2	1	1	1.25
Sample population situated	1	2	2	1	2	2	1	2	2	2	2	2	2	1	2	1	1.69
Participant selection described	2	2	1	1	1	1	1	2	2	1	1	2	2	2	2	2	1.56
Data collection reliable & valid	1	1	1	1	1	1	1	2	1	2	2	1	2	1	1	2	1.31
Data analysis reliable & valid	1	2	2	0	1	0	2	2	2	1	2	2	2	2	1	1	1.44
Findings clearly stated	2	2	2	1	1	1	2	2	1	1	1	2	2	2	2	1	1.56
Comprehensive discussion	2	2	1	2	2	2	2	0	1	2	1	2	1	2	2	2	1.63
Strengths and limitations identified	2	2	2	0	1	0	2	1	1	1	1	2	1	2	1	0	1.19
Justifiable conclusions made	2	2	2	2	0	2	2	2	1	2	1	2	2	2	2	2	1.75
Total	22	26	20	13	22	14	22	26	21	22	21	29	26	27	28	20	
	S	G	S	B	S	B	S	G	S	S	S	G	G	G	G	S	
Medications considered?	N	N	N	N	N	N	Y	N	N	Y	Y	Y	Y	Y	Y	N	

This rating system was used within the scoring grid to help to differentiate between the studies, providing a maximum possible score of 30. On the basis of the ratings, studies fall into one of three categories; Gold (a score of 25 or more) where most of the criteria are met effectively, Silver (a score of 18-24) where most criteria are partially met or Bronze (a score of less than 17) where many of the criteria are not met or are inadequately met leading to reduced confidence in the results of these studies. The studies have been reported in alphabetical order in Table 5, with the category rating given with the total score.

Results from this process identified 6 articles of gold standard, 8 articles of silver standard and 2 of bronze standard. Across the articles some of the quality criteria scored higher than others. The majority of studies scored high on rationale (mean=1.87), selection of method (mean= 1.87) and conclusions (mean=1.75); however across many studies description of hypotheses (mean=1.19), consideration of ethical issues (mean=1.13), and identification of the study's strengths and limitations (mean= 1.19) were of a lesser standard.

There were some key differences between studies which fell into different rating bands, with gold rated studies clearly stating their hypotheses, describing participant selection and stating the study findings, issues that were not clearly explained in the studies of silver and bronze quality. In contrast the bronze rated studies did not adequately describe a rationale, did not report using reliable and valid data analysis methods and failed to identify the strengths or limitations of the research, issues that were addressed by the studies of silver and gold quality.

## **Results**

The articles considered approached the similarities and differences between the neuropsychological profiles of the AS group and S group by considering different aspects of

participants' neuropsychological\* profile. The results of the studies are grouped by IQ, theory of mind, emotional perception, and social skills\*, areas which have been considered in detail by the studies. There are additional sections focusing on symptoms of psychosis and the diagnostic criteria for AS/HFA, directly comparing the groups by applying measures used to inform diagnosis. Each section details the studies included and their rating on the quality grid before comparing and contrasting their findings.

## ***IQ***

Nearly all the articles included in this review tested the IQ of their participants but the degree to which this was reported varies greatly, from just the FSIQ (Studies 1, 2, 3, 5, 6, 10, 12, 15 and 16), to details of the index scores or subtest scores (Studies 4, 8, 11, 13 and 14).

When considering FSIQ on a range of different measures (Leiter R, WAIS-R, WAIS-III, Raven's Progressive Matrices) the majority of studies found no significant differences between the two groups (Studies 3, 4, 5 and 6). These studies were of bronze and silver quality. The studies that did find differences in IQ between the two groups varied in their findings, with one gold and one silver rated study reporting that the S group had a higher IQ than the AS group (studies 10 and 14) but another gold rated study reporting the opposite (study 12).

When IQ is considered in more detail differences become apparent. Study 14 found that the S group scored particularly poorly on the 'Arithmetic' subtest (a test of working memory) of the WAIS-R (Wechsler Adult Intelligence Scale- Revised, Wechsler, 1981); a finding that was not replicated in the AS group which scored worse than expected on tests of verbal abilities.

\*The use of the terms neuropsychological and 'social skills' reflect those used within the reviewed literature rather than referring to the actual concepts

This gold rated study argued that this suggests communication difficulties in the AS group and working memory difficulties in the S group. This finding was reinforced by a bronze quality study (4) which found that the S group scored relatively, but not significantly, better than the AS group on verbal subtests. Furthermore this group scored significantly better on tests of working memory, as measured by the WAIS-R 'Digit Span' subtest (study 4). In contrast, studies of silver (study 11) and gold (study 13) quality found similar scores on the 'Vocabulary' subtest for both groups using the WAIS-R. However in the WAIS-R the 'Verbal Comprehension' index combines working memory and verbal subtests, so it is not surprising that both groups scored at a similar level. The relative weakness on verbal tests in the AS group is likely to have balanced out the relative weaknesses on working memory tasks in the S group.

Overall the IQ of the AS and S groups appear to be similar, however there is some evidence that where the AS group show a relative weakness in verbal abilities, the S group show a relative weakness in working memory abilities.

### ***Theory of mind***

Theory of mind abilities were assessed in nine of the articles included in this review; four of which achieved gold ratings (studies 8, 12, 13 and 14), three which achieved a silver rating (Studies 5, 9 and 11) and two which received a Bronze rating (studies 4 and 6).

Theory of mind is the ability to understand that other people hold representations or beliefs about the world that may be different from your own, and that they behave in accordance with these beliefs (study 4). It has been identified as one of the corner-stones of AS/HFA with widespread difficulties in theory of mind common across all levels of functioning. There are a range of tests used to consider theory of mind, which vary from the 'Mind in the Eyes'

test (MinE) (Baron-Cohen, Wheelwright, Hill, Rate & Plumb, 2001) which focuses on the subject's ability to recognise emotion from a person's eyes, to story-based tasks which present a range of questions to the reader (e.g. 'The Stories Test', Perner & Wimmer, 1985; 'Fact and Value Task', Flavell, Flavell, Green, & Moses, 1990; 'Hints Task', Corcoran, Mercer & Frith, 1995).

Many studies which used MinE test and found that there were no differences between the AS and S groups, with both groups finding it more challenging than typical controls (studies 5, 6, 8 and 12). However, study 11 found that the S group scored significantly worse on this task than controls, whereas they found no significant difference between the AS group and controls. They acknowledged using the child version of this task and the possibility of ceiling effects skewing the data can therefore not be ruled out. A further study found similarities between the S and AS group, with both groups reacting just as rapidly to the MinE task as typical controls but less accurately (study 9).

Using the 'Fact and Value' task (study 14) found similar results; there were no significant differences between AS and S groups, a result which was further reinforced by study 6 which used the 'Hints Task'. An additional test asks participants to describe the relationship of two 'animated triangles', and rates their descriptions in terms of appropriateness and intentionality (Abell, Happe & Frith, 2000; Castelli, Frith, Happe & Frith, 2002). Study 11 found that the S group found both aspects of this task challenging, and were significantly worse at it than the AS group who in turn found it significantly more challenging than the TD group.

Study 4 found that on the 'Stories Test' the S group did significantly worse than both AS and TD groups. However, study 13 found that both AS and S groups found second order theory

of mind tasks more challenging than non-clinical populations. These results were reinforced by two further studies which found that both groups performed equally badly on story based tasks and scored significantly less well than the control group (studies 12 and 14). The reasons for these differing results are unclear as these studies used similar tasks. However, the study which reported that individuals with AS perform in a similar way to controls was only rated bronze on the quality grid (study 4) whilst the other studies were rated silver or gold. This suggests that there are no differences between the performance of the AS and S groups on first and second order theory of mind tasks and that both clinical groups perform less well than peers in the non-clinical population.

### ***Emotional Perception***

Emotional perception abilities were assessed in five of the articles included in this review one of which achieved a gold rating (study 15) and four of which achieved silver ratings (studies 3, 5, 9 and 16).

Whilst the MinE task requires participants to judge a person's emotion from a picture of their eyes, this task is widely reported to measure theory of mind abilities rather than emotional recognition (Baron-Cohen, Wheelwright, Hill, Rate & Plumb 2001). However it could also be considered a test of emotional recognition, and will be included in addition to a range of other measures. Study 3 developed a test which asks participants to identify emotion from a person's face. They found that both the S and TD groups performed at the same level on this task, but the AS group performed worse. This is in contrast to the findings on the MinE test suggesting that whilst the S group may find it equally difficult to read emotions from the eyes as the AS group, they are able to do this effectively when other facial cues are present. This finding was reinforced by study 15 which asked participants to

judge emotions from a picture of a social scene (Adolphs & Tranel, 2003). They found that the AS and S groups were just as good as controls at judging the emotion from the scene but that they spent a reduced amount of time focusing on the faces in the scene. However, they also found that when the faces in the scene were removed the S group spent less time focusing on facial areas, similar to controls. The amount of time the AS group spent focusing on facial areas did not decrease when the faces were removed. They hypothesized that the S group may take longer to focus on a face due to anti-psychotic medication, whereas the AS group may have difficulties identifying or attending to faces (study 15).

Study 9 found that the S group had significantly more difficulty identifying their own face than controls. In this study subjects were briefly presented with images of faces and had to determine whether the face they saw was their own face or someone else's. Furthermore when asked to interpret emotion from body movement in the 'Point-Light-Motion Display' task the S group again scored less well than the TD group and at a similar level to the AS group (study 5).

A further study considered the ability of children with AS and schizophrenia to identify the emotional and linguistic meanings of speech relative to TD children (study 16). Participants were played sentences by tape recorder and asked to choose one of four linguistic and one of four emotional meanings. They found that there was no difference in the three groups when asked to pick out the linguistic meaning of the sentence they heard. However, when asked to give the emotional meaning the AS and S groups scored at the same level, both scoring significantly below the TD group.

It appears that the S group are marginally better at recognising emotions when they are presented with additional cues, such as an entire face, rather than just the eyes, but may

orient to faces more slowly which impairs their performance on timed tasks. The effect of psychotropic medication on this process is unclear. There is some evidence that the S group may have a similar level of difficulty to the AS group when the information available is reduced (to just the eyes) or the task is made more abstract.

### ***Social Skills***

Social skills were assessed in five of the articles included in this review, two of which achieved gold ratings (Studies 2 and 14), two achieved silver ratings (Studies 1 and 5) and one received a Bronze rating (study 6).

When asked to judge the trustworthiness of faces both S and AS groups rated the untrustworthy faces more positively than controls, potentially reinforcing the evidence that they have difficulty reading others' intentions from their faces (study 5). However when asked to deceive the experimenter the S group were significantly more adept than the AS group who found this particularly challenging (study 14).

A study considering attribution style found the S group have more external and global attributions (Weiner, 1980) than the AS group whose performance on such tasks falls between them and the TD group (study 6). This means that they are more likely to explain the cause of events as due to other people or circumstances rather than due to themselves, and they refer to wide reaching rather than specific causes (Stratton et al, 1986). This study was replicated in studies 1 and 2 which concluded that there are no significant differences in externalising or causal attribution bias in AS relative to the TD group. Studies 1 and 2 suggested that the paranoia reported by some of the AS group was a result of confusion about the subtleties of social situations and their misinterpretation. Despite the variation in

quality of these studies there is convincing evidence that the attribution styles of the AS group resembles that of the TD group more than the S group.

There is evidence that the AS group show similar attribution styles to non- clinical populations, although they are likely to find the subtleties of social interactions more challenging, finding it difficult to judge a person's trustworthiness or indeed to deceive others. This is in contrast to the S group which despite showing similar difficulties judging the trustworthiness of others, was more adept at deception and showed external and global attribution styles.

### ***Symptoms of Psychosis***

Symptoms of psychosis were assessed across both the AS and S groups in six of the articles included in this review, one of which achieved gold ratings (study 2), four which achieved a silver rating (Studies 1, 5, 10 and 13) and one which received a Bronze rating (study 6).

Many articles only considered the presence of positive or negative symptoms in the S group, without considering whether any of the AS group might meet diagnostic criteria for schizophrenia (Studies 3, 12, 14 and 16). However there is some evidence that the S group with high levels of negative symptoms have similar scores to the AS group on emotion perception and social skill tasks (studies 5 and 13). Furthermore study 10 found that more of the AS group showed negative symptoms than the S group (6/14 vs 2/14). When positive symptoms of schizophrenia are considered ('Scale for the Assessment of Positive Symptoms'; Andreasen, 1984a) all of the S group and 5 out of 14 in the AS group showed evidence of positive symptoms (study 10). There is therefore some evidence that whilst delusional ideation is found in the AS group, this is at a lower intensity than for the S group.

However, the AS group do show a greater intensity of delusional ideation than the TD group, especially with regard to paranoia and grandiosity (Studies 1, 2 and 6).

Studies have found a greater intensity of delusional ideation in the AS group relative to the TD group, although not as intense or frequent as the delusional ideation found in the S group (Studies 1, 2 and 6). There is also evidence that the AS group show high levels of negative symptoms (study 10), which might lead to them presenting in a similar way to members of the S group who have high levels of negative symptoms.

### ***Symptoms of ASD***

Symptoms of ASD were assessed across both AS and S groups in only two of the articles included in this review both of which achieved a silver rating (studies 7 and 10).

Study 7 found that individuals with positive symptoms of schizotypal personality disorder (see Appendix A) showed higher levels of social impairment, and unusual interests and behaviours than their peers, attributes usually associated with ASD. Furthermore the severity of these difficulties was a strong predictor of positive symptoms of schizophrenia.

These results are unsurprising given the similarities between the two diagnostic criteria (see Appendix A). For example, the criteria for schizotypal personality disorder includes odd thinking and speech, inappropriate or constricted affect, odd or eccentric behaviour, and a lack of close friends or confidants. These are all characteristics that would be expected in individuals who are on the autistic spectrum, and are part of the triad of communication, socialisation and imagination difficulties used to inform diagnosis.

Study 10 found that none of the S group reached the cut off for a diagnosis of AS/HFA, but their scores were relatively higher than controls. However it is difficult to identify the validity of this result given that AS falls on a spectrum; diagnosis is often subjective

according to who carries out the assessment and their interpretation of the behaviours that are reported. No other study which used measures of ASD (studies 3 and 5) administered these to the S group.

Given the overlap in diagnostic criteria between AS/HFA and schizotypal personality disorder it is to be expected that there is a significant overlap between the two disorders. Furthermore, given these similarities, and the social and communication difficulties that develop alongside schizophrenia, the finding that the S group score more highly than the TD group on attributes of ASD is unsurprising (study 10).

## **Discussion**

There are a number of similarities between the AS and S groups. With regard to first and second order theory of mind, emotional recognition from the eyes, voice or body and ability to judge the trustworthiness of others, the AS and S groups score at a similar level and significantly worse than the TD group. However, the S group score significantly better than the AS group when additional cues are provided in emotional recognition tasks, and show a better grasp of complex social interactions such as deception. Although the AS group show higher levels of 'delusional' beliefs than the TD group, these appear to be primarily linked to misinterpretation of, or confusion around, social situations suggesting the importance of understanding the root and extent of any 'delusional' beliefs when an individual presents to services. The impact of anti-psychotic medications, especially on timed tasks, (due to its effect on the processing speed of individuals) is unclear as the majority of studies did not take this into consideration.

There was also a significant difference between how the S group with high levels of positive symptoms scored on emotional recognition and social skills tasks relative to the S group

with high levels of negative symptoms. This clearly effects how their performance compares to the AS group. The S group with positive symptoms showed greater numbers of autistic traits including restricted interests, communication difficulties and social impairment than the TD group. However, they score lower on these traits than the AS group. Conversely almost half of the AS group showed high numbers of negative symptoms, scoring at a similar level to the S group. These included anhedonia, avolition, and alogia (see Appendix A). The AS group may display these symptoms as many prefer their own company, find conversations difficult, find it difficult to start new activities and are heavily reliant on routine. These traits may lead to high scores on measures which identify a range of symptoms without considering their origin (Positive and Negative Symptoms Scale: Kay, Opler & Lindenmayer, 1989; Scale for Assessment of Negative Symptoms: Andreasen 1984b). This suggests that the overlap between the presentations of these two groups may be due to overlap in the diagnostic criteria used to define them, and reinforces the suggestion that a formulation based approach to the individual may provide a better understanding of their difficulties (Robbins, 2013; DCP, 2013)

The highest risk group for the development of the pattern of difficulties labeled as Schizophrenia are individuals of low socio-economic status who have faced multiple challenges in their lives, are under high levels of stress and experienced trauma (Strauss & Carpenter, 1981; Read, Bentall & Fosse, 2009). Furthermore an individual is three times more likely to be given a diagnosis of Schizophrenia if they live in an urban environment (Schizophrenia Commission, 2012). This set of conditions may result in high cortisol levels during early life, affecting subsequent brain development which can lead to difficulties processing complex information and coping with complex social interactions (Read, Bentall & Fosse 2009). There is convincing evidence that individuals who have been abused during

childhood have poorer arithmetic and working memory scores (Carrey, Butter, Persinger & Bialik, 1995) which are cognitive deficits observed in the S group (studies 4 and 14). This suggests that to understand the nature of a person's psychological difficulties, knowledge and full understanding of their previous experiences is required.

Individuals said to have AS/HFA find it difficult to understand social situations (due to deficits in 'theory of mind') and how to respond to them, sometimes resulting in unusual behaviours. Individuals who have been given a diagnosis of Schizophrenia also show similar difficulties with theory of mind tasks, but this may be due to an inability to process this complex social information due to poor working memory skills. There is some evidence for this as when given additional cues to help them to understand social situations the S group performed better at these tasks whereas the AS group was not able to make use of additional social cues. In addition, the negative symptoms observed in both groups may be a product of the individuals trying to cope with a range of challenging circumstances (Oliver, Morris, Johns & Byrne, 2011).

Given these similarities in presentation and diagnostic criteria it is not surprising that there are difficulties with differential diagnosis between these two groups and that misdiagnoses have been made in the past (Perlman, 2000; Dossetor, 2007; Larsen & Mouridsen, 1997; Atlas & Gerbino-Rosen, 1995). This remains a challenge for many services today (Dossetor, 2007), and the evidence that has been gathered in this review does not provide a clear method of distinguishing between the two groups. The key differences identified concern emotion recognition and understanding of complex social interactions, however many similarities between the groups remain. This provides further evidence for the utility of a formulation based approach to individual difficulties, which allows for a person centred assessment and plan for intervention. Furthermore this would prevent some of the

difficulties which currently arise, with services attempting to categorise similar groups of symptoms in individuals who present to services in their teenage years. Some studies have argued that an informed and sensitive developmental assessment would identify theory of mind difficulties and developmental difficulties during earlier childhood (study 14) thus creating a clear AS group, however an individualised approach designed to identify strengths and weaknesses may provide a clearer focus for intervention and prevent the confusion and stigma which can arise when using diagnostic criteria (DCP, 2013).

The stigmatization, discrimination and disempowerment which can result from the use of diagnostic terminology (Mansell & Morris, 2004) suggests that careful consideration needs to be given to the role that a diagnosis would play for the individual concerned before a diagnosis is given. At present statutory services are organised using diagnostic criteria, thus a diagnosis may allow an individual access to services. Furthermore given the public familiarity with the diagnostic approach it may help to explain some of their experiences in life. However if a formulation based approach was adopted by services this could allow individuals to access the services they require without the stigmatizing effect of a diagnosis and may provide a more helpful framework for understanding individual differences rather than attempting to categorise difficulties. This would suggest the need for a multidisciplinary approach to assessment which would consider not only the current difficulties faced by an individual but their strengths, understanding of emotions, core beliefs, social situation and previous experiences in their life.

### ***Clinical Implications***

From the considered literature there is some evidence that some neuropsychological tests considering IQ and theory of mind, in particular deception abilities may be useful to inform

treatment pathways. However, the majority of evidence suggests the importance of developing an understanding of the reasons why certain beliefs or behaviours have developed. For example if the formation of 'delusional' beliefs is due to confusion around social situations, leading to mistrust of others, then clearly the intervention should be different to that for an individual who is showing mistrust despite intact understanding of some social situations and the behaviour of others. This suggests the need for services to be facilitated to provide in depth assessments of an individual's strengths and difficulties to formulate the concerns, rather than relying solely on diagnostic criteria. This is something which is being encouraged in Early Intervention for Psychosis services, with up to a 6 month multidisciplinary assessment period to clarify the nature of any difficulties (Schizophrenia Commission, 2012).

### ***Implications for future research***

Clearly more research needs to be done into whether differences in scores in different IQ subtests and verbal reasoning profiles is a useful and effective way to inform treatment pathways. Furthermore investigation into the role of hallucinatory experiences in individuals with these patterns of strengths and weaknesses may further inform the interventions offered. The degree of overlap between these two groups raises questions about utility of separating them within both the research literature and within services. Identifying and grouping individuals with clusters of strengths and difficulties may continue to be helpful in both finding evidence based interventions and organising service provision, however the utility of the intervention for the individual should be paramount. This may require critical revision of the published literature to consider how studies defined the categories by which they group individuals.

When reviewing these articles there were some common themes which raised concerns about the reliability of these articles. These areas were not considered in the quality grid and it did not feel appropriate to add them to the grid as they were common problems across studies.

Despite the evidence of overlap between the AS and S groups (Clarke et al, 1999), few of the studies considered tested all participants for attributes of both AS and Schizophrenia. This creates significant difficulties as if the groups have not been clearly defined, with individuals within the group sharing a range of characteristics which are different in some way to the other group, then it is difficult to make sense of any results. The majority of studies separated individuals using the presence of a 'diagnosis', without considering the subjective nature of the diagnostic process, or how different individuals within these groups may be from one another. For example there is evidence that the S group with negative symptoms appear more similar to the AS group than those who only have positive symptoms (study 13). However, the majority of articles did not separate these two groups of individuals. Furthermore no consideration was given to whether the participants of the studies had any additional psychological problems such as anxiety or depression both of which are common in individuals with a diagnosis of AS/HFA or Schizophrenia and may have had a significant effect on their performance in tasks (Airaksinen, Larsson & Forsell, 2005; White, Oswald, Ollendick & Scahill, 2009; Achim, Maziade, Raymond, Oliver, Mérette & Roy, 2011) and should be a focus for future research. It would be important for future studies to clarify the current symptoms the participants are displaying and how these might affect performance on any measures used.

A second area of concern was the effect of psychotropic medication on the participants' responses. Antipsychotic medication can have significant side effects ranging from tiredness

to extra pyramidal side effects (Barnes et al, 2011) which may have affected a participant's ability to engage in the tasks set. Five of the studies reviewed reported that some of their participants were taking psychotropic medication, however the remainder of the studies did not comment on this, making it impossible to investigate the effect of medication on the results. In addition, the studies that did consider whether or not the participants were on medication did not consider the type of medication participants were on, or whether they were currently experiencing side effects. Furthermore, in many of the papers there is no information about any positive symptoms the participants might be experiencing at the time of the study which might affect attention span; this could also have had a significant impact on the results. The impact of different medications on performance and presentation should be considered in future studies.

Finally the studies considered used a wide range of different measures. Many of the measures used purported to test a single construct such as theory of mind, but assumed a level of ability in other areas such as emotional perception, for example the 'Reading the Mind in the Eyes' Test. Future studies need to carefully consider the concept validity of the measures that they use to ensure the integrity of their conclusions.

### ***Strengths and limitations of review***

Due to the range of different research measures used, it was difficult to directly compare the studies. However, the grid provided a transparent method for assessing the quality of the studies and this facilitated and objectified the decision process. Nonetheless, there were items on the grid on which the vast majority of articles scored relatively high and other items where the vast majority scored relatively low. In some of these areas this may be due a lack of sensitivity within the grid, suggesting the need for further development of the

quality assessment system. For example the category of whether the method is appropriate to the question refers only to whether a qualitative or quantitative methodology is more appropriate which resulted in the majority of articles achieving a score of 2. Similarly the failure to adequately describe how the author has considered the ethical implications of their work may reflect an expectation that this should be fully described which many authors may consider unnecessary due to the strict processes for ethical approval. Invariably, all of the scores allocated remain dependant on interpretation of both the grid and articles reviewed. Despite this, the intervals set for bronze, silver and gold articles produced meaningful categories of overall quality.

## **Conclusion**

The current review set out to answer three key questions about the overlap between individuals given a diagnosis of AS/HFA and those given a diagnosis of Schizophrenia. It has identified some significant similarities between the presentation of the AS and S groups, most notably in terms of understanding of, and behaviour around, others, which can sometimes create difficulties in clearly defining the groups. Despite this there are some emerging differences in deception abilities, attribution styles and IQ profiles which, with further research, may prove to be a useful tool for clinicians to inform intervention. There is also emerging evidence of greater levels of similarity between the S group with high levels of negative symptoms and the AS group, which should be taken into account in future research. There was clear evidence of similarities in social functioning between the two groups with similarities in difficulties with theory of mind, emotional recognition and judgement of trustworthiness tasks. The current literature suggests that these similar difficulties arise for different reasons which are best understood through knowledge and full understanding of their current and previous experiences. This reinforces the suggestion that

a formulation based approach to individual difficulties may provide a more helpful and effective framework for intervention for both clients and services than the current diagnostic approach.

## References

- Abell, F., Happe, F., & Frith, U. (2000) Do triangles play tricks? Attribution of mental states to animated shapes in normal and abnormal development. *Cognitive Development* 15 (1), 1–16.
- Abell, F., & Hare, D. J. (2005) An experimental investigation of the phenomenology of delusional beliefs in people with Asperger syndrome *Autism* 9 (5), 515-531
- Achim, A. M., Maziade, M., Raymond, E., Olivers, D., Mérette, C., & Roy, M. A. (2011) How Prevalent Are Anxiety Disorders in Schizophrenia? A Meta-Analysis and Critical Review on a Significant Association. *Schizophrenia Bulletin* 37 (4), 811–821
- Adolphs, R., & Tranel, D. (2003). Amygdala damage impairs emotion recognition from scenes only when they contain facial expressions. *Neuropsychologia*, 41, 1281–1289.
- Andreasen, N.C. (1984a) *Scale for the Assessment of Positive Symptoms: (SAPS)* Iowa City: University of Iowa.
- Andreasen, N. C. (1984b). *Scale for the Assessment of Negative Symptoms (SANS)*. Iowa City: University of Iowa.
- American Psychiatric Association. 2000. Diagnostic and Statistical Manual of Mental Disorders: DSM-IV-TR. *American Psychiatric Association*, Washington, DC, USA.
- Airaksinen, E., Larsson, M. & Forsell, Y. (2005) Neuropsychological functions in anxiety disorders in population-based samples: evidence of episodic memory dysfunction. *Journal of Psychiatric Research* 39 (2), 207-214
- Atlas, J. A., & Gerbino-Rosen, G. (1995) Differential Diagnostics and treatment of an inpatient adolescent showing pervasive developmental disorder and mania. *Psychological Reports* 77, 207-210

- Barnes, T. R. E. & the Schizophrenia Consensus Group of the British Association for Psychopharmacology (2011) Evidence-based guidelines for the pharmacological treatment of schizophrenia: recommendations from the British Association for Psychopharmacology *Journal of Psychopharmacology* 25 (5), 567- 620
- Baron-Cohen. S., Wheelwright. S., Hill. J., Rate. Y., & Plumb. I. (2001) The 'Reading the Mind in the Eyes' Test revised version: a study with normal adults and adults with Asperger syndrome or high functioning autism. *Journal of Child Psychology and Psychiatry* 42, 241-251
- Blackshaw, A. J., Kinderman, P., Hare, D. J., & Hatton, C. (2001) Theory of Mind, Causal Attribution and Paranoia in Asperger Syndrome *Autism* 5, 147-163
- Bolte, S. & Poustka, F. (2003) The recognition of facial affect in autistic and schizophrenic subjects and their first degree relatives. *Psychological Medicine* 33, 907-915
- Bowler, D. M. (1992) 'Theory of Mind' in Asperger's Syndrome. *Journal of Child Psychology and Psychiatry*. 33 (5), 877-893
- British Psychological Society. (2012) DSM-5: The future of Psychiatric Diagnosis. Retrieved 15<sup>th</sup> Novemeber 2013 from [www.bps.org.uk](http://www.bps.org.uk)
- Caldwell, K., Henshaw, L., & Taylor, G. (2005). Developing a framework for critiquing health research. *Journal of Health, Social and Environmental Issues*, 6 (1), 45-54
- Carrey, N. J., Butter, H. J., Persinger, M. A., & Bialik, R. J. (1995) Physiological and Cognitive Correlates of Child Abuse. *Journal of the American Academy of Child & Adolescent Psychiatry* 34 (8), 1067-1075
- CASP (2011). Critical Appraisal Skills Programme: Making sense of evidence about clinical effectiveness. Retrieved June 20<sup>th</sup>, 2013 from [www.casp-uk.net](http://www.casp-uk.net)

- CASP (2006) 10 questions to help you make sense of qualitative research. *Public Health Resource Unit in England*.
- Castelli, F., Frith, C., Happe, F., & Frith, U. (2002) Autism, Asperger syndrome and brain mechanisms for the attribution of mental states to animated shapes. *Brain* 125 (8), 1839–1849.
- Clarke, D., Baxter, M., Perry, D., & Prasher, V. (1999) The diagnosis of affective and psychotic disorders in adults with autism: seven case reports. *Autism* 3 (2), 149-164
- Corcoran, R., Mercer, G., & Frith, C.D., (1995) Schizophrenia, symptomatology and social inference: investigating 'theory of mind' in people with schizophrenia. *Schizophrenia Research* 17, 5 – 13.
- Couture, S. M., Penn, D. L., Losh, M., Adolphs, R., Hurley, R., & Piven, J. (2010) Comparison of social cognitive functioning in schizophrenia and high functioning autism: more convergence than divergence. *Psychological Medicine* 40, 569-579
- Craig, J. S., Hatton, C., Craig, F. B., & Bentall, R. P. (2004) Persecutory beliefs, attributions and theory of mind: comparison of patients with paranoid delusions, Asperger's syndrome and healthy controls *Schizophrenia Research* 69, 29– 33
- Division of Clinical Psychology (2013) Division of Clinical Psychology Position Statement on the Classification of Behaviour and Experience in Relation to Functional Psychiatric Diagnoses. Time for a Paradigm shift. Retrieved 15<sup>th</sup> November 2013 from [www.bps.org.uk](http://www.bps.org.uk)
- Dossetor, D. R. (2007) 'All that Glitters is Not Gold'. Misdiagnosis of Psychosis in Pervasive Developmental Disorders – A Case Series. *Clinical Child Psychology and Psychiatry* 12 (4), 537-548

- Esterberg, M. L., Trotman, H. D., Brasfield, J. L., Compton, M. T., & Walker, E. F. (2008) Childhood and current autistic features in adolescents with schizotypal personality disorder. *Schizophrenia Research* 104, 265–273
- Flavell, J. H., Flavell, E. R., Green, F. L., & Moses, L. J. (1990) Young children's understanding of fact beliefs versus value beliefs. *Child Development* 61, 915-928
- Gillberg, C. (1998) Asperger Syndrome and High Functioning Autism. *The British Journal of Psychiatry* 172, 200-209
- Gould, J. (1982). Social communication and imagination in children with cognitive and language impairments. PhD thesis. University of London.
- Heberlein, A. S., Adolphs, R., Tranel, D., & Damasio, H. (2004) Cortical regions for judgments of emotions and personality traits from point-light walkers. *Journal of Cognitive Neuroscience* 16, 1143-1158
- Hirao, K., Miyata, J., Fujiwara, H., Yamada, M., Namiki, C., Shimizu, M., Sawamoto, N., Fukuyama, H., Hayashi, T., & Murai, T. (2008) Theory of mind and frontal lobe pathology in schizophrenia: A voxel-based morphometry study. *Schizophrenia Research* 105, 165–174
- Howlin, P., & Asgharian, A. (1999) The diagnosis of autism and Asperger syndrome: findings from a survey of 770 families. *Developmental Medicine & Child Neurology* 41 (12), 834–839

- Irani, F., Platek, S. M., Panyavin, I. S., Calkins, M. E., Kohler, C., Siegel, S. J., Schachter, M., Gur, R. E., & Gur, R. C. (2006) Self-face recognition and theory of mind in patients with schizophrenia and first-degree relatives. *Schizophrenia Research* 88, 151–160
- Katrak, P., Bialocerkowski, E.E., Massy-Westropp, N., Kumar, S., & Grimmer, K.A. (2004). A systematic review of the content of critical appraisal tools. *BMC Medical Research Methodology* 4, 22-33.
- Kay, S. R., Opler, L. A., & Lindenmayer, J. P. (1989) The positive and negative syndrome scale (PANNS): rationale and standardisation *British Journal of Psychiatry* 155 (Suppl 7), 59-65
- Konstantareas, M. M., & Hewitt, T. (2001) Autistic Disorder and Schizophrenia: Diagnostic Overlaps *Journal of Autism and Developmental Disorders*, 31 (1), 19-28
- Larsen, E. W. & Mouridsen, S. E. (1997) The outcome in children with childhood autism and Asperger syndrome originally diagnosed as psychotic. A 30-year follow-up study of subjects hospitalized as children. *European Child & Adolescent Psychiatry* 6, 181-190
- Lugnegård, T., Hallerbäck, M. U., Hjärthag, F., & Gillberg, C. (2013) Social cognition impairments in Asperger syndrome and schizophrenia. *Schizophrenia Research* 143, 277–284
- Mansell, W., & Morris, K. (2004) A survey of parents' reactions to the diagnosis of an autistic spectrum disorder by a local service: Access to information and use of services. *Autism* 8 (4), 387-407
- McPartland, J. C., Reichow, B., & Volkmar, F. R. (2012) Sensitivity and Specificity of Proposed DSM-5 Diagnostic Criteria for Autism Spectrum Disorder. *Journal of the American Academy of Child & Adolescent Psychiatry* 51 (4), 368-383

- Murphy, D. (2006) Theory of mind in Asperger's syndrome, schizophrenia and personality disordered forensic patients, *Cognitive Neuropsychiatry*, 11 (2), 99-111
- Oliver, J., Morris, E., Johns, L., & Byrne, M. (2011) *ACT for Life: Group Intervention for Psychosis Manual* South London and Maudsley NHS Foundation Trust/ Institute of Psychiatry, King's College London
- Ozguven, H. D., Oner, O., Baskak, B., Oktem, F., Olmez, S., & Munir, K. (2010) Theory of Mind in Schizophrenia and Asperger's Syndrome: Relationship with Negative Symptoms. *Bulletin of Clinical Psychopharmacology* 20, 5-13
- Perlman, L. (2000) Adults With Asperger Disorder Misdiagnosed as Schizophrenic. *Professional Psychology: Research and Practice* 31 (2), 221-225
- Perner, J., & Wimmer, H. (1985) "John thinks that Mary thinks that..." Attribution of second order false beliefs by 5- to 10- year old children. *Journal of Experimental Child Psychology* 39, 437-471
- Pilowsky, T., Yirmiya, N., Arbelle, S., & Mozes, T. (2000) Theory of mind abilities of children with schizophrenia, children with autism, and normally developing children. *Schizophrenia Research* 42, 145-155
- Punshon, C., Skirrow, P., & Murphy, G. (2009) The 'not guilty verdict': Psychological reactions to a diagnosis of Asperger Syndrome in adulthood. *Autism* 13 (3), 265-283
- Read, J., Bentall, R. P., & Fosse, R. (2009) Time to abandon the Bio-bio-bio model of Psychosis: Exploring the epigenetic and psychological mechanisms by which adverse life events lead to psychotic symptoms. *Epidemiologia e Psichiatria Sociale* 18 (4), 299-310

- Robbins, B. D. (2013) After the DSM-5, Then What? The Future of Diagnosis in Psychiatry and Clinical Psychology. <http://Dxsummit.org> . 514
- Sale, J.E.M., & Brazil, K. (2004). A strategy to identify critical appraisal criteria for primary mixed-method studies. *Quality and Quantity*, 38, 351-365.
- Salter, K., Hellings, C., Foley, N., & Teasell, R. (2008). The experiences of living with stroke: A qualitative meta-synthesis. *Journal of Rehabilitation Medicine*, 40, 595-602.
- Sasson, N., Tsuchiya, N., Hurley, R., Couture, S. M., Penn, D. L., Adolphs, R., & Piven, J. (2007) Orienting to social stimuli differentiates social cognitive impairment in autism and schizophrenia *Neuropsychologia* 45, 2580–2588
- Schizophrenia Commission (2012) *The Abandoned Illness. A report by the Schizophrenia Commission*. Rethink Mental Illness.
- Sharp, J., & Lewis, S. (2013) The process of diagnosing Asperger's syndrome. *Clinical Psychology Forum* 249, 34-37
- Sporn A. L., Addington, A. M., Gogtay, N., Ordoñez, A. E., Gornick, M., Clasen, L., Greenstein, D., Tossell, J. W., Gochman, P., Lenane, M., Sharp, W. S., Straub, R. E., & Rapoport, J. L. (2004) Pervasive Developmental Disorder and Childhood- Onset Schizophrenia: Comorbid Disorder or a Phenotypic Variant of a Very Early Onset Illness? *Biological Psychiatry* 55, 989-994
- Stahlberg, O., Soderstrom, H., Rastam, M., & Gillberg, C. (2004) Bipolar disorder, schizophrenia, and other psychotic disorders in adults with childhood onset AD/HD and/or autism spectrum disorders *Journal of Neural Transmission* 111 (7), 891-902
- Stewart, M. E., Barnard, L., Pearson, J., Hasan, R., & O'Brien, G. (2006) Presentation of depression in autism and Asperger syndrome. A review. *Autism* 10 (1), 103-116

- Stratton, P., Heard, D., Hanks, H.G., Munton, A.G., Brewin, C., & Davidson, I., (1986) Coding causal beliefs in natural discourse. *British Journal of Social Psychology* 25, 299– 313.
- Strauss, J. S., & Carpenter, W. T. (1981) *Schizophrenia*. New York: Plenum
- Van Lancker, D., Cornelius, C., & Kreiman, J. (1989) Recognition of emotional-prosodic meanings in speech by autistic, schizophrenic, and normal children, *Developmental Neuropsychology*, 5 (2-3), 207-226
- White, S. W., Oswald, D., Ollendick, T., & Scahill, L. (2009) Anxiety in children and adolescents with autism spectrum disorders. *Clinical Psychology Review* 29 (3), 216– 229
- Wing, L. (1981) Language, social and cognitive impairments in autism and severe mental retardation *Journal of Autism and Developmental Disorders*, 10, 31–44
- Wechsler, D. (1981) WAIS-R manual: Wechsler adult intelligence scale-revised Psychological Corporation, San Antonio, Texas, USA.
- Wechsler, D. (1997) Manual for the Wechsler Adult Intelligence Scale, 3rd ed (WAIS-III). Psychological Corporation, San Antonio, Texas, USA.
- Weiner, B. (1980) A cognitive (attribution)-emotion-action model of motivated behavior: An analysis of judgments of help-giving. *Journal of Personality and Social Psychology*, 39 (2), 186-200
- Wing, L., Gould, J., & Gillberg, C. (2011) Autism spectrum disorders in the DSM-V: Better or worse than the DSM-IV? *Research in Developmental Disabilities* 32 (2), 768–773

EMPIRICAL PAPER:

**Moving from primary to secondary school: how do young people with Asperger Syndrome experience this transition?**

## **Abstract**

### *Background*

There is clear evidence that individuals with Asperger Syndrome (AS) find transitions more challenging than their typically developing peers, with the majority of research focusing on transition from school to work. However as the majority of young people with Asperger Syndrome (AS) are now schooled through mainstream school there has been increasing interest in supporting transition from primary to secondary school. Current research has focused on information from education providers and caregivers which suggests that peer relationships, frequent changes of room and teacher, and anxiety levels cause significant difficulties for these young people. A range of strategies have been suggested to ease transition, however, little consideration has been given to how young people experience this transition or the strategies used to aid it.

### *Method*

Semi-structured interviews were carried out with seven young adults with AS. They were asked to reflect on their transition from primary to secondary school. Interviews were audio recorded digitally and transcribed. The data was then analysed using Interpretive Phenomenological Analysis and themes were identified across the transcripts.

### *Results*

Four super-ordinate themes were identified. These were: 'understanding self in context', 'relationships' with peers and teachers, understanding the 'school environment' and 'coping with difficulties' which arose at school.

## *Conclusion*

The results are discussed in relation to the current understanding of this experience and the adaptations currently offered by schools and recommendations to ease the transition are made. Suggestions for future research in this area are offered.

Key words: Asperger syndrome, school, transition, experience

## Introduction

Asperger syndrome (AS) is a specific type of autism spectrum disorder (ASD), characterised by difficulties with social interaction, communication, and imagination (Wing, 1981; Gould, 1982). Individuals with AS often show poorer social skills than their typically developing peers and have difficulties with theory of mind (Bowler, 1992; Baron-Cohen, 1992; Leslie & Frith, 1990). As a result they can have difficulties making and keeping friends (Myles & Simpson, 1998), often show a need for routine and find it hard to cope with change (Frith, 1991; Van Bourgondien & Woods, 1992; Myles & Simpson, 1998). Individuals with AS are usually of average or above average intelligence (APA, 1994; Ehlers et al, 1997) and consequently are schooled through mainstream schooling (National Research Council, 2001; Parsons et al, 2011; Humphrey & Symes, 2013). However there is evidence that many individuals with AS find the transition from primary to secondary school challenging (Konza, 2005; Lawrence, 2010; Adreon & Stella, 2001).

There has been much interest in how individuals with AS cope with transitions in life, with the majority of research focusing on the transition from school to work. Studies have found that this transition can be successful if correctly managed, with the individual's level of communication skills key in determining the ease of transition (Higgins, Koch, Boughman & Vierstra, 2008). Higgins et al (2008) found that young adults with reasonable communication skills and ability to form peer relationships were more likely to make a successful transition to work than those who found these skills more challenging. Lawrence, Alleckson & Bjorklund (2010) concluded that appropriate support from a range of interlinked agencies was important and argued that for transition to be successful it needs to be undertaken slowly, with sufficient time for individuals to learn new skills.

There is limited research on how children with AS manage the transition from primary to secondary school, with the main sources of information consisting of parental reports (e.g. Brewin, Renwick & Schormans, 2008; Lawrence, 2010) and reports from education providers (e.g. Adreon & Stella, 2001; Konza, 2005). There are many significant differences between primary and secondary school environments including; the number of pupils, the number of teachers each pupil comes into contact with, and the classrooms used. Many primary school pupils have all their lessons in a single room, whilst secondary school pupils are often expected to move to different rooms. Coping with frequent changes in rooms and teachers may present particular challenges for children with AS. Moreover, with an increased number of peers in secondary school it is unsurprising that relating to peers also poses challenges. Evidence shows that as individuals with AS mature, their communication and socialisation (ability to relate to peers) skills improve. However, these skills do not improve at the same rate as those of their peers and during early adolescence become increasingly disparate from those of their peer group (McGovern & Sigman, 2005; Gabriels, Ivers, Hill, Agnew & McNeill, 2007).

There is also evidence that children with AS find friendships challenging, struggling to recognise peer advances or to make any advances of their own (Lord & Magill-Evans, 1995; Carrington, Templeton & Papinczak, 2003). Indeed Carrington et al (2003) report that individuals with AS find it difficult to understand what a friend is, who is not a friend and to fully understand social relationships. As developing friendships has been shown to be an important part of managing a successful transition, individuals with AS may need additional support to engage successfully with peers (Gabriels et al, 2007) and thus cope effectively with transition from primary to secondary school.

A study by Adreon and Stella (2001) reported numerous difficulties during transition to high school in individuals with AS including increased anxiety levels, difficulties making friends and difficulties with planning. They argued the need for strategies such as repeated school visits prior to transition, training for school personnel, classroom adaptations and support around unstructured times. These suggestions were reinforced by Konza (2005) who found similar areas of difficulty, whilst Lawrence (2010) identified these, but also argued the importance of considering the emotional impact of transition on individuals with AS.

As the impact of this transition has been considered almost exclusively using parental report or professional opinions to explore concerns (Adreon & Stella, 2001; Konza, 2005; Brewin, Renwick & Schormans, 2008; Lawrence, 2010), there is a lack of information about the subjective experience of the individual. As individuals reach adolescence there is increasing divergence between individual and parental report (Lawrence, Alleckson & Bjorklund, 2010), therefore there is a need to consider the perspective of the individual with AS. This will aid understanding of how they experience transition and the supports which are put into place.

There have been two qualitative studies on the experiences of people with AS in education. A study by Simmeborn Fleischer (2012) considered the experience of three males with AS who had recently moved to university. She found that the students reported feelings of alienation from peers and a sense of struggle to cope. A larger study of 94 parents of children with AS, and adults with AS also identified difficulties in peer relations but suggested some additional difficulties with relationships with teachers (Sciutto, Richwine, Mentrikoski & Niedzwiecki, 2012).

The current study aims to investigate how individuals with AS make sense of the experience of moving from primary to secondary school. This will be achieved by getting a detailed

account from young adults with AS about what made transition easier or harder for them. A retrospective approach was used as despite the concerns that individuals with AS may have difficulties recalling personal experiences (Millward, Powell, Messer & Jordan, 2000; Bruck, London, Landa & Goodman, 2007), there was an ethical concern about placing an additional burden on individuals currently experiencing transition and thus possibly distress.

## **Method**

### ***Design***

As the aim of this study was to investigate how individuals with AS make sense of the experience of moving schools, Interpretative Phenomenological Analysis (IPA) was considered the most appropriate methodology. IPA is concerned with '*the detailed examination of lived experience*' (Smith, Flowers & Larkin, 2009, p 45) and employs a combination of hermeneutic and phenomenological insights to better understand the process through which an individual makes sense of their experiences. In order to create a rich and detailed data set, participants were invited to take part in semi structured interviews.

### ***Participants***

Participants were recruited from five support groups for individuals with AS run by charitable organisations. Around forty individuals were approached, of which seven agreed to take part. Potential participants were told about the study and given the information sheet (see Appendix C). They were then invited to either contact the researcher or indicate they wanted to be contacted. Interested individuals were encouraged to ask questions about the study before completing the consent form (see Appendix D), then given the option to complete the interview immediately or schedule a different time for the interview.

Before conducting the interview potential participants were asked about their recollection of the transition from primary to secondary school. Four potential participants were excluded from the study as they reported finding it difficult to recall this period of their life. The participants included seven adults between the ages of 18 and 21 (see Table 1).

<b>Name*</b>	<b>Age</b>	<b>Age at diagnosis</b>	<b>Type of school attended</b>
Jessica	18	14	Mainstream
Tom	21	16	Mainstream
Katie	19	18	Specialist school for people with physical and mental health problems.
Matt	20	19	Mainstream
Chris	21	21	Mainstream
Lily	19	7	Mainstream
Nick	20	20	Mainstream

\*No real names have been used

*Table 1:* Information about participants included in the study

### ***Ethical approval***

Ethical approval was granted through the University of Birmingham (see Appendix E). Each charitable organisation approached was informed of the ethical review process and invited to apply their own where applicable.

### ***Procedure***

Participants were invited to take part in a semi structured interview at a place of their choosing. They were encouraged to choose somewhere quiet and private but could choose to be seen at home or in a private room in the building where they attended the support group. The interviews lasted between 30 and 80 minutes (average 50 minutes) during which the participants were asked six open ended questions (see Appendix F). This process was recorded using a digital voice recorder.

### ***Measures***

The interview schedule was developed using published data about the areas of difficulty during transition periods (Adreon & Stella, 2001; Lawrence, 2010) and information gathered at a conference focusing on autism in schools, which was attended by parents. These questions were then further developed in consultation with a 14 year old with AS and her family. This led to six key questions (see Appendix F) with prompts if required. Additional questions and prompts were used to encourage participants to further reflect on their experiences to ensure a rich data set.

### ***Analysis***

The interviews were transcribed and the recordings were listened to twice to ensure no errors had occurred in transcribing the data. The transcripts were then read twice, during which time the first four levels of analysis were completed as described by Smith et al (2009). These constituted: descriptive comments focusing on the content of the text; linguistic comments, focusing on the use of language by the participant; conceptual comments exploring the questions raised by the text and subjective interpretations; and

identifying emergent themes from the text (see Figure 2). An example of the analysis process is shown in Appendix G.

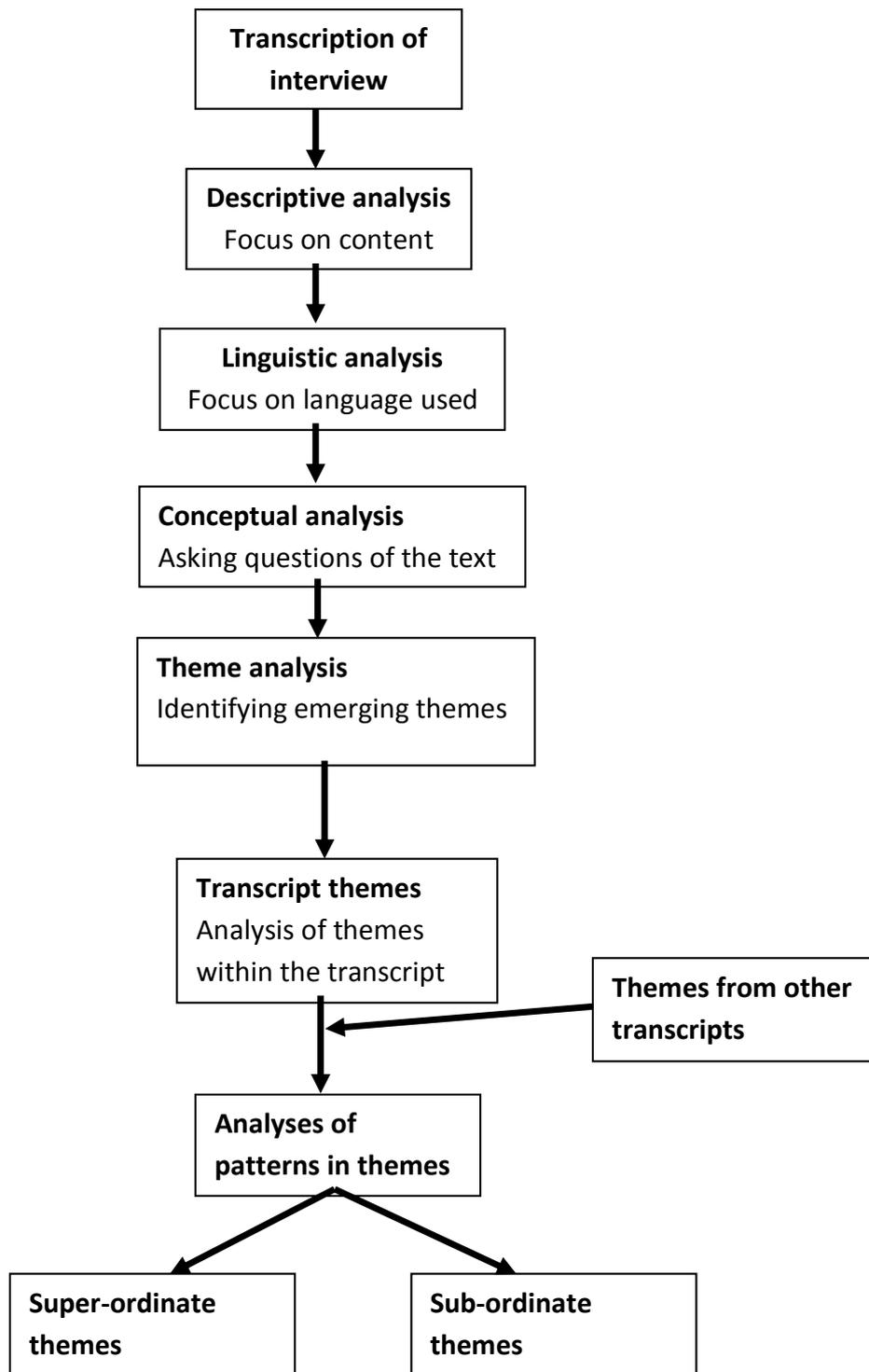


Figure 2: Analysis of transcripts

Having completed these levels of analysis, connections were explored between the themes within a transcript, before considering patterns or themes across all seven transcripts. These were then split into super-ordinate and sub-ordinate themes for presentation to the reader.

### ***Personal Experience***

I became interested in this area having volunteered as a befriender to someone with AS five years ago. When I first got to know this young person she was in her final year of primary school, and I was struck by how anxious she was about the move to secondary school. It led me to reflect on the process of moving school and the things which are different about this time. As I watched my friend struggle with this transition and to make sense of the changes, I began to explore the research literature and was amazed at how little information there was available to her and her family, and how isolated they felt. There was some literature on parents' experiences but very little about transition from the perspective of the young person. This led me to consider how other young people with AS might make sense of this move and to want to explore the individual's perspective.

### **Results**

Overall four super-ordinate themes were identified (see Table 2). The first theme concerns how individuals try to understand themselves in the context of the secondary school and includes issues around differences, how they defined themselves, and how they tried to fit into a group. The second theme considers the relationships they encountered, including those they observed between peers, their relationship with peers, relationships with teachers and their understanding of social situations. The third theme considers the school environment in more detail, focusing on the demands placed on them in lessons and the physical attributes of the school. The final theme focuses on how they coped with the

difficulties they faced, their emotional reactions to these difficulties and how they made sense of these, and the strategies and adaptations which helped them to cope. These will each be considered in depth and illustrated by the use of direct quotes.

<b>Super-ordinate themes</b>	<b>Sub-ordinate themes</b>
Understanding self in content	Sense of self Fitting in Sense of difference
Relationships	Understanding of Others Peer relationships Relationship with teachers
School Environment	Lessons Physical attributes of school
Coping with difficulties	Emotional reactions to difficulties Making sense of difficulties Coping strategies and adaptations

Table 2: Super-ordinate and sub-ordinate themes

### ***Understanding of self in context***

#### Sense of self

There was a clear struggle evident in all the participants' accounts in terms of how to define or describe themselves. Tom described how he didn't feel he had a 'blip' (his word for identity) '*I was I was kind of low on the radar I was kind of like ... everyone has has has has their own blip err so to speak and it felt like I didn't have mine..*', whilst Chris described a struggle to understand himself '*maybe there is something wrong with me but I am how I am and I will just pretend that there is something wrong with everyone else*'. This was reflected in all the interviews with participants struggling to define themselves in terms of

intelligence, importance and behaviour. Katie summed up how she felt she changed her definition of herself *'I went from feeling like very umm confused and feeling very... I don't know unintelligent to going to secondary school and suddenly being told that I'm really intelligent'*, a struggle echoed by others. Some even questioned their own importance: *'I didn't think it was important enough to let people know'* (Jessica), whilst others felt they needed to change who they were to cope *'I had to try and adapt and make conversation to make ease that to make new friends, and to do things cos I don't cos I knew it worked for them'* (Lily).

The way they behaved caused difficulties for many of the participants with Lily blaming herself for being bullied *'then I'd say well it must be my fault that they are bullying me sort of thing.'*, whilst Chris said *'I probably deserved a few a bit of ostrasization as I was a bit of a prat and I was contemptful of others'*. Participants also blamed themselves for their behaviour and judged themselves as a result, with Jessica commenting on the effect it had on her school work *'I think just mostly played computer games like I didn't even bother doing school stuff I just didn't feel motivated and thought I don't care.'*

### Fitting in

Many of the participants found it a challenge to work out how to fit in. Chris describes his ambivalence *'you need friends, you have the need to want to get on with people but you just don't want to at the same time'*. There was a clear journey which was described by many of the participants, beginning with a struggle to make friends, then feeling part of a group, and finally developing friendships. All the participants described parts of this process; for example to begin with Tom felt he had to use his instincts to survive *'umm I suppose it's just survival instincts really...'* whilst Jessica explained the struggle she had to be accepted *'like*

*oh so I get pushed away and I have to try really hard for like a whole year just to sort of try and get accepted'. As they got used to secondary school the participants described times when they felt their difficulties were shared by others. For example Chris described 'I would rather not push through a crowd, I'd rather not you know, I don't think anybody wants to push through a crowd really' whilst Matt described a sense of belonging through these shared difficulties; 'it did take me longer to pick it up but it was it was it was the situation that the group of people I hung around with were sort of in line with what I was doing. So they were also sort of catching up'.*

The majority of the participants described reaching a point where they felt that they were fitting in with their peers. Nick described how he found some friends, an experience which was shared by Lily, *'I had a couple of friends there because we all... we all there was only literally four of us..'*, and Chris *'well after I erm well there was a close group of three friends'*. Matt and Tom recognised the importance of a shared interest which helped them to make friends, *'I do I do really think we shared similar interests with the people I got on with', 'I used to play 'Ugir'I [game] and my mate used to play 'Ugir'I and we played each other for some time'*, whilst Katie talked about the sense of relief and support, *'I made friends with him for a while yep and it I was really happy... '*.

### Sense of difference

All the participants talked about feeling different from their peers, with the majority finding this confusing due to a lack of diagnosis. Jessica described *'So I've always had that problem cos I don't feel like I fit in with the freaky kids but I don't feel like I fit in with the normal kids'*, and Tom explained *'it's like a normal person would be able to take it'*. Lily (who received a diagnosis before going to secondary school) used the word 'they' when describing her peers

*'They just flip and all and even when you are out of high school they just change like that because they don't know what they haven't they don't know what to do with themselves'.*

Jessica summed up the frustration of feeling there was something different about her but not yet having a diagnosis *'it's very awkward to know that you know you are a bit off compared to other people you know but not really know what it was'*. The exceptions to this sense of difference were Matt and Chris who felt that they wanted to show their individuality; *'I had a problem wearing uniform because I didn't like being the same as everyone else'* (Matt).

## **Relationships**

### Understanding of others

Many participants described confusion about social rules; Nick explained *'I've never got why people smoke in school and erm... (sigh).... There were girls wearing thongs...'*. Other participants described difficulties understanding boundaries, *'occasionally I'd make friends and found it hard to tell them that I didn't want to be friends with them anymore for whatever reason'* (Katie); confusion over social expectations *'first thing is that you want to be err cool with everyone... and make make everyone laugh and my first thing is thing was to erm was to actually make fun of someone... And that and that's already err and you're in foul of err of the rules'* (Tom), and a lack of understanding of how to talk to friends *'for one thing you don't know how to talk properly in situations'* (Lily). There was also a sense that social rules felt unnatural to some of the participants, as Chris explains *'I know how to interact with people, sort of. Erm (laughs) it's just it just erm that it generally doesn't feel natural to me'*.

## Peer relationships

Despite their confusion over social rules, some participants noticed a hierarchy among their peers. Jessica described *'it's almost like kids are trying to challenge each other in the first year in a way I don't know'*, whilst the others noted the struggles between groups *'there would just be groups just pushing against each other on mass and no one was getting anywhere'* (Matt), *'you know putting themselves into groups, kicking out the other ones, asserting social dominance'* (Chris). All the participants described incidences of being bullied by their peers; *'girls can be... honestly bitchy... absolute bitches but boys are quite straight forward in their bullying'* (Lily), *'my friends used to bully me but I also has a group who just used to bully me, they didn't even pretend to be my friend, they just used to bully me,... umm yeah it was tricky...'* (Katie). Furthermore several participants commented on how they felt victimised, *'I kind of feel really angry cos it's like no one [friends] comes out of their way to try and help me but they'll go and defend or help that person [bully]...'* (Jessica).

The experience of being bullied was reinforced by a sense of exclusion that participants described both directly and indirectly. Jessica described peers *'having to go out of their way to say bad things about you to other people. To make you even more isolated'*, Lily described *'ummm bullying was one of the factors that meant I was quite... umm... yeah... and as along with that quite a lot of social isol social isolation ,'* whilst Chris explained *'It was practically the cool thing to do to just not like me.'* Tom and Katie described a more indirect feeling of exclusion; *'everyone had their own erm their own clique their own gangs, their own erm small tiny circle of friends... eventually I came into mine'* (Tom), *'there'd be like groups of friends who if you tried to sit next to them then you get penalised for it'* (Katie).

All seven participants talked in detail about their sense of being alone at school. Tom talked about his experience of joining secondary school *'I spent a lot I spent quite a lot of time alone either in the canteen or in the library'* whilst Katie explained *'all my friends moved to another school that was nearer to them and I was kinda left on my own in my school so it was really hard'*, whilst Chris talked about a really extreme experience he had at a party *'I didn't really go with any friends, just went on my own because it just seemed like the right thing to do and I ended up at the after party getting my suit ruined and a leg broken to a beating'*.

In all of the transcripts there is a strong sense of emotional isolation but there is also clear evidence of physical isolation. Matt explained how he experienced this in class *'I did it find it difficult sometimes because sometimes I would feel sometimes I would be left out; and I'd have to.. there would be a table and all the places at that table were taken so I had to sit somewhere else'* whilst Jessica explains how she felt that she was missing out on physical affection *'I remember thinking god actually the popular girls are sort of touchy feely and yet I'm in with a group of people that never seem to like touch each like...'*

Some participants also described feeling unsafe at times as a result of their peers. This was explained by Katie who felt she had to put up with her friends bullying her *'I didn't have anybody else so what else could I do? I couldn't walk around on my own cos that was being like a walking target in that school, so you just had to kind of put up with it'*, and Matt who fell target to bullies when alone *'when that happened they [friends] weren't really around cos I wasn't really travelling with people that I knew, I was sort of kinda I was travelling on my own really.'* Lily also described a general sense of being unsafe with teachers failing to do anything about a trend among the girls *'well "the best way to express ourselves is just to push people over"'*. Katie remembered vividly the feeling she had when she left her first

secondary school to attend a more supportive school *'I imagine it was like what being let out of prison must feel like...'*

### Relationships with teachers

In addition to struggling with peer relationships, experiences of relationships with teachers varied greatly among the participants with some teachers described as helpful and supportive whilst others were considered more punitive.

All the participants had experienced teachers as unsupportive at times, as explained by Tom *'all the teachers say just come and tell us but rarely is actually well is actually something done about it,'* and Jessica *'I think a lot of teachers sort of well they don't want to get involved in things'.* Other participants even suggested that teachers went as far as to bully them, *'I mean she was the teacher was also making me feel awful even low about stuff because I was not one of her chosen few...'* (Lily), *'that was another complaint [fidgety] that teachers always made.... cos I found it really difficult I just used to look out of the window.'* (Katie). Many felt that unfair treatment by the teachers was inevitable *'it's misinterpreting me and seeing me as more of a rude rebellious child...'* (Jessica), *'I was often brought up on it by the teacher and then I'd get picked on for it again'* (Katie) and *'they just couldn't be bothered of it they just didn't see it they were just completely ignorant to it.'* (Lily).

However in contrast to these more negative experiences the participants explained a range of things teachers did to help such as allowing them to stay behind after class, *'I had a teacher there who would let me stay behind after class cos at secondary school I was badly bullied'* (Katie), or recognising their potential; *'she was probably the nicest one of the nicest ones to me as well. Like, in that nice, more genuine sort of way and like I felt like a human being.'* (Chris). All of the participants commented on some teachers trying to support

them and caring about their progress; *'she always tried to get the best out of me.'* (Nick), *'she moved to be head teacher and umm she was more understanding'* (Matt).

## **School Environment**

### Lessons

Lessons raised a range of difficulties for the participants with many feeling hopeless about their progress. Katie complained that her work never seemed to improve *'they would say what was wrong with the story so I could change it the next time and I'd change it and then they'd still say that was wrong...'* whilst Nick felt that there was nothing he could do if he didn't understand the lesson *'sometimes I made the effort and put my hand up and ask for help and then he would come and tell me something and then he would go away again so I just gave up in the end on trying'*. Discipline was also raised as a difficulty by Nick *'they couldn't control the class so I didn't really learn anything'*. These difficulties were shared by Chris and Matt who described frustration at the lack of control in classes *'they caused destruction and that's the most frustrating part' 'it was just too much time spent on ummm... umm... discipline'*.

Some talked about having difficulties concentrating *'I was always you know fidgety in class'* (Katie) and *'if there is anything else to distract me I'm done'* (Lily). Others had difficulties understanding their teachers and getting things right; Jessica explained *'to be honest I was kind of confused about what we were being asked'*, whilst Chris described *'looking at these diagrams and it was just like sensory overload, you just hit a wall and you just stop there you just stop thinking you just can't focus on it'*.

## Physical attributes

All seven participants commented on initial difficulties with the size of the school '*especially cos it was a very big school I could get really lost...*' (Lily), especially the number of students '*I'm like I'm over here and my classroom's over there and I wanna get through and I don't like crowds...*' (Tom) , and finding their way around '*they'd give you a timetable so you know what class is coming up but you don't know... you can't remember where it's supposed to be...*' (Katie), '*Umm there was confusion of finding my way around all the time because compared to the primary school; primary school was just always in the same classroom, same teacher and everything whereas High school was a sprawling big place and I had to use a map for a couple of months.*' (Chris). Tom explained how the unpredictability of secondary school affected him '*A lot of unknowns and that is what really scared me the most...*', a concern that was echoed by others.

There were also aspects of the school buildings which created difficulties, with some complaining about the noise levels within the buildings '*all the noise but it used to be quite an overwh.. sensory overload*' (Lily), whilst Lily and Katie also described feeling visually overwhelmed '*if it was like I don't know a corridor showing pictures of technology bits of some kinds of art I would get really overwhelmed and just sort of stand there*', '*Umm at secondary school they were a bit bright umm they were a bit hard to cope with... you know all the lights*'. Lily described the relief when she was offered some time out from the stimulation '*it was nice at the new school, you could just sit facing a nice blank wall no stim no over stimuli stimulus over stimulation so you could just stare into space*'.

## ***Coping with difficulties***

### Emotional reactions to difficulties

The emotions which featured most strongly in the participants' descriptions were those of fear, anger and frustration. There was a clear sense of fear of the unknown with Tom describing *'A lot of unknowns and that is what really scared me the most'*, whilst many individuals described being fearful of their peers; Katie explained *'they used to say just go and tell the teacher and I used to say well I can't cos.... I've seen it happen to other people from there, they used to tell then they'd [bully] get suspended and then when the kid was brought back they'd get picked on even more'* and Nick described *'I remember just putting up with it but I felt really terrible with it...'*. For Jessica and Katie this fear became so severe that they felt they had become paranoid; *'it made you paranoid as well...'* (Katie), *'I feel like there is always someone sort of out to get me in a way. And ruin things... I think people just don't like to see me happy'* (Jessica).

Frustration was also a common theme due to difficulties being understood and a lack of recognition of their efforts; Matt explained *'I found it quite frustrating'*. Others explained how frustration would lead to anger *'I was only naughty when I got really frustrated'* (Katie), *'it's probably more properly frustration cos I'm just trying to tell ....I'd just get really really sort of sort of steamed up'* (Lily). Several of the participants described angry outbursts where they could no longer contain their emotion *'so I went and punched that person in the face and of course made her bleed and it's a good thing I did.'* (Jessica), *'And next day I walked into school with a knife... and err I was I was like if I see him I'm going to stab him'* (Tom). Many participants became angry or defensive when recounting their experiences, judging their peers as *'vile'*, *'horrible'*, *'malicious'* or *'scumbags'*. Others however seemed

detached from what had happened; Tom's demeanour in particular was often incongruent *'I was like the teacher's going to kill me...'* (laughs).

Another common emotion described was hopelessness, primarily around peer relationships. Lily described *'I guess it would have really mattered if I'd turned up late or not I would have done something to get picked that day.'* Jessica summed it up, saying *'there was a group of girls that I thought within my form group I thought they looked pretty decent and like they were gonna be nice and stuff but like immediately they were sort of ... it's like god damn how many judgemental shovey shovey away people are there?'*

There was also a strong sense of relief in some of the participants when they found themselves supported or able to cope. Lily described *'but just having the second bit of support and not having to shout out oh teacher and there were also ones that meant I could just be quiet and absorb everything and erm I could ask questions if I wanted to'* whilst Nick explained his sense of relief at knowing what to expect *'So that was like a bit of a weight off me'*.

### Making sense of difficulties

The majority of participants had experienced a lack of control, that the situations they were in, or the people they were with, made them do or believe things, and there was a strong sense of helplessness over social relationships. Jessica described being made to believe things *'she was quite bossy and she kind of she kind of made you believe stuff that wasn't real'*, whilst Katie complained of having to do things she did not want to *'we used to play pretend a lot and I was always made to play the boy because I used to get on well with boys, so that was really annoying'*. In addition to feeling powerless in social relationships some participants described the difficulties of trying to develop relationships and the lack of

control they felt they had. This is evident in Tom's use of the phrase 'came along' *'I don't think friends err came along until err two years after'* and Lily's confusion around how she made friends *'I don't know... I'm not well it's not as if I could go from the... I never knew how to make friends'*. Chris also showed some confusion over friendships and how he might have been able to keep them *'I don't know how it happened but yeah we were friends and at the end of school we just sort of drifted off from there, like you know, like we just don't talk anymore'*. A common theme was also a sense of helplessness about bullying; Nick explained *'I remember just putting up with it but I felt really terrible with it... until he got bored in year 9.'*, while Kate said when asked why she couldn't tell anyone *'well I can't cos they'll bring it back anyway and then it will get even worse'*

Finally there was a sense of injustice around how hard the participants felt they were trying to cope and yet that their effort was not recognised; *'I was naughty at times but not very much I was only naughty when I got really frustrated'* (Katie), *'I got well sort of they were thinking I was starting trouble but I just wanted to have some space to me'* (Lily). Jessica and Tom felt this injustice even more strongly with Jessica explaining the teachers' response to her reaction to a child picking on her *'when I finally have a go at this kid and it's like he tries to block me block the kid from me and it's like you just felt like they were protecting that kid and that after all the time that I've been struggling'*, while Tom explained how his bus pass was stolen and when he took a knife into school to defend himself *'And well basically I was the one who got err got excluded for err err emm for a week and err he got off scot free'*.

### Coping strategies and adaptation

There were several things which the participants explained helped them to cope within the school environment. In particular predictability played a clear role in the participants' sense

of being able to cope; *'Having knowledge of what's gonna happen like see for for everything like next lesson we are gonna do this and that'* (Lily). They explained how visits helped them to feel more comfortable and get a sense of the size of the school; *'I got told that the first day in Year 7 would be like the taster day. So that was like a bit of a weight off me'* (Nick) *'they gave me a three day trial when I could try everything out in the new secondary school... I got to see how other people were how to act and be accepted by people'* (Lily). Many Participants commented on the reassurance of having set seats in a classroom; *'I mean it helped when we had like assigned seating cos then you didn't have to like awkwardly like find somewhere to sit'* (Jessica), *'Sometimes it's just less hassle to have set places'* (Matt). Knowledge of the school routine also helped some participants settle in; *'Mainly just the routine that we go through. My sister explained to me it was erm basically you get on a bus, you go there, we go to we each do whatever our timetable tells us to do in conjunction with a map and that's all it really was, there wasn't much fuss about it to begin with'* (Chris).

Lily described how associations helped her to learn *'having associations sort of like having certain classes in that room and having well it just helps me it helps me immensely'*, something which Nick agreed with *'I sometimes associate that place with where it [lesson] happened'*.

Many schools provided physical adaptations to support their students such as the provision of maps (Chris and Katie), the availability of a quiet area *'did help that I could go to the rtm [quiet] room'* (Lily) and the use of computer equipment to help with note taking.

Several of the participants talked about how feeling safe at home helped them to cope at school and how they made the most of their time at home. When asked what helped Katie said *'My family... my family did, knowing that there was a good home to go to after*

*school...’, whilst Chris explained ‘It’s just like when I get home from work, when I get home from [place] even I just do not want to talk to anybody, I do not want to be presented with anything that requires effort.’*

## **Discussion**

### ***Summary***

Although the information from the interviews has been presented in four distinct super-ordinate themes, they are linked and interwoven within each individual account. It is clear that how individuals understand themselves, (theme 1) has a big impact on how they relate to others and behave in relationships (theme 2), which may also change the degree to which they feel able to cope with their experiences (theme 4). Furthermore, their perception of and reactions to the school environment (theme 3) may have an impact on not only what they perceive as difficulties, but also the skills they are able to use to cope with these (theme 4).

The themes identified clarify the range of challenges faced by individuals with AS when they move from primary to secondary school. There was a strong sense of the participants’ struggle to define themselves and feel comfortable with who they were, feeling different to their peers and questioning how they might begin to fit in. This is particularly striking considering six out of the seven interviewees received a diagnosis after this transition. Furthermore there was a sense of confusion over social situations and how to make sense of others, which led to difficulties understanding relationships with both peers and teachers. There was an overwhelming sense of injustice and victimisation within many of the

relationships described, however when participants were able to develop positive peer or teacher relationships there was a sense of relief and safety.

The differences in the school environment were also identified as a major theme, with participants commenting on the differences in how lessons felt in secondary school compared to primary school. Many experienced a reduction in the levels of discipline and subsequently had difficulties concentrating. The size and layout of the school was also a significant change which was noted, resulting in difficulties coping with the number of students, the sensory demands and navigating around the school. Despite these concerns a range of aspects of the school were found to be positive, such as the use of break out areas and ability to associate lessons with certain rooms.

Where difficulties arose, a range of emotions accompanied them, particularly a sense of anger or frustration and hopelessness, usually followed by relief as the difficulties were addressed or alleviated. All of the participants described times when it was hard for them to make sense of their difficulties, with many describing a lack of control over what was happening and a sense of injustice. Despite these difficulties however some were supported by being provided with predictable routines, practical aids such as maps, and a sense of safety and security from home.

### ***Overlap with previous research***

Many of the themes identified were similar to those identified both in previous research with parents and support providers. In particular, difficulties understanding others and developing peer relationships have been identified in a range of previous studies considering school age children with AS (Lord & Magill-Evans, 1995; Carrington, Templeton & Papinczak, 2003; McGovern & Sigman, 2005; Gabriels et al, 2007). In the subthemes of

'understanding of others' and 'fitting in', several of the participants described a lack of understanding around how to make friends; something Carrington et al (2003) and Simmeborn Fleischer (2012) also identified. In the current study there was a clear sense of relief throughout the transcripts as individuals found out how to make friends or began to fit in, something which Gabriels et al (2007) suggested is vital if children with AS are to manage a successful transition. However, the time lapse between the transition and development of friends was much longer than Gabriels et al (2007) reported.

The theme of 'coping with difficulties' also replicated previous research with the emotional difficulties, identified by Adreon and Stella Durocher (2007) and Lawrence (2010), being very similar to those reported in the current 'emotional reactions to difficulties' subtheme.

However, these accounts did not fully consider the level of hopelessness or feelings of injustice and lack of control described by the participants of this study. Many of the adaptations suggested by Adreon and Stella Durocher (2007) and Lawrence (2010), such as visits to the school, classroom adaptations and support around unstructured times, were adaptations which the participants identified as being particularly helpful. Furthermore they recognised the need for predictability which the current participants also reported.

The evidence from this study also showed significant overlap with the difficulties expected for typically developing children who are transitioning from primary to secondary school. Challenges around developing good peer relationships (Topping, 2011), coping with difficulties (Pietarinen, 2000), and maintaining self-esteem (Barber & Olsen, 2004) when moving to a larger school with more challenging work were also reported in typically developing children. However there was evidence that these difficulties rapidly normalized with two thirds of pupils no longer having difficulties with friendships after only four weeks of being at the new school (Elias, Gara & Ubriaco, 1985). Furthermore the third who

continued to have difficulties showed rapid improvements over time. There is no evidence that typically developing pupils have difficulties in their relationships with teachers when they first enter secondary school. This is in contrast to young people with AS in the current study who showed significant difficulties with teacher relationships.

This study also raised a number of novel themes which warrant further investigation.

Previous research has not considered the effect of transition on an individual's sense of self, something which all the participants commented on. Participants reported not only a sense of difference, but also difficulties understanding themselves as a result of the transition.

This compounded difficulties identifying their desired roles within a peer group and had a significant effect on their ability to build relationships with other pupils.

Furthermore the role of relationships with teachers has not been adequately considered in previous accounts, with only a brief consideration by Sciotto et al (2012). A recent study considering teachers' understanding of students with AS focused primarily on ability and environmental differences and did not comment on teachers' abilities to relate to students (Linton, Germundsson, Heimann & Danemark, 2013). In the current study the range of roles teachers can play in the transition of a young person with AS has been identified, exerting both positive and negative influences.

When reading the accounts it is striking not only how frustrating it is for young people with AS to be misunderstood, but also the degree to which they felt some teachers actively impeded their settling in process. The opposite was also true, that when teachers showed patience and understanding this had a significant effect and helped the individual to settle more rapidly. Many of the participants did not have a diagnosis at the time of the transition, which raises questions about how teachers may be able to show more understanding to

young people who might be experiencing difficulties and whether this interpretation of teacher behaviour is unique to individuals with AS.

Finally we have gained a greater understanding of the role the school environment can play within the transition, not just in terms of size and layout which had been previously identified, but also in terms of aspects such as classroom layout. It is well substantiated that individuals with AS have sensory integration problems and may be hypersensitive to sensory information (Pfeiffer, Kinnealey, Reed & Herzberg, 2005). In a school environment which is designed to be stimulating for the typically developing pupil, individuals with AS can end up feeling overwhelmed by the amount of sensory information. This was clear from the participants' reports, with visual over-stimulation such as the number of posters in a room just as aversive as auditory over-stimulation.

### ***Recommendations***

These experiences suggest several recommendations for young people with AS, their parents and those supporting them during transition from primary to secondary school. Developing a sense of belonging and a stable group of friends was key for many of the participants. This suggests that where possible young people should be allowed to remain with pupils they know from their primary school when making this transition, both in form groups and lessons. In addition a hobby or activity could be encouraged from a young age to support the development of a stable sense of identity. This transition led many individuals to challenge their knowledge of themselves and having a hobby which provides a sense of achievement and a consistent peer group could support individuals to maintain their sense of identity.

Simple adaptations such as a quiet area, with minimal visual stimulation, to go to during break times, and a number of opportunities to visit the new school prior to transition made a significant difference for the participants. They may also need an opportunity to share some of their feelings of frustration with the difficulties they are facing. Some parents may be able to offer this support, however many participants described wanting to keep home and school separate, so the opportunity to do this at school with a supportive adult, or counsellor who has knowledge of AS could be helpful.

### ***Limitations***

All of the participants were recruited from support groups, which may mean that only participants who had had difficult experiences were included. There is some evidence that individuals who find things challenging are more likely to join support groups (Hicks Patrick, Pruchno & Rose, 1998), therefore by recruiting through the support groups we may have only recruited from a specific group of individuals. In addition because many of the participants did not receive a diagnosis until after they made the transition they may have experienced it very differently to individuals who were given a diagnosis prior to transition and possibly had specialist educational support put into place beforehand. This is suggested by the amount of additional support Lily (who was diagnosed at age 7) was offered.

The use of a sample of young adults instead of interviewing pupils who had experienced the move more recently may mean that some of the emotions and the significance of the difficulties were lost over time. There is some evidence that individuals with autism spectrum disorders have poorer episodic memory recall than typically developing individuals, in the context of intact semantic recall (Klein, Chan & Loftus, 1999; Millward et al, 2000; Goddard, Howlin, Dritschel, & Patel, 2007). On recall tasks individuals with ASD

showed poorer recall for events involving themselves (Millward et al, 2000) and significantly poorer cued and free recall of events when given a limited time to respond (Goddard et al, 2007; Crane & Goddard, 2008). However, there is also evidence that on interview based memory tasks, whilst the recall of individuals with ASD may lack specificity in terms of time or place, there is no significant difference in the narrative volume produced relative to typically developing individuals (Crane & Goddard, 2008). The reduction in episodic memory recall over time was a consideration when designing this study. However, due to the concern of adding to the burden of pupils with AS undergoing this transition, interviewing young adults at a later stage in their life was considered a justifiable ethical compromise.

Finally there was one participant (Nick) who had recently been given a diagnosis of depression. This significantly affected his ability to share his experiences within the interview, with increased memory problems and difficulties elaborating on his experiences. This meant that there were significantly less data from his interview and he needed many additional prompts. Despite this, the decision was made to include him in the sample due to the high prevalence of depressive illness in young people with AS (Pfeiffer et al, 2005). Moreover, the themes identified within his interview were broadly similar to those identified by the other participants.

### ***Future directions***

This research has identified a range of areas which may present a challenge for individuals with AS. There needs to be a good awareness of these difficulties and the subjective understanding of young people with AS in schools and children's services to aid the rapid identification of problems and maximise the support which is offered. This would also help to identify individuals who have not previously been given a diagnosis but are presenting

with similar difficulties (e.g. difficulties with peer relationships or coping with their new environment), to ensure they receive the support they require and if appropriate are assessed for AS.

In terms of future research there is a clear need to consider the development of a sense of self in young people with AS and to consider how this process can be nurtured. There is evidence that in typically developing adolescents an increased sense of achievement and decrease in diffusion is key to developing a sense of self within relationships (Meeus, ledema, Helsen & Vollebergh, 1999). This review suggests a model for the development of both relational and societal identity which could be used to inform research into the development of identity in adolescents with AS. In addition further research into the role of relationships with teachers throughout a young person's time at school may provide further recommendations for supporting these individuals. This may support either specialist teacher training or access to external consultants who specialise in AS who can support teachers in their understanding of AS.

## **Conclusion**

This study considered the subjective experiences of young people with Asperger Syndrome moving from primary to secondary school. Their experiences identify why this transition is challenging for many individuals and the range of internal and external difficulties that are faced. In addition it suggests a range of coping strategies and supportive measures which can be employed to facilitate transition. The study identified a need for a greater understanding of the development of a sense of self in individuals with AS and to further elucidate the role of teachers in the smooth transition of pupils with AS.

## References

- American Psychological Association (1994) 'Diagnostic Criteria for 299.80 Asperger's Disorder' *Diagnostic and Statistical Manual of Mental Disorders: DSM IV* Washington, DC.
- Adreon, D., Stella, J. (2001) Transition to Middle and High School: Increasing the Success of Students with Asperger Syndrome. *Intervention in School and Clinic*. 36 (5) 266-271
- Adreon, D., Stella Durocher, J. (2007) Evaluating the College Transition Needs of Individuals With High-Functioning Autism Spectrum Disorders. *Intervention in School and Clinic* 42 (5) 271-279
- Barber, B. K., Olsen, J. A. (2004) Assessing the transitions to middle and high school. *Journal of Adolescent Research* 19 (1) 3–30.
- Baron-Cohen, S. (1992) The theory of mind hypothesis of autism: History and prospects of the idea. *The Psychologist*, 15, (1), 9-12
- Bowler, D. M. (1992) 'Theory of Mind' in Asperger's Syndrome. *Journal of Child Psychology and Psychiatry*. 33, (5) 877-893
- Brewin, B. J., Renwick, R., Schormans, A. F. (2008) Parental Perspectives of the Quality of Life in School Environments for Children With Asperger Syndrome *Focus on Autism and Other Developmental Disabilities* 23 (4) 242-252

- Bruck, M., London, K., Landa, R., Goodman, J. (2007) Autobiographical memory and suggestibility in children with autism spectrum disorder. *Development and Psychopathology* 19 (1) 73-95
- Carrington, S., Templeton, E., Papinczak, T. (2003) Adolescents With Asperger Syndrome and Perceptions of Friendship. *Focus on Autism and Other Developmental Disabilities* 18 (4) 211-218
- Crane, L., Goddard, L. (2008) Episodic and Semantic Autobiographical Memory in Adults with Autism Spectrum Disorders. *Journal of Autism and Developmental Disorders* 38, 498–506
- Ehlers, S., Nyden, A., Gillberg, C., Dablgren Sandberg, A., Dahlgren, S., Hjelmquist, E., Oden, A. (1997) Asperger Syndrome, Autism and Attention Disorders: A Comparative Study of the Cognitive Profiles of 120 Children. *Journal of Child Psychology and Psychiatry* 38, (2) 207-217.
- Elias, M. J., Gara, M., Ubriaco, M. (1985) Sources of stress and support in children's transition to middle school: An empirical analysis. *Journal of Clinical Child Psychology* 14, (2), 112–118.
- Frith, U. (1991). Asperger and his syndrome. In U. Frith (Ed.), *Autism and Asperger Syndrome* (pp. 1-36). Cambridge, UK: Cambridge University Press.
- Gabriels, R. L., Ivers, B. J., Hill, D. E., Agnew, J. A., McNeill, J. (2007) Stability of adaptive behaviours in middle school children with autism spectrum disorders. *Research in Autism Spectrum disorders* 1, 292-303

- Goddard, L., Howlin, P., Dritschel, B., Patel, T. (2007). Autobiographical memory and social problem solving in Asperger syndrome. *Journal of Autism and Developmental Disorders*, 37 (2), 291–300.
- Gould, J. (1982). Social communication and imagination in children with cognitive and language impairments. *PhD thesis*. University of London.
- Hicks Patrick, J., Pruchno, R. A., Rose, M. S. (1998) Recruiting Research Participants: A Comparison of the Costs and Effectiveness of Five Recruitment Strategies. *The Gerontologist* 38 (3): 295-302.
- Higgins, K. K., Koch, L. C., Boughman, E. M., Vierstra, C. (2008) School-to-work transition and Asperger Syndrome. *Work* 31 291-298
- Humphrey, N. & Symes, W. (2013) Inclusive education for pupils with autistic spectrum disorders in secondary mainstream schools: teacher attitudes, experience and knowledge. *International Journal of Inclusive Education* 17 (1) 32-46
- Klein, S. B., Chan, R. L., Loftus, J. (1999). Independence of episodic and semantic self-knowledge: The case from autism. *Social Cognition*, 17 (4), 413–436.
- Konza, D. (2005) Secondary school success for students with Asperger's syndrome. *Australasian Journal of Special Education* 29 (2) 128-139
- Lawrence, C. (2010) *Successful School Change and Transition for the child with Asperger Syndrome*. London: Jessica Kingsley Publishers
- Lawrence, D. H., Alleckson, D. A., Bjorklund, P. (2010) Beyond the Roadblocks: Transitioning to Adulthood with Asperger's disorder. *Archives of Psychiatric Nursing* 24 (4) 227-238

- Leslie, A. & Frith, U. (1990). Prospects for a cognitive neuropsychology of autism: Hobson's choice. *Psychological Review*, 97, 122-131.
- Linton, A. C., Germundsson, P., Heimann, M., Danemark, B, (2013) Teachers' social representation of students with Asperger diagnosis *European Journal of Special Needs Education* 28 (4) 392-412
- Lord, C., Magill-Evans, J. (1995) Peer interactions of autistic children and adolescents. *Development and Psychopathology* 7, 611-626
- Lounds, J., Seltzer, M. M., Greenberg, J. S., Shattuck, P. T. (2007) Transition and change in Adolescents and young adults with Autism: Longitudinal effects on Maternal Well-Being. *American Journal on Mental Retardation*. 112 (6) 401-417
- McGovern, C. W., Sigman, M. (2005) Continuity and change from early childhood to adolescence in autism. *Journal of Child Psychology and Psychiatry* 46 (4) 401-408
- Meeus, W., Iedema, J., Helsen, M., Vollebergh, W. (1999) Patterns of Adolescent Identity Development: Review of Literature and Longitudinal Analysis. *Developmental Review* 19 (4) 419-461
- Millward, C., Powell, S., Messer, D., Jordan, R. (2000) Recall for Self and Other in Autism: Children's Memory for Events Experienced by Themselves and Their Peers. *Journal of Autism and Developmental Disorders* 30 (1) 15-28
- Myles, B. S., & Simpson, R. L. (1998). *Asperger Syndrome: A guide for educators and parents*. Austin, TX: PRO-ED.
- National Research Council. (2001) *Educating Children with Autism*. Washington DC: National Academy Press

- Parsons, S., Guuldberg, K., MacLeod, A., Jones, G., Prunty, A., Balfe, T. (2011) International review of the evidence on best practice in educational provision for children on the autism spectrum *European Journal of Special Needs Education* 26 (1) 47-63
- Pfeiffer, B., Kinnealey, M., Reed, C., Herzberg, G. (2005) Sensory Modulation and Affective Disorders in Children and Adolescents With Asperger's Disorder. *American Journal of Occupational Therapy* 59 (3) 335-345
- Pietarinen, J. (2000) Transfer to and study at secondary school in Finnish school culture: Developing schools on the basis of pupils' experiences. *International Journal of Educational Research* 33, 383-400.
- Sciotto, M., Richwine, S., Mentrikoski, J., Niedzwiecki, K. (2012) A Qualitative Analysis of the School Experiences of Students With Asperger Syndrome. *Focus on Autism and Other Developmental Disabilities* 27 (3) 177-188
- Simmeborn Fleischer, A. (2012) Alienation and struggle: everyday student-life of three male students with Asperger Syndrome. *Scandinavian Journal of Disability Research* 14 (2) 177-194
- Smith, J. A., Flowers, P., Larkin, M. (2009) *Interpretative Phenomenological Analysis. Theory, Method and Research*. London: SAGE
- Smith L. E., Greenberg J. S., Seltzer M. M., Hong J. (2008) Symptoms and Behaviour Problems of Adolescents and Adults with Autism: Effects of Mother-Child Relationship Quality, Warmth and Praise. *American Journal on Mental Retardation* 113 (5) 387-402

Topping, K. (2011) Primary–secondary transition: Differences between teachers’ and children’s perceptions *Improving Schools* 14, (3), 268-285

Van Bourgondien, M. E., Woods, A. V. (1992). Vocational possibilities for high-functioning adults with autism. *High functioning individuals with autism*, 227-242.

Wing, L. (1981) Language, social and cognitive impairments in autism and severe mental retardation *Journal of Autism and Developmental Disorders*, 10, 31–44

PUBLIC DOMAIN BRIEFING PAPER:

**Asperger Syndrome; diagnostic uncertainty and  
subjective experience.**

## **Introduction**

This briefing paper aims to provide a summary of two pieces of research. Firstly it summarises a review of the literature regarding the similarities and differences in the neuropsychological profiles of individuals with the diagnosis labels of Asperger Syndrome and Schizophrenia. Secondly it will describe the subjective experience of young people with the label of Asperger Syndrome when they transition from primary to secondary school.

### **Literature Review:**

#### **Similarities and differences between attributes and symptoms of individuals with schizophrenia and individuals with autism spectrum disorders: A systematic review**

##### **Introduction**

There has been some debate about the usefulness of labeling experiences of psychological distress. Many of the diagnostic categories include a collection of difficulties which are shared across different groups. For example difficulties getting along with others could fit the diagnostic criteria for either schizophrenia or Asperger syndrome (APA, 2000). This has raised questions about the degree of overlap in profiles of strengths and difficulties between individuals who have been given a diagnosis of Asperger Syndrome and those who have been given a diagnosis of Schizophrenia and has led to interest into how best to separate these two groups of individuals to suggest appropriate support and intervention (DCP, 2013). The helpfulness of putting individuals into these groups has therefore been questioned; especially given the impact a diagnosis can have (Mansell & Morris, 2004). This has led to the suggestion of a formulation based approach to individual difficulties (DCP, 2013). This review critically evaluates the evidence of similarities and differences between the neuropsychological presentations of these groups of individuals before considering the utility of the current diagnostic system.

## **Method**

A systematic search of PsycINFO, and Medline was carried out. Sixteen articles which addressed the current topic were selected and appraised.

## **Results**

As expected, significant similarities between the two groups were reported in the majority of studies. This was especially evident in terms of understanding of, and behaviour around, others, and ability to understand emotions. There was some evidence of differences between the groups with those with the diagnostic label of schizophrenia showing an superior ability to deceive, greater likelihood of explaining the cause of events as due to other people or circumstances rather than due to their own actions, and poorer working memory skills than individuals with the diagnostic label of Asperger Syndrome. However this evidence was based on a small number of studies and needs further investigation.

## **Discussion**

Despite some emerging differences between these two groups the degree of overlap in strengths and difficulties has created challenges clearly defining them. Some authors suggest the need to fully understand the reasons for the difficulties a person is experiencing rather than just how they present. For example individuals said to have AS/HFA find it difficult to understand social situations and know how to respond to them, sometimes resulting in mistrust of others. The same behaviour may be evident in individuals who have been given a diagnosis of Schizophrenia but this mistrust may be due to an inability to process this complex social information as there is evidence that with additional cues these individuals are better able to understand social situations.

This evidence suggests the adoption of a formulation based approach to understanding individual strengths and difficulties. This may provide clearer goals for intervention which could be beneficial for both services and service users.

### **Empirical Paper:**

#### **Moving from primary to secondary school: how do young people with Asperger Syndrome experience this transition?**

##### **Background**

The majority of young people with Asperger Syndrome (AS) are now schooled through mainstream school (Parsons et al, 2011). There is clear evidence that individuals with a diagnosis of Asperger Syndrome find change difficult to cope with (Van Bourgondien & Woods, 1992) and there has been significant interest in how they transition from school to work. However there is still limited evidence describing how young people experience the transition from primary to secondary school and how best to support them. Current research has focused on information from education providers and caregivers which suggests that peer relationships, frequent changes of room and teacher, and anxiety levels cause significant difficulties for these young people (Konza, 2005; Lawrence, 2010). Consequently a range of strategies have been suggested to ease transition, however, little consideration has been given to how young people experience this move or how helpful they find the strategies put in place to help them transition.

##### **Method**

Seven young adults with Asperger Syndrome were interviewed about how they found the move from primary to secondary school. The interviews were analysed using Interpretative Phenomenological Analysis and common themes were identified.

## **Results**

Overall four main themes were identified. The first concerned how the young people tried to understand themselves in the context of the secondary school; especially the sense of difference to peers, their sense of self, and how they tried to fit into a group. The second theme considers the relationships they encountered, including those they observed between peers, their relationship with peers and teachers and their understanding of the complexities of social situations. The third theme considered the school environment in more detail, especially the demands placed on the young people in lessons and the physical environment. The final theme explores the coping strategies they used, their emotional reactions to the difficulties they faced and how they made sense of these. It also considered the strategies and adaptations which helped them to cope.

## **Discussion**

The findings suggest that young people with a diagnosis of Asperger Syndrome find the transition to secondary school difficult for a range of reasons. These include difficulties understanding others, coping with over-stimulating and frequently changing school environments and understanding themselves in a new context. Most interviewees reported that familiar peers within their classes aided transition, as did teachers who had some understanding of their difficulties. Furthermore the availability of quiet areas when things were challenging aided the transition process.

It is therefore recommended that young people with a diagnosis of Asperger Syndrome are supported to remain with pupils they are familiar with from primary school, and, where possible, are encouraged to develop an interest which can support a stable sense of identity (Meeus, Iedema, Helsen & Vollebergh, 1999). Furthermore the provision of quiet areas within

secondary school and the opportunity to visit the new school should be considered. Finally additional training of school staff on the experiences of young people with Asperger Syndrome may help them to understand the challenges these young people face. Future research should focus how young people with Asperger Syndrome develop a sense of self and how this could be nurtured within the school environment.

## References

- American Psychiatric Association. 2000. Diagnostic and Statistical Manual of Mental Disorders: DSM-IV-TR. *American Psychiatric Association*, Washington, DC, USA.
- Division of Clinical Psychology (2013) Division of Clinical Psychology Position Statement on the Classification of Behaviour and Experience in Relation to Functional Psychiatric Diagnoses. Time for a Paradigm shift. Retrieved 15<sup>th</sup> November 2013 from [www.bps.org.uk](http://www.bps.org.uk)
- Konza, D. (2005) Secondary school success for students with Asperger's syndrome. *Australasian Journal of Special Education* 29 (2) 128-139
- Lawrence, C. (2010) *Successful School Change and Transition for the child with Asperger Syndrome*. London: Jessica Kingsley Publishers
- Mansell, W., & Morris, K. (2004) A survey of parents' reactions to the diagnosis of an autistic spectrum disorder by a local service: Access to information and use of services. *Autism* 8 (4), 387-407
- Meeus, W., Iedema, J., Helsén, M., Vollebergh, W. (1999) Patterns of Adolescent Identity Development: Review of Literature and Longitudinal Analysis. *Developmental Review* 19 (4) 419-461

Parsons, S., Guuldberg, K., MacLeod, A., Jones, G., Prunty, A., Balfe, T. (2011) International review of the evidence on best practice in educational provision for children on the autism spectrum *European Journal of Special Needs Education* 26 (1) 47-63

Van Bourgondien, M. E., Woods, A. V. (1992). Vocational possibilities for high-functioning adults with autism. *High functioning individuals with autism*, 227-242.

## APPENDIX A

### DSM-IV Criteria for Asperger syndrome/ HFA

*An Asperger/HFA screening tool must meet all six areas defined by the DSM-IV description of Asperger Syndrome (A-F below) to qualify for a positive rating from First Signs:*

A. Qualitative impairment in social interaction, as manifested by at least two of the following:

(1) marked impairment in the use of multiple nonverbal behaviors, such as eye-to-eye gaze, facial expression, body postures, and gestures to regulate social interaction

(2) failure to develop peer relationships appropriate to developmental level

(3) a lack of spontaneous seeking to share enjoyment, interests, or achievements with other people (e.g., by a lack of showing, bringing, or pointing out objects of interest to other people)

(4) lack of social or emotional reciprocity

B. Restricted, repetitive, and stereotyped patterns of behavior, interests, and activities, as manifested by at least one of the following:

(1) encompassing preoccupation with one or more stereotyped and restricted patterns of interest that is abnormal either in intensity or focus

(2) apparently inflexible adherence to specific, nonfunctional routines or rituals

(3) stereotyped and repetitive motor mannerisms (e.g., hand or finger flapping or twisting, or complex whole-body movements)

(4) persistent preoccupation with parts of objects

C. The disturbance causes clinically significant impairment in social, occupational, or other important areas of functioning.

D. There is no clinically significant general delay in language (e.g., single words used by age 2 years, communicative phrases used by age 3 years).

E. There is no clinically significant delay in cognitive development or in the development of age-appropriate self-help skills, adaptive behavior (other than in social interaction), and curiosity about the environment in childhood.

F. Criteria are not met for another specific pervasive developmental disorder or schizophrenia.

## **DSM-IV-TR Criteria for Schizophrenia**

A. Characteristic symptoms: Two (or more) of the following, each present for a significant portion of time during a 1-month period (or less if successfully treated):

- (1) delusions
- (2) hallucinations
- (3) disorganized speech (e.g., frequent derailment or incoherence)
- (4) grossly disorganized or catatonic behaviour
- (5) negative symptoms, i.e., affective flattening, alogia (poverty of speech), or avolition (lack of motivation)

Note: Only one Criterion A symptom is required if delusions are bizarre or hallucinations consist of a voice keeping up a running commentary on the person's behavior or thoughts, or two or more voices conversing with each other.

B. Social/occupational dysfunction: For a significant portion of the time since the onset of the disturbance, one or more major areas of functioning such as work, interpersonal relations, or self-care are markedly below the level achieved prior to the onset (or when the onset is in childhood or adolescence, failure to achieve expected level of interpersonal, academic, or occupational achievement).

C. Duration: Continuous signs of the disturbance persist for at least 6 months. This 6-month period must include at least 1 month of symptoms (or less if successfully treated) that meet Criterion A (i.e., active-phase symptoms) and may include periods of prodromal (symptomatic of the onset) or residual symptoms. During these prodromal or residual periods, the signs of the disturbance may be manifested by only negative symptoms or two or more symptoms listed in Criterion A present in an attenuated form (e.g., odd beliefs, unusual perceptual experiences).

D. Schizoaffective and Mood Disorder exclusion: Schizoaffective Disorder and Mood Disorder With Psychotic Features have been ruled out because either

- (1) no Major Depressive Episode, Manic Episode, or Mixed Episode have occurred concurrently with the active-phase symptoms; or
- (2) if mood episodes have occurred during active-phase symptoms, their total duration has been brief relative to the duration of the active and residual periods.

E. Substance/general medical condition exclusion: The disturbance is not due to the direct physiological effects of a substance (e.g., a drug of abuse, a medication) or a general medical condition.

F. Relationship to a Pervasive Developmental Disorder: If there is a history of Autistic Disorder or another Pervasive Developmental Disorder, the additional diagnosis of Schizophrenia is made only if prominent delusions or hallucinations are also present for at least a month (or less if successfully treated).

## DSM-IV Criteria for Schizotypal Personality Disorder

**A.** A pervasive pattern of social and interpersonal deficits marked by acute discomfort with, and reduced capacity for, close relationships as well as by cognitive or perceptual distortions and eccentricities of behavior, beginning by early adulthood and present in a variety of contexts, as indicated by five (or more) of the following:

- ideas of reference (excluding delusions of reference)
- odd beliefs or magical thinking that influences behavior and is
- inconsistent with subcultural norms (e.g., superstitiousness, belief in clairvoyance, telepathy, or “sixth sense”; in children and adolescents, bizarre fantasies or preoccupations)
- unusual perceptual experiences, including bodily illusions
- odd thinking and speech (e.g., vague, circumstantial, metaphorical, overelaborate, or stereotyped)
- suspiciousness or paranoid ideation
- inappropriate or constricted affect
- behavior or appearance that is odd, eccentric, or peculiar
- lack of close friends or confidants other than first-degree relatives
- excessive social anxiety that does not diminish with familiarity and tends to be associated with paranoid fears rather than negative judgments about self

**B.** Does not occur exclusively during the course of [Schizophrenia](#), a Mood Disorder With Psychotic Features, another Psychotic Disorder, or a Pervasive Developmental Disorder.

**C.** The disturbance is not due to the direct physiological effects of a substance (e.g., a drug of abuse, a medication) or a general medical condition.

**Note:** If criteria are met prior to the onset of [Schizophrenia](#), add “Premorbid,” e.g., “Schizotypal Personality Disorder (Premorbid).”

## APPENDIX B: QUALITY FRAMEWORK FOR QUANTITATIVE STUDIES

Quality criteria	Specific questions to consider when rating
1. Rationale clearly described?	<ul style="list-style-type: none"> <li>• Does the author(s) describe the current evidence base?</li> <li>• Does the author(s) identify the gaps in the evidence base?</li> <li>• Does the author(s) justify the need for the area of research?</li> </ul>
2. Research aims clearly stated?	<ul style="list-style-type: none"> <li>• Does the author(s) clearly state what they plan to research?</li> </ul>
3. Ethical issues addressed?	<ul style="list-style-type: none"> <li>• Does the author(s) state that ethical approval was sought?</li> <li>• Does the author(s) demonstrate an awareness of the ethical issues raised by the study? (E.g. informed consent, confidentiality, responding to upset or distress, withdrawal etc.).</li> </ul>
4. Methodology appropriate to the research question?	<ul style="list-style-type: none"> <li>• Is the use of quantitative methodology appropriate to the research aims? (E.g. to determine relationships between a number of variables).</li> </ul>
5. Study design identified and the rationale for choice evident?	<ul style="list-style-type: none"> <li>• Does the author(s) clearly state the design of the study?</li> <li>• Does the author(s) justify the research design used? (E.g. longitudinal, cross sectional etc.).</li> </ul>
6. Experimental hypotheses stated?	<ul style="list-style-type: none"> <li>• Does the author(s) clearly state what they expect to find?</li> </ul>
7. Key variables identified?	<ul style="list-style-type: none"> <li>• Does the author(s) identify the main variables investigated in the study?</li> </ul>
8. Sample population situated?	<ul style="list-style-type: none"> <li>• Does the author(s) adequately describe the sample (E.g. Gender, age, relationship to care receiver etc.) so that the reader can determine transferability of findings?</li> </ul>
9. Selection of participants adequately described?	<ul style="list-style-type: none"> <li>• Does the author(s) describe the context of where the samples were recruited from?</li> <li>• Does the author(s) describe the method of recruitment used? (E.g. the sampling method, recruitment procedure etc.)</li> <li>• Does the author(s) identify the inclusion criteria?</li> </ul>
10. Method of data collection reliable and valid?	<ul style="list-style-type: none"> <li>• Does the author(s) justify that the measure is suitable for this population?</li> <li>• Does the author(s) use measures that measure the desired constructs?</li> <li>• Does the author(s) indicate whether the measures used have good psychometric properties? (E.g. test-retest reliability, inter-rater reliability, internal reliability and internal consistency (Cronbach's</li> </ul>

	<p>alpha)).</p> <ul style="list-style-type: none"> <li>• Does the author(s) indicate that the measures used have demonstrated validity?</li> </ul>
11. Method of data analysis reliable and valid?	<ul style="list-style-type: none"> <li>• Does the author(s) state which statistic tests were used?</li> <li>• Does the author(s) use statistical tests that appear to be appropriate to the nature of the data collected? (E.g. Does the data meet the assumptions of the test).</li> <li>• Were the statistical tests used appropriate to the research question?</li> <li>• Does the author(s) consider the impact of extraneous variables and control for these within the analysis process?</li> <li>• Does the author(s) provide evidence of statistical findings? (E.g. Data within the text, tables etc.).</li> <li>• Does the author(s) state the levels of significance?</li> </ul>
12. Findings clearly stated?	<ul style="list-style-type: none"> <li>• Does the author(s) explicitly state their findings?</li> <li>• Does the author(s) present the statistical data in a clear manner?</li> <li>• Does the author(s) clearly differentiate between significant and non-significant findings?</li> </ul>
13. Comprehensive discussion?	<ul style="list-style-type: none"> <li>• Does the author(s) summarise the main findings?</li> <li>• Does the author(s) link their findings back to the research aims?</li> <li>• Does the author(s) link their findings current literature and/or psychological theory?</li> <li>• Does the author(s) consider the clinical usefulness of their findings?</li> </ul>
14. Strengths and limitations identified?	<ul style="list-style-type: none"> <li>• Does the author(s) indentify the limitations of the research? (E.g. Sample size, recruitment strategies, method of data collection, analysis etc.)</li> <li>• Does the author(s) identify the strengths of the research? (E.g. Its usefulness etc.)</li> </ul>
15. Justifiable conclusions made?	<ul style="list-style-type: none"> <li>• Does the author(s) make conclusions that are supported by their discussions of their findings?</li> </ul>

***PARTICIPANT INFORMATION SHEET***

*Title of Project: Moving from Primary to Secondary School; What do young people with Asperger Syndrome think about it?*

*Researchers: Victoria Thurston, Biza Stenfert Kroese (Academic Supervisor)*

*We are hoping to find out how young people with Asperger Syndrome find the move from primary to secondary school. We want to do this by asking young adults like yourself to tell us about how they found the move and the things that made it easier or harder for them. If you agreed to take part I would meet with you for 60 to 90 minutes to ask some general questions about how you found the move from Primary to Secondary School. I'm interested in your experience whether it was good or bad, to understand how it was for you at the time.*

*We are trying to find out why for some young people this is an easy move that they manage well, but for other young people it is hard and they struggle. This information would help us to advise schools and health professionals working with young people with Asperger Syndrome how best to support them through this time and help workers understand how the young person might be feeling about the move. I am carrying out this research with Biza's support as part of my research thesis. I have had an interest in Autism for many years and met a young person making this move 3 years ago as part of a befriending scheme; this has made me think about how young people might feel about the change of school.*

*What is the aim of this study?*

We aim to find out how young people with Asperger Syndrome find the move from primary to secondary school and to work out what could make it easier for them. We hope that this information will help schools and health professionals to support young people with this move.

*Who would we like to take part?*

We would like to hear from young adults aged 18 to 25, who have a diagnosis of Asperger Syndrome, and would be happy to talk about moving from primary to secondary school

*What will happen if I agree to take part?*

I will arrange to meet with you to ask you questions about the move from primary to secondary school. We could meet in any public place that is easy for you to get to, perhaps a local cafe. We would meet to talk for 60-90 minutes, and I would record our conversation using a Dictaphone. If at any time during this meeting you changed your mind you would be free to leave. When I have typed up our conversation you may read what we talked about and ask for any information you are not happy with to be removed. I can meet with you to

talk about this or send it to you by post. The information you have given me will then be made anonymous so that you cannot be identified.

What will happen if I do not want to carry on with the study?

You are free to pull out of this study at any time, this will not affect your membership of any groups. You can do this by contacting me by email, telephone or post. Any information I have already received will still be used so if you would like to take back any of the information given, please let me know.

Will I get paid?

Unfortunately I am not able to pay you for taking part in this study. We can pay you for any travel expenses.

What will happen to the results of the research study?

When I write up my report, all details which might allow someone to recognise you will be removed. I will publish the results in my University thesis and a journal for health professionals.

What if I have any other questions?

If you have any questions or would like more information about the study before you make a decision please contact me, Victoria Thurston; my contact details are at the end of this letter.

What should I do next?

If you have read this information sheet and would like to take part in this study please fill in the attached consent form and either post it to me at the address below or give it to a staff member at meeting where you heard about the study.

If you would like to talk more about this study please contact me:

Tel:

Email:

Post: [Redacted]  
[Redacted]  
[Redacted]  
[Redacted]  
[Redacted]  
[Redacted]

CONSENT FORM

Moving from Primary to Secondary School; What do young people with Asperger Syndrome think about it?

Participant Identification Number:.....

Researchers: Victoria Thurston, Biza Stenfert Kroese

Please initial box

I confirm that I have understood the Participant information sheet dated 24/09/2012 (version 2) for the above study. I have had the chance to consider the information, ask questions and have had these answered satisfactorily.

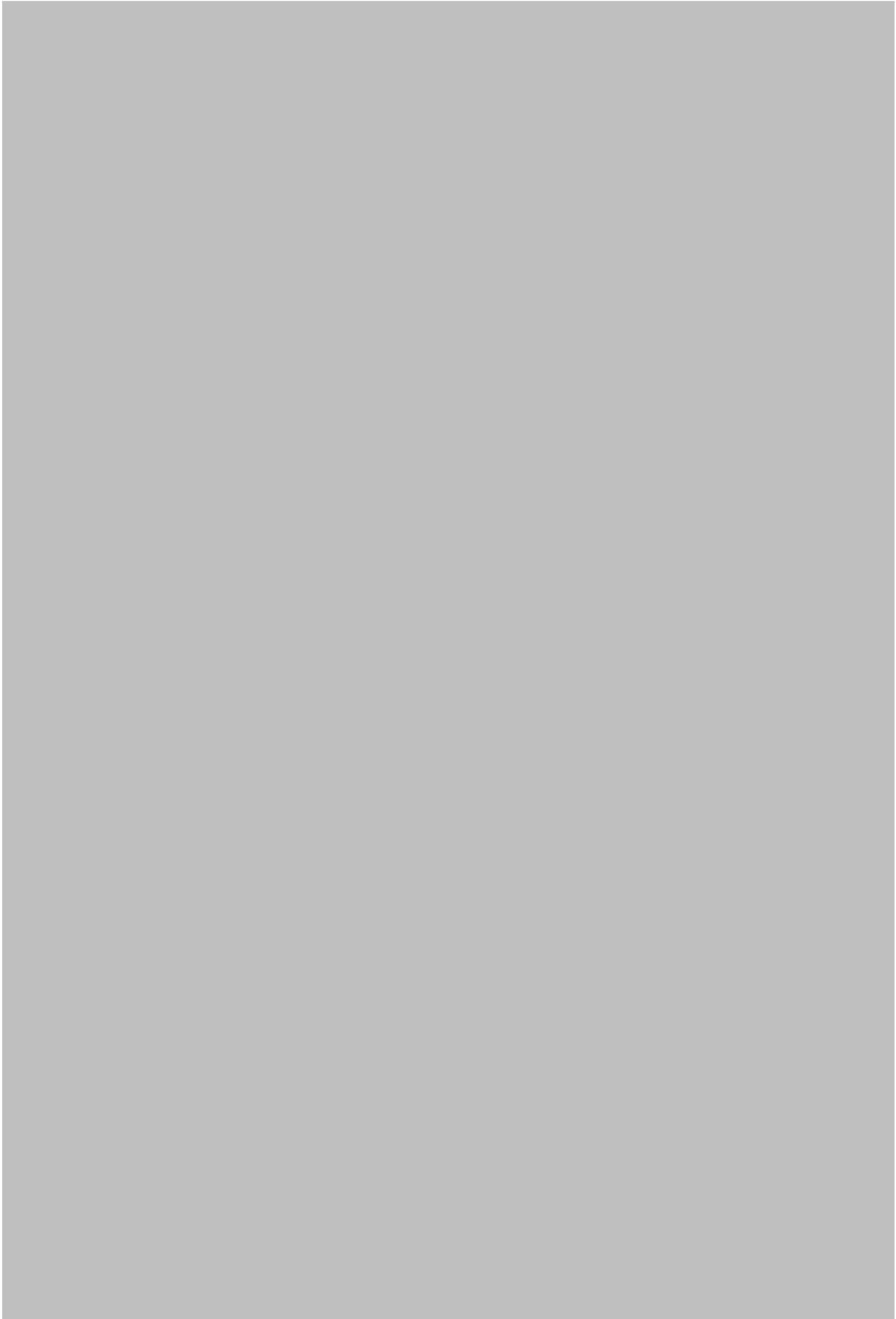
- 1. I understand that participation is voluntary and that I am free to withdraw at any time during the research process, without giving any reason, without my medical/social care or legal rights being affected.
2. I understand that the research interview will be recorded using a Dictaphone
3. I understand that I am free to withdraw part or all of my responses for up to two weeks after the interview, without giving any reason, without my medical/social care or legal rights being affected.
4. I understand that the data collected during this study will be looked at by the researchers and one of the directors of research for the Clinical Psychology Doctorate at the University of Birmingham to ensure that the analysis is a fair and reasonable representation of the data.
5. I understand that direct quotes from my responses may be published in any write-up of the data, but that my name will not be attributed to any such quotes and that I will not be identifiable by my comments.
6. I agree to take part in the above study.

Name of participant Date Signature

Name of researcher Date Signature

The best number to contact me on is .....

## Appendix E





## Appendix F

### Question schedule

1. Tell me about the change from primary to secondary school; what made it easier or harder?
2. Did you know what to expect when you moved to secondary school? Tell me how important this was for you; were there things that you weren't told that you think would have helped?
3. Tell me how you got on with the other young people in secondary school? Which things were different about making friends from being at primary school?
4. When you first went to secondary school were you expected to know things even though you hadn't been told them? Tell me about what this was like for you.
5. Were things changed to help you settle into secondary school (such as using your hobbies to help you or helping you to cope with your worries)? What were they? Did they work for you and if not what would you have liked instead?
6. What were the school buildings like in secondary school? Were there things you could see, hear or had to touch which made it harder for you to settle in? If there was, what were these and was anything done to change them?

Is there anything else that I haven't asked you that you would like to tell me about?

## Appendix G

### Example of analysis of transcript

Emergent Themes	Line	Original Transcript	Exploratory comments Descriptive comments <u>Conceptual comments</u> and <i>linguistic comments</i>
Likes rules  Mistakes catastrophic  Inability to cope  Struggle  Panic	133 134 135 136 137 138 139 140 141 142 143 144 145 146 147 148 149	P: It's like one week I'm in the mindset that I've got maths than I've got science then the following Monday it turns out that I've got German then I've got RE and I'm like oh my god... I've got my maths books and I've forgot to do my German homework... oh my god (laughs) <i>I: Gosh so there was a lot to remember (laughing)</i> P: Yeah... <i>I: In terms of when lessons were and changes to the timetable</i> P: Yeah its it was like I couldn't I couldn't really memorise all the lessons that I had then I had to constantly I had to constantly err go and err check back err what week I am I on what lesson have I got next what time is it... <i>I: Yep</i> P: Err what homework is due err what homework do I	Planned lessons. <u>'Mindset' need for things to be the same inflexibility? Need for routine in AS</u> Got it wrong, wrong homework, books. <i>Enormity of mistakes. Catastrophic when things go wrong; inability to cope? What happened in he did get it wrong? Did other kids get it wrong?</i>  Couldn't manage, constant checking. <u>Effort putting into getting it right, sense the effort shouldn't be necessary</u> <i>Repetition of sense of struggle</i>  Check homework <u>Sense of panic – always behind</u>

	150	err do I have to catch up with etc	
	151	<i>I: So there was a lot to keep track of then...</i>	Enormity of task. <u>Not the same as other kids</u>
Difference	152	P: There was a lot to keep track of... especially for me	<i>Sense of difference</i>
	153	(laughing)	Reflecting change in room and teacher and lesson
	154	<i>I: Were they all with different people in different places</i>	
	155	<i>and... For each lesson</i>	
	156	P: Yeah	
Mistakes	157	<i>I: Did that erm did that make any difference to you? Did</i>	
significant	158	<i>that make it easier or harder?</i>	<i>Degree to which things became harder.</i>
	159	P: Erm err it did make it much harder because eerr as I	Emphasis on amount. <u>Concern about mistakes – what does it</u>
	160	say one day I had maths and science in one room and	<u>say about him if he gets it wrong?</u>
	161	the week after I've got German and err ... German and	Sheer number of lessons
Embarrassment	162	RE in 2 completely separate rooms. And err in one class	Confusion – in wrong lesson for entire time.
	163	I was in a class of year 9s saying umm err saying at the	<u>Sense of embarrassment; importance of mistakes – was this</u>
	164	end err isn't this the classroom for maths! I I took my	<u>not normal for new students?</u>
	165	diary... sorry...	
Need for plan	166	<i>I: No it's...</i>	<i>Significance of using Oh my God</i>
	167	P: I'd come back in and was 5 minutes late... oh my	Reflecting emotion shown by body language
	168	god...	In trouble <i>Enormity of problem – catastrophic. Felt like the</i>
Catastrophising	169	<i>I: Oh and how embarrassing for you as well</i>	<u>end of the world.</u>
	170	P: Yeah... I was like the teacher's going to kill me...	
	171	(laughs)	
	172	<i>I: (laughs) Gosh so did that happen a lot that you would</i>	Common problem to begin with. <i>Hesitant when describing</i>
Difference	173	<i>be in the wrong room...</i>	<u>difficulties. Different because everyone else got lost with their</u>
	174	P: Urrr well the first... umm the first few days yeah	<u>friends? Or did other people not get lost?</u>
Effort	175	<i>I: Yeah</i>	<u>Developing strategies. Putting effort in to make the situation</u>

<p>Incongruence</p> <p>Detached from peers</p> <p>Threat</p> <p>Need to be social</p> <p>Agency?</p> <p>Time</p> <p>Passive</p> <p>Relationship quality</p>	<p>176</p> <p>177</p> <p>178</p> <p>179</p> <p>180</p> <p>181</p> <p>182</p> <p>183</p> <p>184</p> <p>185</p> <p>186</p> <p>187</p> <p>188</p> <p>189</p> <p>190</p> <p>191</p> <p>192</p> <p>193</p> <p>194</p> <p>195</p> <p>196</p> <p>197</p> <p>198</p> <p>199</p> <p>200</p> <p>201</p>	<p>P:Afterwards I got into err into the habit of always checking back into my diary to see what is next</p> <p><i>I: Yeah yeah</i></p> <p>P:So yeah</p> <p><i>I: It sounds like that was a good strategy to use...</i></p> <p>P: Yeah (laughing)</p> <p><i>I: Ok Umm what about the other people... so your peers at secondary school, how did you get on with them? You said you kinda kept your head down...</i></p> <p>P: Yeah Umm I as I say the first two years I just erm kept my head down, wasn't really all too bothered about anyone else... umm I suppose it's just survival instincts really...</p> <p><i>I: What happened after that?</i></p> <p>P: After 2 years I made erm one one or two friends and we erm hung out for a while and err yeah it was just just kind of went on from there...</p> <p><i>I: So was that easier when you had a couple of mates?</i></p> <p>P: Yeah cos I've got someone to talk to I've got someone to help me err pass the time</p> <p><i>I: Yeah .... so break times and lunch times and stuff</i></p> <p>P:Yeah</p> <p><i>I: And was that different erm in primary school did you have a good group of mates or...</i></p> <p>P: I spose yeah I spose I would yeah I would say that I did yeah and umm a few a few of them did come along</p>	<p><u>manageable. Structure helping.</u></p> <p><u>Incongruence – laughing when describing efforts to make it manageable.</u></p> <p>Peer relationships?</p> <p><u>What did he mean by keeping his head down? Chameleon? Detached? Silent?</u></p> <p>Not bothered about engaging with others</p> <p><i>Tailing off emphasizing isolation? Trying to convince self he doesn't care? <u>Extreme situation – needed survival instincts</u></i></p> <p><u>What changed to help him make friends? How was he successful? Sense of agency?</u></p> <p>Sense that things got easier.</p> <p><i>Passive? <u>What is the role of friends? Sense of friends as someone to talk to to pass the time?</u></i></p> <p><u>No sense of what drew him to friends or what they had in common.</u></p> <p>Trying to get a sense of what the difference was</p> <p><i>Repetition of I and yeah – Unsure? <u>Would he have described them as good friends? Quality of these relationships?</u></i></p> <p><i>Some hesitance sense of lack of agency?</i></p> <p>Friends came along... <u>What is linked to AS and what is</u></p>
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Difference	202	to the same erm same secondary school but erm I	<u>'normal' in his mind? Lack of understanding of others?</u>
	203	spose they went off and they did their own thing	
Alone, lost	204	<i>I: Yeah... so it felt like even though you have been</i>	Left by friends. <u>Feeling lost? In the corner like has been</u>
	205	<i>friends with some of them everyone dispersed</i>	<u>naughty? Sense of being alone</u>
	206	P: Yeah everyone dispersed and I'm just there erm in	School helping?
	207	the corner like...	
	208	<i>I: Was there any effort made by the secondary school to</i>	Split into forms. <u>Lack of control.</u> Everyone else had someone.
	209	<i>keep kids that knew each other together?</i>	
Overwhelmed	210	P: No... erm what happened was was that err we each	<u>Overwhelming sense of being alone... lots of hesitation.</u>
Alone	211	err had our forms err everyone that I knew had at least	Sense that it is not fair, not own fault – <u>Does he feel it would</u>
	212	someone else that they knew from our previous school	<u>have been different if he wasn't left alone?</u>
	213	and I'm just left on my own... in my form alone...	Can't get any worse. <u>Catastrophising. Would be ok if he has a</u>
Catastrophising	214	<i>I: Oh no</i>	<u>friend? Sense of threat.</u>
	215	P: I'm like this can't get any worse.... (laughs) Its like urr	It is not ok to spend time alone.
	216	ok so my former mate has him from from err primary	
	217	school so he'll be alright and he's got err so and so and	
Alone	218	I'm here alone...	

