

What are the experiences of educational psychologists when  
working with adolescent girls with social communication  
difficulties in mainstream education? An exploratory study.

A thesis submitted as part of the requirements of the University of East London for the  
Doctorate in Educational and Child Psychology

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## Abstract

Historically, Autism Spectrum Disorder (ASD) and associated social communication difficulties (SCD) have been regarded as predominantly male disorders (Sayal et al., 2006). Based on limited research, it has been suggested that the presentation of ASD in girls varies greatly from that in boys (Cridland et al., 2014). The aim of this research was to explore the female presentation of SCD by investigating the experiences of Educational Psychologists (EPs) in order to consider how the role of the EP can be adapted to support girls with ASD and SCD. The research specifically focused on adolescent girls as the local context highlighted this as a critical time within their education.

The research was conducted from a critical realist stance and used qualitative data collection methods. Initially a focus group was conducted with members of an Outer London Borough Local Authority Educational Psychology Service (n = 5) to provide an overview of EPs' experiences when working with adolescent girls with SCD in mainstream education. Through thematic analysis (Braun & Clarke, 2006) it was possible to identify key themes that then fed into an interview schedule. The second phase of the research involved conducting semi-structured interviews with individual EPs (n = 8) to gain a richer picture of their experiences. The data collected from the individual semi-structured interviews was also analysed through thematic analysis, resulting in a number of themes, subthemes and features being identified.

Areas highlighted by the data included the presentation of adolescent girls with SCD in mainstream education, which was often described in terms of identifiable and overlooked behaviours and featured aspects of vulnerability. Another common theme which emerged from the data was the need to provide support for the young person, schools and families, with support being individual to each young person. The importance of having knowledge of ASD was raised, and it was felt that knowledge was gained through research and personal experience. Participants reflected on the impact that the availability of resources has on their work. Finally, working with others was discussed with reference to multiagency working, systemic thinking and the conflict that can be experienced within this work. The need for good channels of communication was highlighted as a necessity within this theme. The implications of the findings are discussed in relation to the impact that these may have on the role of the EP.



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#### Contents of CD

- The full transcription of the focus group
- The codes and themes identified from the focus group
- The full transcription of eight interviews
- The codes and themes identified from each interview

## Abbreviations

ASD	Autism Spectrum Disorder
CYP	children and young people
SCD	social communication difficulties
EP	Educational Psychologist
SENCo	Special Educational Needs Co-ordinator
EPS	Educational Psychology Service
DSM	Diagnostic and Statistical Manual
APA	American Psychiatric Association
EBD	emotional and behavioural difficulties
IPA	interpretive phenomenological analysis
OCD	Obsessive Compulsive Disorder
ADHD	Attention Deficit Hyperactivity Disorder
SEMH	social, emotional and mental health
EHC	Education, Health and Care
BME	Black and Minority Ethnic
CP	Clinical Psychologist
TA	teaching assistant
SEN	special educational needs
UK	United Kingdom
TEP	Trainee Educational Psychologist
DfEE	Department for Education and Employment
NICE	National Institute for Health and Care Excellence

## Chapter 1. Introduction

### 1.1. Introduction

The main purpose of this research was to explore the experiences of educational psychologists (EPs) when working with adolescent girls with social communication difficulties (SCD) in mainstream education. The research stems from increased concern regarding adolescent girls' vulnerability to exclusion from mainstream education as a result of SCD which presents as behavioural difficulties (Barnard, Prior & Potter, 2000). The research wished to explore whether these findings are also reflected in the experiences of EPs when working with adolescent girls with SCD in mainstream education, whilst also broadening the focus wider to explore the role of the EP in general when working with this population. The research findings will be discussed in terms of the implications that they may have for EP practice with regard to adolescent girls with SCD in mainstream education. The findings also present an opportunity to highlight the need to implement changes to ensure this population of students is being identified and supported as early as possible, reducing their vulnerability to exclusion and subsequently their vulnerability heading into adult life.

### 1.2. Background and Terminology

#### *- 1.2.1. Autism Spectrum Disorder and Social Communication Difficulties*

The term 'autism' was coined by Austrian-American psychiatrist Leo Kanner in 1943. Simultaneously, the Austrian paediatrician Hans Asperger also identified the condition, naming it Asperger's Syndrome. Since then, the label of Autism Spectrum Disorder (ASD) has grown to incorporate a spectrum of disorders, including autistic disorder, Asperger's Syndrome and Pervasive Developmental Disorder not otherwise specified (American Psychiatric Association, APA, 2013). It is generally accepted that the presentation of ASD can be summarised by the triad of impairments (Wing & Gould, 1979); that is, a lack of social communication, poor social interaction and repetitive and restricted thinking.

The prevalence of ASD appears to be increasing over time with figures growing from under 0.5 in 1,000 (Gillberg & Wing, 1999) to 15.7 in 1,000 (Baron-Cohen et al., 2009). This increase has been attributed to a number of reasons including the number of incidents of ASD increasing, increased public awareness of ASD and subsequently better identification, clearer definitions, better assessment processes, increased research

and better provision and services. Despite evidence of increasing figures, there is still a lack of clarity around the exact prevalence of ASD.

Common features shown by children and young people (CYP) with ASD include limited language skills, poor eye contact, an inability to read facial expressions and body language, a lack of theory of mind, obsessional behaviours and social isolation. Hence, diagnostic processes look for a range of behaviours that include some of those mentioned in order to provide a label for a child's behaviour. Obtaining a label can lead to increased access to resources, heightening the importance of an accurate diagnosis process. However, with an emphasis being placed on exploring the differences between boys and girls with ASD, it has been suggested that girls do not present with the same characteristics as boys (Cridland, Jones, Caputi & Magee, 2014; Hendrickx, 2015; Kothari, Skuse, Wakefield & Micali, 2013). This has significant implications for the initial assessment and diagnostic process.

### **- 1.2.2. *Gender Differences***

Although there appear to be discrepancies around the figures reported with regard to the prevalence of ASD, with prevalence appearing to be increasing, the ratio of ASD in males to females seems to have remained constant for a number of years. Fombonne (2003) reported a ratio of 4:1, males to females with a diagnosis of ASD, with Holtmann, Bölte and Poustka (2007) reporting a similar figure. However, researchers are beginning to question the accuracy of this ratio (Attwood, 2006; Dworzynski, Ronald, Bolton & Happé, 2012). For example, May, Cornish and Rinehart (2014) reported that the under-diagnosis in the female population may be the result of girls presenting as less hyperactive and so being “overlooked for assessment and educational support” (May et al., 2014, p. 1085). This would suggest that the ratio is correct in terms of the number of females able to access an ASD diagnosis, but that the criteria for diagnosis may be inaccurate with regard to the presentation of ASD in females.

### **- 1.2.3. *Cultural Influences***

As the diagnosis of ASD relies heavily upon observation and parental report, it could be argued that ASD is a socially constructed phenomenon. By that, socially appropriate behaviour (and consequently, socially inappropriate behaviour) is defined by what is perceived as acceptable by the general population. This is supported by the finding that ASD is often under-diagnosed in CYP from a number of different cultural backgrounds,

namely of Asian and Chinese heritage (Lindsay, Pather & Strand, 2006), suggesting that these cultures do not perceive specific behaviours associated with ASD to be inappropriate. In addition, it has been suggested that the diagnostic tools used during the assessment of ASD are not culturally-sensitive or fair, creating skewed representations of the prevalence of ASD within Black and Minority Ethnic (BME) communities (Desforges, Mayet & Vickers, 1995).

#### ***- 1.2.4. Support***

Even after receiving a diagnosis of ASD, it would appear that there is a limited amount of support available for CYP with ASD and their parents. Additionally, given the presentation of ASD as a predominantly male disorder (Sayal, Hornsey, Warren, MacDiarmid & Taylor, 2006), a lot of the support available appears to be targeted at boys, isolating girls with ASD further still (Cridland et al., 2014).

With more CYP with special educational needs (SEN) being educated within mainstream settings, it is important that school staff are able to appropriately differentiate work to meet the needs of their students. Equally, senior leadership teams within schools should be appropriately equipped to support teachers working with children with SEN. One survey which investigated the inclusion of CYP with ASD in mainstream schools suggested that staff were not receiving adequate training and did not feel confident with this element of their teaching role (Barnard et al., 2000).

##### ***- 1.2.4.1. Educational Psychology Involvement***

The role of the EP has been the subject of debate (Farrell et al., 2006). Greig and MacKay (2005) proposed that EPs should be involved in working within systems, academia and at an individual level with CYP. This would suggest that there are a number of possible ways in which EPs can aid in the support of CYP with ASD. In particular, it would appear that EPs are well placed to provide appropriate support and intervention for girls with ASD using a gender neutral approach. However, there appears to be a lack of research specifically supporting this. Further still, it would appear that EPs do not receive appropriate training and development in specialised areas such as cultural influences on ASD (Rapasinha, 2015) and so they are therefore unlikely to have a very large impact on the way in which mainstream schools, and the education system as a whole, approach the social perception of and support provided for adolescent girls with SCD in mainstream education.

#### **- 1.2.4.2. *Other Professionals***

EPs are not alone in working with CYP with ASD. In order to receive a diagnosis of ASD, National Institute for Health and Care Excellence (NICE) guidelines suggest that best practice would indicate CYP undergoing assessment completed jointly by a paediatrician and/or a child and adolescent psychiatrist, speech and language therapists and clinical and/or educational psychologists (NICE, 2011), as required by the Autism Act (2009). Therefore, increased awareness of the subtleties of the presentation of SCD in girls needs to be discussed more broadly than just within the field of educational psychology.

Beyond diagnosis, EPs work jointly with other professionals in a range of settings. Although service delivery models vary between Educational Psychology Services (EPSs), many work closely with schools and so it is important that professionals such as Head Teachers and Special Educational Needs Co-ordinators (SENCOs) are also fully aware of the characteristics associated with ASD and, more specifically, girls with ASD and SCD.

### **1.3. Context**

#### **- 1.3.1. *National Context***

The Salamanca Statement (UNESCO, 1994) and introduction of the Special Educational Needs and Disabilities Act (Department for Education & Employment, DfEE, 2001) have resulted in a large impetus for schools to create an inclusive environment where all CYP have the opportunity to be educated within a mainstream setting, as far as possible. This has resulted in reports of an increased number of CYP with ASD being educated within mainstream settings (Geneva Centre for Autism, 2010; McLeskey, Henry & Hodges, 1999). Further to this, the production of the Autism Act (2009) increased the profile and heightened awareness of ASD.

Barnard, Broach, Potter and Prior (2002) found that inclusion of CYP with ASD was visible within the Early Years of education, however there appeared to be ‘missing children’ within the secondary population, with the number of CYP with ASD in mainstream education dropping dramatically during the transition from primary to secondary school. Nationally, Barnard et al. (2000) investigated the rate of school exclusions and found that 20% of CYP with an ASD diagnosis had been subjected to an exclusion at some point during their education. This is something which is of concern within the local area where the current research was conducted as well.



### **- 1.3.2. Local Context**

This research has been conducted within an Outer London Borough EPS. Within the Local Authority, through anecdotal report, there have been a number of cases where adolescent girls have been at risk of exclusion from mainstream education due to behavioural concerns expressed by the school. After EP involvement, the girls have later gone on to receive a diagnosis of ASD and, with this in place, have been given the appropriate support to continue to access mainstream education.

In addition to this, over 80% of the CYP being educated within maintained schools within the Outer London Borough in which the research was conducted are recorded as BME (figure obtained through Local Authority records, not referenced, 2012). It is therefore extremely important for the EPS to take into consideration the cultural influences that may be impacting on the diagnosis of girls with ASD prior to adolescence, but to also ensure that the service demonstrates equality and inclusive practices, providing all CYP with the appropriate support needed.

The research was approved by the Principal EP within the Outer London Borough EPS.

### **1.4. Researcher's Position**

The researcher's interest in the area of ASD and society's perception of it has developed through her role as a Trainee EP (TEP) as well as previous experience working as a Psychology Assistant and working within an ASD special school. In particular, the researcher has become increasingly aware of how schools react to certain presentations of behaviour and the impact that this can have on CYP with ASD. The decision to focus upon mainstream education as opposed to specialist ASD provisions was, in part, because the number of female students attending specialist ASD schools is extremely low (Stampoltzis, Papatrecha, Polychronopoulou & Mavronas, 2012). Furthermore, the experience of practice as a Psychology Assistant and a TEP on placement led the researcher to believe it was the students who have not been diagnosed, or who have been misdiagnosed who required the most support and that ethically, she felt that it is important for research to be conducted in areas where there is the greatest need (therefore, researching undiagnosed or misdiagnosed cases).

An additional factor influencing the researcher's desire to conduct research around adolescent girls with SCD was having had a close female friend with a diagnosis of ASD. Having observed the successes and struggles that she has experienced

throughout her life made this an area of particular personal interest. Supported by growing evidence (Cridland et al., 2014; Kothari et al., 2013; Shefeyk, 2015), the researcher believed that ASD and SCD within the female population was an area where increased awareness is needed and that the EP was well positioned to support this process, hence the rationale for completing this research.

### **1.5. The Current Research**

This research hoped to explore the experiences of EPs when working with adolescent girls with SCD in mainstream education in order to address the gap in the literature surrounding the role of the EP and the difficulties faced by adolescent girls with SCD. This was aimed to be achieved through interviewing qualified EPs working in an Outer London Borough EPS, using an interview schedule generated from a focus group (also held within the Outer London Borough EPS).

The research wished to answer the following questions:

1. What are the experiences of EPs when working with adolescent girls with SCD in mainstream education?
2. What is the role of the EP when working with adolescent girls with SCD in mainstream education?
3. What support is deemed appropriate and effective for adolescent girls with SCD in mainstream education?
4. How can the EPS support EPs and other professionals in providing appropriate and effective support for adolescent girls with SCD in mainstream education?

## **2.1. Systematic Literature Search**

### ***- 2.1.1. Introduction***

Historically, ASD and similar SCD have been regarded as male disorders (Sayal et al., 2006), with researchers such as Knickmeyer and Baron-Cohen (2006) promoting the idea of ASD being the manifestation of the ‘extreme male brain’. However, there has been a recent shift with regard to the social narrative which surrounds ASD and SCD, with public female figures such as Temple Grandin and Liane Holliday Willey presenting themselves as having a diagnosis of ASD. Although there may be a shift in public perception of the presentation of ASD with regard to gender, research is still heavily dominated by samples consisting of entirely male participants. Further still, the ratio of males to females receiving a diagnosis of ASD is quoted at around 4:1 (Fombonne, 2003), suggesting that the female population remains overlooked with regard to ASD diagnosis and research.

Moreover, the role of the EP linked specifically with ASD does not appear to have been greatly explored. Although there is a wealth of information advising parents and school staff on ways of working with CYP with ASD, it would appear that the view of the EP has been overlooked when generating such research.

The purpose of the current research was to investigate the EP role when working with adolescent girls with SCD in mainstream education. To gain a better understanding of this area, a critical analysis of existing research focusing upon the role of the EP in relation to girls with SCD was conducted. In particular, the literature review focused upon adolescent girls, as it was felt that this was an area of concern within the local context due to anecdotal reports of a number of adolescent girls having been excluded because of behavioural difficulties that might otherwise have been classified as SCD. Research was selected based upon distinct inclusion criteria, targeting the female population, adolescence, mainstream education and ASD/SCD. Emphasis was also placed on the research focusing upon adolescent girls themselves, rather than the experiences of friends or family members. The research was then critically analysed in order to develop an overall impression of the current thinking around adolescent girls with SCD and the role that the EP should play in supporting this population.

### - 2.1.2. Review Question and Database Search

Initially, the following review question was used:

*What are the experiences of EPs when working with adolescent girls  
with SCD in mainstream education?*

The database search engines EBSCOHOST (accessing PsycINFO) and Scopus were used to systematically search for articles relating to the review question. In order to address the review question, search terms including ‘social communication difficulties’, ‘adolescent girls’ and ‘role of the educational psychologist’ were used. However, these search terms did not produce results which addressed the review question and so alternative review questions were generated, expanding the focus of the systematic literature review.

Two systematic searches were conducted using different search terms. Initially, the search engines were used to explore the results created from ‘difficulties’ AND ‘girls’ AND ‘autism’ as well as ‘role of the educational psychologist’ AND ‘autism spectrum disorder’. The search terms were selected based upon the resulting findings. Full details of the searches are displayed in Tables 1 and 2. It was hoped that the following review questions would be address through these separate searches:

*What are the experiences of adolescent girls with SCD within  
mainstream education?*

*What is the role of the Educational Psychologist when working with  
CYP with SCD?*

Table 1. Systematic Literature Search 1.

<b>Search date</b>	11/02/16
<b>Databases searched</b>	<ul style="list-style-type: none"><li>• EBSCO (PsycINFO)</li><li>• Scopus</li></ul>
<b>Key words used</b>	‘difficulties’ AND ‘girls’ AND ‘autism’
<b>Results</b>	N = 258

Table 2. Systematic Literature Search 2.

<b>Search date</b>	11/02/16
<b>Databases searched</b>	<ul style="list-style-type: none"> <li>• EBSCO (PsycINFO)</li> <li>• Scopus</li> </ul>
<b>Key words used</b>	‘role of the educational psychologist’ AND ‘autism spectrum disorder’
<b>Results</b>	N = 16

The titles and abstracts of the papers identified through the systematic literature search were read and papers were excluded based upon duplication or the inclusion criteria noted in Table 3.

Table 3. Exclusions during the systematic literature search.

<b>Exclusion Criteria</b>	<b>Number</b>	<b>Percentage (one decimal place)</b>
1) Not concerned with adolescents	56	20.4
2) Not written in English	19	6.9
3) Not concerned with SCD	82	29.9
4) Not focused on the individual with SCD (e.g. focused on parental or sibling pressures)	3	1.1
5) Not conducted within a mainstream education setting	29	10.6
6) Not a published paper	6	2.2

The application of the exclusion criteria resulted in 12 papers being selected from the first search and 4 papers being selected from the second search. In addition, a hand search was conducted using Google and Google Scholar. One further paper contributed to the first search and a further two papers contributed to the second search. All the selected papers were then critically analysed and contributed to the following literature review. Details of the exclusion process can be found in Figures 1 and 2.

Figure 1. A flow chart representing the process by which research was systematically selected for the literature review (Search 1).

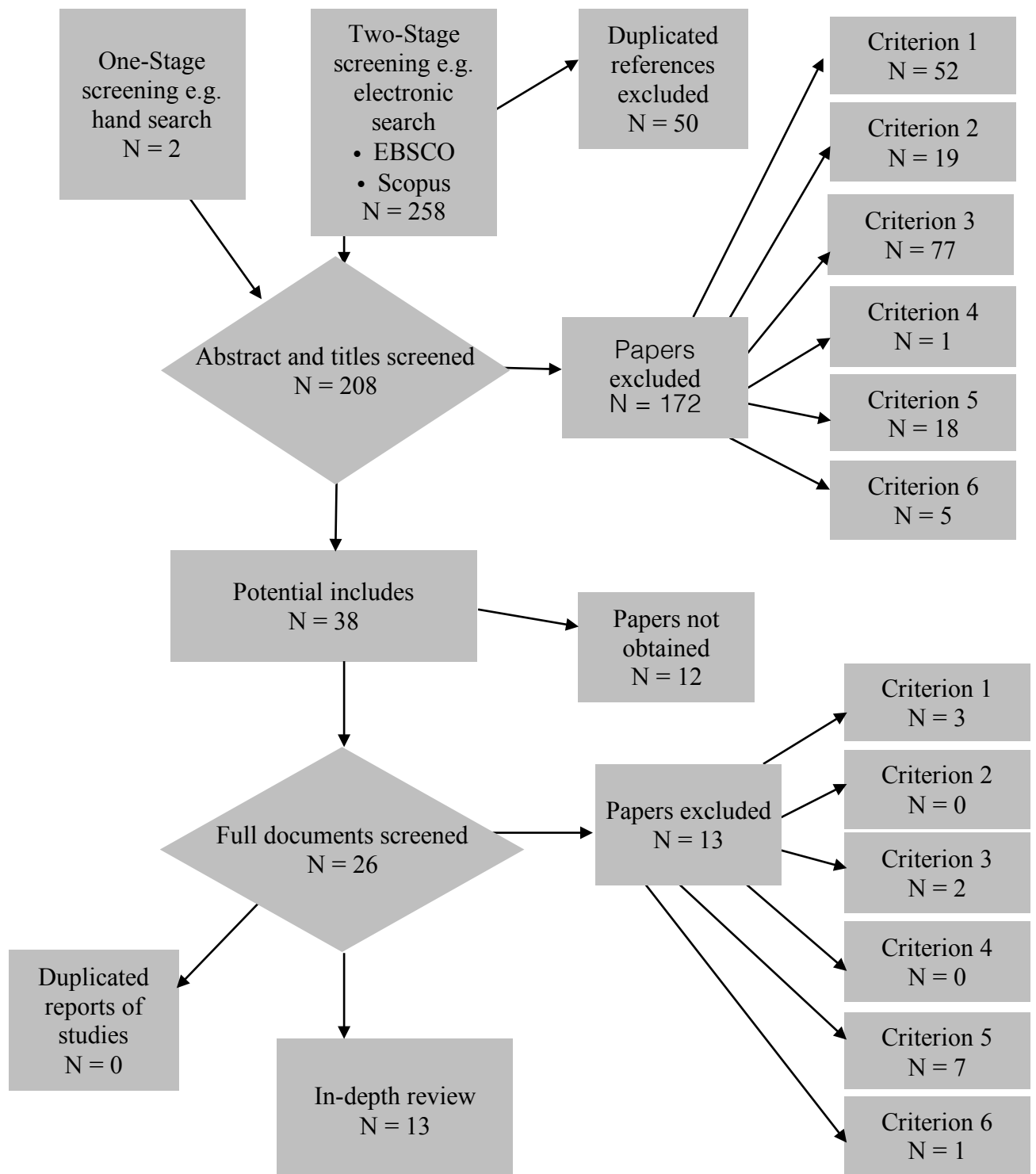


Figure 2. A flow chart representing the process by which research was systematically selected for the literature review (Search 2).

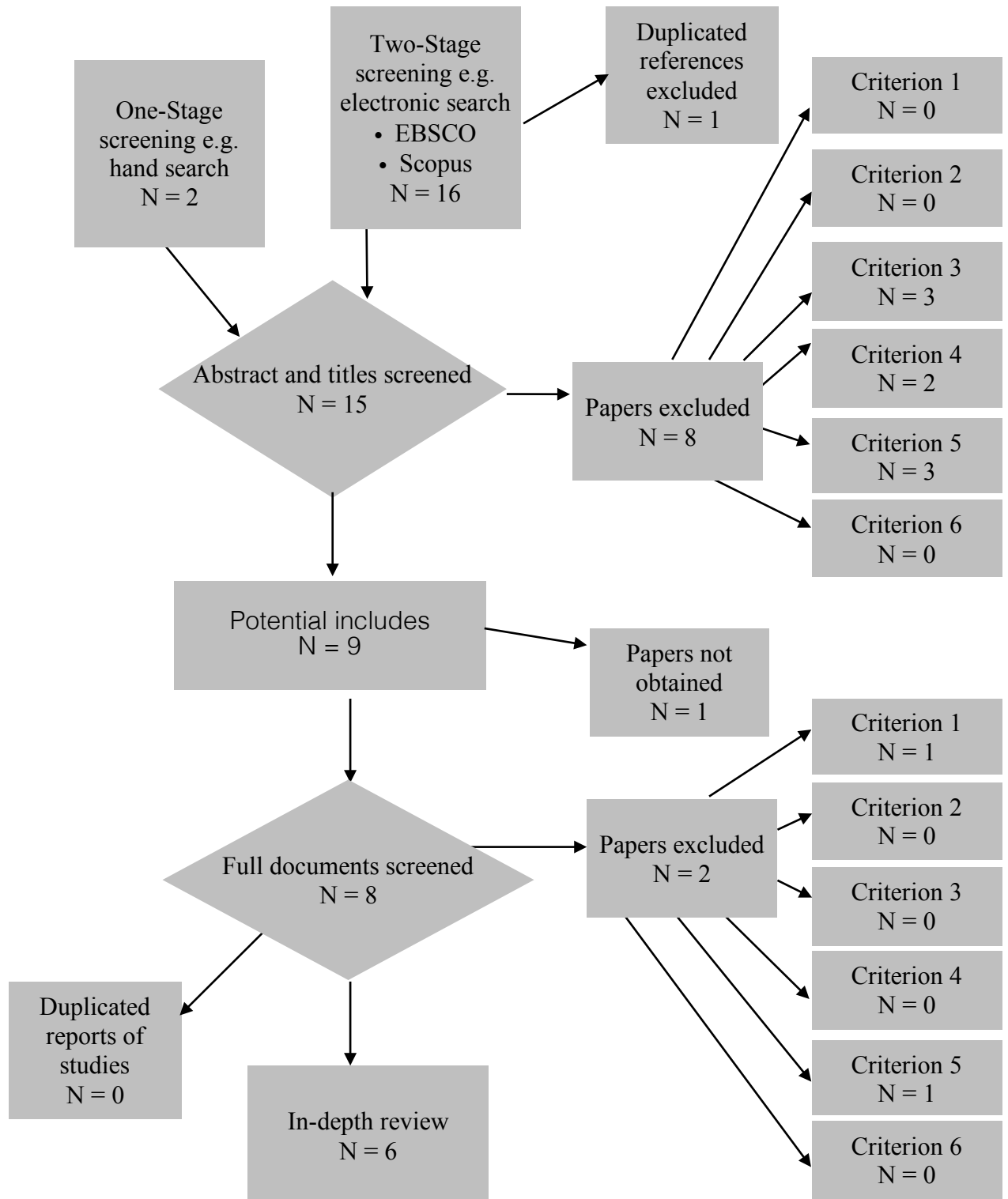


Table 4 provides a list of the 19 studies selected to contribute to the literature review, displayed in reverse chronological order. A table of the strengths and weakness of each paper can be found in Appendix 1.

Table 4. A list of studies included in the systematic literature review.

*Egerton, J., & Carpenter, B. (2016). <i>Girls and Autism: Flying under the radar. A quick guide to supporting girls with autism spectrum conditions.</i> Staffordshire: Nasen.
Rupasinha, J. (2015). Addressing an imbalance? Educational psychologists' considerations of ethnic minority cultural factors in assessments for autistic spectrum condition. <i>Educational and Child Psychology</i> , 32(2), 77 – 88.
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## 2.2. Critical Analysis of the Literature

### - 2.2.1. Introduction

Although there is a wealth of research within the field of ASD and SCD, there appears to be a limited amount of research that focuses on girls with ASD or SCD (Shefcyk, 2015). It is only within the last 20 years that SCD such as ASD and Asperger's Syndrome have become known disorders within the classroom (MacKay, 2003; Greig & MacKay, 2005; Gross, 1994) and moreover, it is only within recent years

that the profile of ASD amongst girls has increased, ASD having previously been perceived as a male disorder (Cridland, et al., 2014; Sayal et al., 2006; Shefcyk, 2015). Consequently, the majority of the research currently available is based upon male dominated samples of participants, in part due to the difficulty of finding females presenting with ASD (Domellöf, Hedlund & Ödman, 2014; MacKay, Knott & Dunlop, 2007; Russell, Steer & Golding, 2011; Shefcyk, 2015; Thompson, Caruso & Ellerbeck, 2003). The research that does seek to include female participants usually takes the form of qualitative research, investigating the experiences of the participants and their families (for example, Cridland et al., 2014).

In parallel with this, the role of the EP when working with individuals with a diagnosis of ASD does not appear to have been clarified. The role of the EP is a heavily debated topic, with much research being published attempting to define the way in which an EP does or should work (Greig & MacKay, 2005; MacKay, 1990; Rupasinha, 2015). However, when connected with ASD and SCD, there is limited information available on the ways EPs should support CYP with ASD, or the ways in which the EPs themselves should be supported in return.

This literature review will therefore focus upon the definition of ASD and SCD, including the diagnostic processes and the limiting factors that gender, culture and comorbidity appear to play on the receipt of a diagnosis. It will then go on to consider the increased emphasis on inclusive practice within schools and the impact that this has had on professionals, specifically EPs. The review will conclude by summarising the needs raised by the critical analysis of current research and will provide a rationale for the completion of this piece of research.

#### **- 2.2.2. *Autism Spectrum Disorder and Social Communication Difficulties***

ASD is generally characterised by impairments in social communication, social interaction and a rigidity of thought and imagination (Wing & Gould, 1979). As a spectrum disorder, ASD was previously considered to incorporate a number of different diagnostic labels including autistic disorder, Asperger's Syndrome, childhood integrative disorder and Pervasive Developmental Disorder not otherwise specified (APA, 2000). With the introduction of the updated Diagnostic and Statistical Manual (DSM), ASD is now described as a continuum, with any presentation of the

abovementioned conditions falling somewhere within the spectrum, varying in position based upon severity (APA, 2013).

A diagnosis of ASD is considered a life long condition (Assouline, Foley Nicpon & Doobay, 2009; MacKay et al., 2007; Klin, Volkmar & Sparrow, 2000; Stampoltzis et al., 2012), with research suggesting that CYP showing characteristics of the disorder (whether or not diagnosed) are likely to experience increased difficulties as they enter adolescence (Cridland et al., 2014; Horiuchi et al., 2014; Soppitt, 2006).

Given the nature of autistic traits falling along a spectrum, it is difficult to critically analyse and compare research produced in this field as the target population (CYP with ASD) is a very “heterogeneous group” (Russell et al., 2011, p. 1291). Therefore, direct comparisons are not always possible if the severity of ASD is not objectively recorded. In addition, Constantino and Todd (2003) expressed concern that, with regard to research, the severity of ASD is an arbitrary measure, making it extremely difficult to be objective in distinguishing between presentations of ASD.

There is a vast history surrounding the diagnosis of ASD. Infantile autism became regarded as a medically diagnosable condition in 1980, with its appearance in the DSM-III (APA, 1980). At this stage, difficulties were believed to emerge before the age of 30 months (Masi, DeMayo, Glozier & Guastella, 2017) however further developments occurred with the revision of the DSM-III to broaden the diagnosis beyond infancy. This alteration in the diagnostic process meant children displaying less severe SCD were now being diagnosed as having Autistic Disorder (Volkmar, Bregman, Cohen & Cicchetti, 1988), based upon meeting eight out of the 16 criteria required. With the introduction of the DSM-IV (APA, 1994), a greater distinction was made between Autistic Disorder and Asperger’s Syndrome. However, in 2013, these distinctions were eliminated and the definition of ASD became far less specific (APA, 2013). This was felt most appropriate due to the heterogeneous nature of ASD, meaning the validity of specific disorders within the category of ‘ASD’ was often questioned.

To date, there is no medical test for ASD, so to obtain a diagnosis, a multi-disciplinary team consisting of paediatricians, psychologists, speech and language therapists and occupational therapists usually complete observations and behaviour checklists with CYP and parents. A number of researchers propose that a more sophisticated diagnostic process is necessary in order to ensure all CYP with ASD are

being identified and consequently receiving the appropriate support (Kothari et al., 2013; Rivet & Matson, 2011). With diagnostic criteria commonly developed within Western cultures (Masi et al., 2017), diagnostic tools are often queried as being either culture- or gender-biased. The majority of assessments for ASD rely upon observation; however, areas such as the rate of language development (Daley & Sigman, 2002) or what is perceived to be appropriate with regard to eye contact (Bernier, Mao & Yen, 2010) varies between cultures. Further to this, even within the Western culture, research suggests that girls with ASD present differently in some areas to boys with ASD, and subsequently are able to mask their difficulties, causing them to be misdiagnosed or undiagnosed (Egerton & Carpenter, 2016; Kothari et al., 2013; Shefcyk, 2015). Therefore, it requires a highly experienced and knowledgeable professional to look beyond the typical diagnostic criteria of ASD to correctly identify ASD in girls (Gould & Ashton-Smith, 2012). In addition, as is the case with a range of assessment tools (such as psychometric assessments), techniques that were once assumed culturally fair are now being questioned (Desforges et al., 1995).

Given the proposed risk of misdiagnosis or missed diagnosis within the female population, the researcher will use the terms ASD and SCD interchangeably throughout the research as the current research not only wishes to explore the experiences of EPs when working with adolescent girls in mainstream education with ASD but also those who present with SCD who have not received a diagnosis. For this research, SCD have been defined as difficulties that incorporate the traits and characteristics of ASD, however a formal diagnosis of ASD has not been received.

#### **- 2.2.2.1. Prevalence**

The prevalence of ASD appears to have increased along with an increase in public awareness (Greig & MacKay, 2005; Ozonoff & Rogers, 2003). Gillberg and Wing (1999) reviewed 20 studies based around the world between 1966 and 1997. Within that timeframe, they found the reported prevalence of ASD had increased from under 0.5 in 1,000 to around 1 in 1,000. More recently, Baron-Cohen et al. (2009) conducted a parental survey in Cambridgeshire, attempting to estimate the prevalence of both diagnosed and undiagnosed cases of ASD in children aged five to nine years. Through this, Baron-Cohen et al. (2009) reported the overall prevalence to be 15.7 in 1,000 when including undiagnosed cases. Further still, they found a ratio of 3:2 when exploring known to unknown cases. These figures were supported by Russell et al. (2011) who concluded that there may be a substantial number of CYP with autistic traits

that meet the severity of an ASD diagnosis but who have not been identified. However, Russell et al. (2011) based their research on a sample of children aged between two and a half years and four years. At that age, the children would not have begun school and so their opportunity to develop social skills would have been limited, meaning that they may have been displaying autistic traits that would have reduced through social learning experiences. Further to this, ASD is often not identified until the child attends school as this is the first situation in which the parents are able to compare their children to others. Through comparison, the parents may then become aware that their child's development appears delayed and so they might seek help from educational and health professionals. It is therefore unsurprising that Russell et al. (2011) found a significant number of children showing autistic traits without an ASD diagnosis, particularly in the case of first born children.

Nonetheless, reports of increasing prevalence appear to be consistent throughout the research. Although there is no clear cause for this rapid increase in prevalence, there are a number of different explanations as to why this may be occurring. As well as the possibility that the number of incidents of ASD has increased, reasons for this growing prevalence include an increased public awareness, clearer definitions, better assessment processes, increased research and better provision and services. Reflecting upon the 3:2, known to unknown cases ratio reported by Baron-Cohen et al. (2009), it would appear that this increase in prevalence is unlikely to be entirely the result of improved assessment processes as there remains a high proportion of undiagnosed cases.

#### **- 2.2.2.2. Gender Differences**

*“Girls and women are a nearly invisible population within ASD, both understudied and underserved.”*

(Shefcyk, 2015, p. 131)

Within this research, a key area of ASD when considering prevalence, is the gender balance and the ratio of males to females receiving diagnoses. This ratio is commonly quoted as 4:1, males to females (Fombonne, 2003; Holtmann, Bolte & Poustka, 2007; Stampoltzis et al., 2012). However, Baio (2014) found that the ratio of males to females with a diagnosis of ASD but no intellectual disabilities was 10:1. Egerton and Carpenter (2016) and Stampoltzis et al. (2012) reflect on the fact that the original reports of ASD given by Kanner (1943) and Asperger (1944) also provide an account with an overemphasis on male patients, suggesting that ASD has always been a

male dominated phenomenon. However, variables such as cultural and historical factors as well as methods of reporting may have influenced the initial reporting of ASD. This remains the case to the present day (Stampoltzis et al., 2012).

In contrast, Russell et al. (2011) highlighted the possibility of gender stereotyping leading to an under-diagnosis in girls and Kothari et al. (2013) described a systematic observer bias when recognising ASD. Although identifying the impact that societal norms and stereotyping might have on diagnosis with regard to the observer (usually a clinical professional), Kothari et al. (2013) failed to acknowledge the bias that can occur through parental report, and the influence this can have over the receipt of a diagnosis of ASD. Knapp, Romeo and Beecham (2009) recognised that bias leading to missed or misdiagnosis creates a level of controversy around the diagnosis of ASD and the access to resources that can be obtained as a result. It is therefore important to approach this topic with a level of sensitivity in order to ensure equality whilst also contributing valid and accurate research.

Constantino and Todd (2003) believed that males and females with ASD are genetically similar and that it is environmental factors that promote social competency. The 'female protective model' (Shefcyk, 2015) suggests that women may be predisposed to ASD but that the characteristics of the disorder are only presented if triggered by environmental factors. To some extent, Russell et al. (2011) propose a similar model, suggesting that social and demographic attributes may present risk factors that influence the presentation and consequently the diagnosis (or misdiagnosis) of CYP with ASD. They found that lower maternal educational attainment appeared to be associated with undiagnosed autistic traits, in keeping with previous research (Baird et al., 2006). They also investigated 'access barriers' which they viewed differently to risk factors, suggesting 'access barriers' simply prevent CYP from gaining a diagnosis, rather than risk factors which may trigger predisposed autistic traits. They found strong links between maternal depression and a lack of ASD diagnosis, either because mothers felt unable to seek help or because health professionals were inclined to attribute the mothers' concerns to symptoms of their depression. Although likely to influence the prevalence rate of ASD, this should not contribute towards the imbalance in the ratio of males to females with ASD however, as it can be assumed that maternal depression would have occurred in situations where both boys and girls were experiencing SCD, resulting in Russell et al. (2011) failing to account for the gender difference seen with regard to prevalence.

Unlike other research, Kothari et al. (2013) separated their participants by gender when investigating the emotion recognition of CYP with and without SCD, allowing for a direct comparison between male and female participants. The CYP were presented with two different tasks; at age eight and a half years the participants were asked to complete a facial emotion recognition task and at 13.5 years they were presented with an emotion recognition from social cues task. Through the use of a longitudinal study, Kothari et al. (2013) were able to make direct comparisons between the two age groups by using the same participants, removing the need to control for difference between two samples. At eight and a half years, Kothari et al. (2013) found that boys made more mistakes than girls, suggesting that girls with SCD may have developed coping mechanisms at this age to interpret facial emotion responses in others. However, by 13.5 years, girls were found to be significantly less able than boys at successfully completing the emotion recognition from social cues task. Given that the clinical assessment of ASD usually takes place between the ages of five and eight years (Siklos & Kerns, 2007; Turk et al., 2009) and incorporates an element of facial emotion recognition, it could be that girls with SCD are being missed due to their ability to successfully complete this task at the age of eight and a half years. This research therefore has real life application, with Kothari et al. (2013) concluding that increased subtlety is needed with regard to assessments in order to ensure the identification of girls with ASD. Although not mentioned in the discussion, it is interesting to reflect upon the failure of the girls to complete the emotion recognition task at aged 13.5 years. This appears to be in line with the evidence that girls with unidentified SCD often encounter increased problems around adolescence (Cridland et al., 2014) and hence supports the need for the current research.

In addition to the unbalanced prevalence of ASD with regard to gender, research also suggests that girls receive their diagnosis of ASD later than boys. As previously stated, the average age of diagnosis appears to be between five and eight years (Siklos & Kerns, 2007; Turk et al., 2009) however it would appear that girls experience delays in diagnosis, often not being diagnosed until adolescence (Begeer et al., 2013; Bolick, 2001; Egerton and Carpenter, 2016; Shefcyk, 2015; Willey, 2003). Given the wealth of information available in favour of early intervention (Egerton & Carpenter, 2016; Horiuchi et al., 2014), this statistic may provide a deeper understanding of the severity of difficulties that girls with an ASD diagnosis face when they reach adolescence (Cridland et al., 2014). It also highlights the need to explore diagnosis in more detail, as it may be that girls are not receiving appropriate and adequate support for their SCD.

This was reflected in the qualitative feedback gathered by Cridland et al. (2014), who reported that mothers of daughters with ASD found it harder to obtain a diagnosis than their friends with sons with ASD. This research was conducted in Australia however, so it may not be possible to generalise these findings to the United Kingdom (UK) population. Through investigating social and demographic factors that influence the diagnosis of ASD, Russell et al. (2011) found that even when controlling for severity, boys were still significantly more likely to be diagnosed with ASD. Unfortunately, due to difficulties with recruiting an appropriate ASD sample, Russell et al. (2011) did not match their diagnosed ASD group and undiagnosed ASD group, making it harder to draw direct comparisons between the two groups of participants. They also had an extremely small sample of female participants so although results were significant, this was based on limited numbers. That aside, further research has been conducted which supports these findings (Baldwin & Costley, 2016; Cheslack-Postava & Jordan-Young, 2012).

In contrast, Stampoltzis et al. (2012) found no difference in the mean age of diagnosis for boys and girls within their sample. Their sample mimicked the 4:1, males to females ratio previously mentioned, with the mean age of diagnosis within the sample being reported at six years four months. Based within Greece, Stampoltzis et al. (2012) discussed that this age is still somewhat delayed in comparison to other countries, and they considered this to have an impact on the quality of education that CYP are therefore able to access. It is important to consider that the range of ages of diagnosis stretched from two years to 13 years however, suggesting that there is vast variation in the diagnostic experiences of CYP and their parents. Within their sample, only boys were attending specialist educational provisions and a greater number of boys received support in mainstream school. Stampoltzis et al. (2012) concluded that “boys are likely to be more severely affected by autism than girls” (Stampoltzis et al., 2012, p. 1302) based on these findings. However, this raises the question of whether boys experience ASD to a greater severity, or whether, due to the perception that ASD is a male dominated disorder, society gravitates towards providing greater access to resources for boys. The presentation of girls with ASD was also overlooked, with no reference being made to the possibility of girls adapting their behaviour to mask their difficulties. Furthermore, linked with previous research around social and historical context, it might be that society still places a higher value on the education of boys over girls, possibly unconsciously. As data was not collected regarding cognitive level, language skills or social adaptability, it is not possible to draw such definitive



conclusions around the severity of ASD within the male and female population from this research.

Although reporting that some difficulties experienced by those with ASD are the same for both boys and girls, Cridland et al. (2014) found there were a number of areas of difficulty “unique” (Cridland et al., 2014, p. 1270) to girls with ASD. These included diagnostic issues, being surrounded by boys, experiences of high school, complexity of adolescent female relationships, puberty and its related issues and sexual relationships and concerns. In addition, they also developed a theme around the impact on the mother of having an adolescent daughter with ASD. Although providing a very detailed balanced account, Cridland et al.’s (2014) research places a greater emphasis on the mothers’ experiences than those of the adolescent girls themselves due to the nature of their questioning. Cridland et al. (2014) used open questions to allow the participants to determine the direction of the interviews. This resulted in the mothers contributing more information, as would be expected given the deficits in social communication and interaction experienced by CYP with ASD. It might have been possible to capture the views of the adolescent girls through alternative methods such as through written report or from analysing diary entries. Furthermore, Cridland et al. (2014) deliberately chose to narrow their focus upon the female population in order to add to the limited research currently available for this cohort. Although this has helped promote the need for specific research to be conducted with regard to girls with ASD, the lack of a male control group meant that any conclusions drawn from the findings relating to gender difference were based upon speculation and information provided by previous research, rather than through direct exploration within the study. As the only research of its kind, there is currently a lack of supporting evidence around the specific conclusions presented by Cridland et al. (2014); however, anecdotal accounts provided by Hendrickx (2015) appear to closely replicate the findings of Cridland et al.’s (2014) research.

#### **- 2.2.2.3. *Cultural Differences***

Similar to gender differences, the influence that culture has over what is considered to be acceptable behaviour weighs heavily upon the diagnosis of ASD, both as a standalone influence but also when combined with gender stereotypes. Lindsay et al. (2006) found that CYP with South Asian heritage were less likely to receive a statement of special educational needs than Caucasian CYP when ASD was the primary need. Rupasingha (2015) suggested cultural factors influencing diagnosis may include

parental attitudes towards schooling, play and language. Based on current diagnostic tools that utilise parental report as a prominent part of the assessment process, this is likely to have a large impact on diagnosis figures. Lindsay et al. (2006) also considered the impact of learning English as an additional language. Given the large emphasis that ASD places on social interaction and social communication, it is possible that professionals may overlook the diagnosis of ASD, attributing CYP's failure to communicate to a limited English language ability.

Within research, cultural influences are also often overlooked. For example, although Kothari et al. (2013) provided a control sample in the form of boys with and without SCD when investigating the presentation of SCD in girls, the participants who provided a full set of data were predominantly white and from a higher social class. Therefore, it is not possible to generalise their findings beyond this population. Given the context of the current research, with over 80% of the school age population in the Outer London Borough classified as BME (figure obtained through Local Authority records, not referenced, 2012), it is unlikely that Kothari et al.'s (2013) findings will map directly onto this Outer London Borough.

The research conducted by Cridland et al. (2014) should also be interpreted with caution as it was based upon an Australian population, rather than being based within the UK. Equally Domellöf et al. (2014) and Asberg, Kopp, Berg-Kelly & Gillberg (2010) conducted their research in Sweden, Stampoltzis et al.'s (2012) research was based in Greece and Williams, Johnson and Sukhodolsky (2005) completed their review in America. It is therefore not possible to fully generalise the findings of these studies to the Outer London Borough in which the current research was conducted.

#### **- 2.2.2.4. Comorbidity**

As well as cultural differences, another factor that is likely to have a large impact on the receipt of a diagnosis of ASD is its common co-occurrence with other conditions (Asberg et al. 2010; Egerton & Carpenter, 2016; Mattila et al., 2010). This raises the question of whether there is an under-diagnosis of CYP with ASD due to other conditions masking their SCD (Cridland et al., 2014).

Although Russell et al. (2011) provided a control group in the form of CYP without a diagnosis of ASD, they did not record whether any alternative diagnoses were present. Given the high prevalence of comorbidity within the ASD population, this would have been valuable information when analysing and evaluating their findings.

For example, Dworzynski et al. (2012) found that girls were more likely to be diagnosed with ASD if they had an additional difficulty, whereas Turk et al. (2009) found the comorbidity of epilepsy resulted in a greater proportion of girls receiving a delayed diagnosis of ASD. Whilst investigating the impact of epilepsy and ASD on CYP they found a ratio of 2:1, males to females within their epilepsy and ASD group, compared to 6.5:1, males to females within their ASD only group. Turk et al. (2009) concluded that this implies females need to display a greater severity of difficulty with regard to another disorder (in this case, epilepsy) in order for ASD to be identified. The number of female participants in Turk et al.'s (2009) research was relatively small and the research did not seek to specifically explore gender differences, meaning that it is not possible to draw firm conclusions from this research without further investigation being undertaken. For example, it could be interpreted that girls may be more vulnerable to the comorbidity of conditions.

When considering emotional and behavioural difficulties (EBD), De Bruin, Ferdinand, Meester, de Nijs and Verheij (2007) reported EBD are common within the ASD population but are often undiagnosed due to SCD experienced by CYP with ASD or due to the impact that ASD has on the presentation of EBD. In contrast, Horiuchi et al. (2014) proposed that ASD acts as a mask for EBD. Using a matched control group, they explored the strengths and difficulties of CYP with and without a clinical diagnosis of ASD. Results showed that the CYP with ASD had a significantly higher score for all subscales, suggesting emotional difficulties, conduct problems, hyperactivity/inattention, poor peer relationships and limited prosocial behaviour. More specifically, the total difficulties, hyperactivity/inattention and conduct problems scores were all significantly higher in girls with ASD than boys with ASD. This is out of line with the general population, whereby in the control group, boys generally scored higher than girls in these areas. In order to measure EBD, parents were requested to complete a questionnaire. It is therefore possible that the parents of CYP who had received a diagnosis of ASD were more aware of the difficulties presented by their children or more willing to openly acknowledge them and so they might have rated difficulties as more extreme than the parents of typically developing CYP, where a high rating on each scale might instead suggest a deficiency in parenting.

Horiuchi et al. (2014) also investigated the influence of age on EBD, finding that the difficulties scores increased with age. This would suggest that adolescent girls with ASD would be classified at the highest level in respect of total difficulties,

hyperactivity/inattention and conduct problems. These findings supported previous research (Steinhausen and Metzke, 2004) although they are out of line with the views presented by Cridland et al. (2014). Unfortunately, due to Horiuchi et al. (2014) basing their research on CYP with a clinical diagnosis of ASD, it would be unethical to generalise the findings to a population of CYP with undiagnosed ASD. However, it does raise awareness of the vulnerability of girls with an ASD diagnosis.

### **- 2.2.3. *Inclusion***

When considering the factors affecting an ASD diagnosis and the role that EPs can play in supporting CYP within mainstream education with SCD, it is essential to discuss inclusive education in its historical context. The inclusion agenda has become increasingly more prominent with the introduction of a number of government policies. The Salamanca Statement (UNESCO, 1994) and the Special Educational Needs and Disabilities Act (DfEE, 2001) have contributed to increased numbers of CYP with ASD being educated within mainstream settings (Geneva Centre for Autism, 2010; McLeskey et al., 1999). With 67% of teachers reporting to be working with more CYP with ASD than 5 years previously (Barnard et al., 2002), this has created pressure for professionals such as EPs to adapt their practice in order to support teachers and other school staff who may have very little prior experience of CYP with ASD (Greig & MacKay, 2005).

Greig and MacKay (2005) presented a case study of an adolescent boy with Asperger's Syndrome who was receiving Cognitive Behavioural Therapy. Their study has limited generalisability in this situation based on its single male participant design; however, they reflected upon the number of CYP with difficulties that are viewed as "subtle" (Greig & MacKay, 2005, p. 5) attending mainstream education. They described how their participant was making satisfactory progress but that this was not in line with his potential (an area also reported by Barnard et al., 2000 and Barnard et al., 2002). Greig and MacKay (2005) implemented an intervention based around Cognitive Behavioural Therapy in order to support the participant within secondary school and reported positive findings. However, since the intervention took place over an extended period of time and without a control participant, it is not possible to determine whether accelerated progress was due to the intervention or the consequence of an external factor, not controlled for within the experiment. Williams et al. (2005) predicted that the role of the EP would increasingly involve facilitating the inclusion of CYP with ASD into mainstream schools in America and Stampoltzis et al. (2012) found 89% of

their sample of CYP clinically diagnosed with ASD were currently attending mainstream education. This they attributed to the introduction of the Law 3699 (a Greek law promoting parental right to choose which setting they wished their child to be educated in). Within the UK, the Special Educational Needs and Disabilities Code of Practice (Department for Education, 2014) also promotes parental rights to select the preferred educational setting for their children. Previous research would suggest that inclusion was more successful at primary level than secondary (Barnard et al., 2002), with difficulties in inclusive education at secondary level being explained by high curriculum demands, a lack of teacher differentiation and a lack of training provided for school staff. When considering the alternative to mainstream education, Barnard et al. (2002) reported that 88% of special school staff received ASD training compared to just 14% of staff in mainstream schools, suggesting that although mainstream teachers are increasingly teaching CYP with ASD, this is not being acknowledged with regard to their training needs. It is also interesting to consider the high response rate reported by Barnard et al. (2002), suggesting that school staff saw the research as necessary and an opportunity to highlight the difficulties within their inclusive practice.

Barnard et al. (2002) also investigated the number of children with ASD diagnoses at primary school level compared to the number of adolescents at secondary school. Following research reporting a positive picture for Early Years provision for children with ASD (Barnard et al., 2000), Barnard et al. (2002) found that there were three times more children with an ASD diagnosis within primary schools than within secondary schools. This raised concerns around the 'missing children', suggesting that there may be adolescents who are at risk of and experiencing exclusions based upon their undiagnosed or misdiagnosed ASD. This hypothesis is supported by Barnard et al. (2000) who found a high number of autism-related exclusions occurring at secondary level, with one in five children with ASD experiencing a school exclusion at some point during their education. Although this research sought the views of a range of different individuals including school staff, parents and CYP with ASD, the CYP response rate was particularly low and so the research was unable to draw detailed conclusions around the experiences of CYP themselves.

Although not directly reporting on inclusion, Horiuchi et al. (2014) described how CYP with ASD often present with EBD. This is likely to have a large impact on their ability to be successfully included within whole class teaching, as well as influencing the perceived confidence of teachers when working with CYP with ASD

and SCD (Barnard et al., 2000), which may lead to exclusions. Other factors that might create difficulties when trying to include CYP with ASD in whole class teaching include their difficulties with attention, organisation, verbal and non-verbal communication and disruptive behaviour (Greig & MacKay, 2005). With the increase in prevalence of ASD, it is likely that the role of the EP needs to be re-evaluated to reflect the increase in need from the ASD population, with a focus on clarifying the specific difficulties experienced by females within that population (Egerton & Carpenter, 2016; Greig & MacKay, 2005).

#### **- 2.2.3.1. Role of the EP**

*“EPs should be totally committed systems psychologists, totally committed academic psychologists and totally committed individual psychologists.”*

(Greig and MacKay, 2005, p. 4)

The role of the EP has greatly changed and developed since Cyril Burt, the first recognised child psychologist, in 1913. Greig and MacKay (2005) and Williams et al. (2005) felt the role of the EP was one of a holistic nature, falling within two categories; to provide therapeutic intervention to CYP directly on an individual level as well as providing knowledge and support to other professionals through working collaboratively. There has been a shift away from individual assessment towards systemic working within schools and communities (Farrell et al., 2006). Greig and MacKay (2005) reported that the value placed upon the work of EPs had increased over the preceding 10 years and the Special Educational Needs and Disabilities Code of Practice (Department for Education, 2014) specifically name EPs as statutory professionals within the assessment process, suggesting that the value placed upon the role of the EP has increased further in the 10 years that followed.

Barnard et al. (2002) reported that “successful education of children on the spectrum will... require input from... educational psychologists” (Barnard et al., 2002, p. 9) among other professionals. Greig and MacKay (2005) stressed the importance of EPs having a good knowledge of Asperger’s Syndrome and Cridland et al. (2014) concluded that there needs to be greater awareness around ASD and its presence within the female population in order to facilitate the diagnostic process. Furthermore, given the demand for better training of school staff (Barnard et al., 2002; Stampoltzis et al., 2012), it could be argued that EPs need to increase their awareness of ASD within the female population in order to upskill the school staff whom they regularly work in

partnership with (Rupasinha, 2015). It is not only teaching staff who would benefit from increased awareness. For example, Humphrey and Symes (2010) reported on the importance of providing peer education and coaching in order for a greater understanding of ASD within the school context. Again, through therapeutic interventions, EPs are well placed to deliver such education and coaching, with some academics believing that these activities should be considered core duties of the EPS (Greig & MacKay, 2005; Gross, 1994; Williams et al., 2005).

When interviewing the mothers of adolescent girls with ASD, a common theme identified by Cridland et al. (2014) was the lack of support following diagnosis. Many mothers felt that there were limited services provided to support their understanding or help them adapt to their daughters' diagnoses. This perceived lack of awareness of possible support raises questions around whether there are enough services available to provide post-diagnosis support or whether there is appropriate communication in place to provide parents with the information they need in order to access these services. EPs are well positioned to work systemically with families and schools as well as individual CYP (Farrell et al., 2006; Gillham, 1978). From investigating the impact of ASD on mothers as well as their adolescent daughters, it would appear that there is an element of emotional distress and isolation experienced by mothers which then impacts on their daughters (Cridland et al, 2014). Therefore, providing post-diagnosis support for all members of the system (Bronfenbrenner, 1979) is something that could fall within the role of the EP. Again, mothers spoke at length about their close involvement with school; however, at no point were EPs mentioned during Cridland et al.'s (2014) report of adolescent and parental experiences of receiving a diagnosis of ASD. This would suggest that the role of the EP within the field of adolescent girls with ASD and their mothers is not considered prominent or important. In contrast, Barnard et al. (2002) conducted a nationwide school survey in which 72% of schools mentioned the involvement of an EP when discussing specialist input they had received for the CYP with ASD, although this figure was not deconstructed to evaluate the number of males and females accessing EP services.

It is vital that the EP takes into consideration cultural factors in order to ensure that a shared understanding is established between the EPS, schools and parents with regard to ASD (Rupasinha, 2015; Williams et al., 2005) as well as to bridge the gap between research and practice through the use of evidence-based practice (Hoagwood & Johnson, 2003) as was achieved by Assoline, Foley Nicpon and Doobay (2009).

Further to this, through interviewing EPs about their practice within schools when working with CYP with ASD of BME heritage, Rupasinha (2015) reported the necessity to build a positive, working relationship with schools in order to implement change. Linked to the systemic nature of the work of the EP, this provides evidence for an additional skill that must be developed by the EP so as to fulfil their role within the education system. Rupasinha (2015) implemented a multiple embedded case study methodology however, which meant only three EPs were interviewed. Of the three participants, only one EP worked within a Local Authority EPS and so it would be useful for this research to be replicated using a larger sample in order to ensure transferability.

#### **- 2.2.3.2. *Voice of the EP***

It is important to reflect on the connection between the role of the EP and the voice of the EP. Although a number of research papers support the idea that EPs now work systemically rather than as individual assessors, Rupasinha (2015) suggested that EPs may “exert an influence on whether the *status quo* is maintained or challenged” (Rupasinha, 2015, p. 77) when discussing the diagnostic trends of ASD. Desforges et al. (1995) reported that, with regard to the assessment of CYP of BME heritage, EPs were aware that assessment tools were not culturally fair, however they did not reflect this knowledge in their practice, failing to adapt their practice to ensure there was no cultural bias. Could the same be said for EPs when working with adolescent girls with SCD in mainstream education?

When discussing the training and development needs of EPs, Rupasinha (2015) fed back that EPs felt their knowledge relied heavily upon their own experience rather than training, and that “*if the LA [Local Authority] don’t see it as a priority, it doesn’t happen*” (quoted by a participant in Rupasinha, 2015, p. 85). This would suggest that to some extent it is the responsibility of the EP to raise areas of professional development that need addressing and to provide continuous feedback to the Principal EP and other authority figures within the EPS and Local Authority in order to ensure that the needs of all CYP are being met. This also raises questions around the extent to which EPs feel confident working with girls with SCD in mainstream education given their potential lack of articulated experience in this area.

Overall, Barnard et al. (2002) argue that the “overriding and frequently forgotten priority is the child’s entitlement to education” (Barnard et al., 2002, p. 19). It is



therefore essential that the EP acts as an advocate for all CYP with ASD and SCD to ensure that they are given equal opportunities and appropriate support to access the education system in a way that matches their individual needs.

#### **- 2.2.4. *Summary of the Literature***

To summarise, within recent years there appears to have been a shift in public perception around the nature of ASD, reducing the tendency to regard ASD as a predominantly male disorder. Nonetheless, academic research still appears to be heavily based around male dominated samples when investigating the impact of ASD and SCD on CYP. Although no clear cause has been identified, the prevalence of ASD appears to be increasing and that, along with the introduction of a more inclusive education system, has resulted in a greater number of CYP with ASD and SCD being educated within mainstream settings. Unfortunately, it would appear that teacher training has not recognised the need for better knowledge in this area and a number of school staff do not feel appropriately equipped to support these CYP.

Furthermore, the presentation of ASD in girls appears to vary from that of ASD in boys. Through the systematic literature review, it would appear that research is calling for more investigation to be carried out with regard to the diagnostic process, making it more sensitive to the female population. It is also important to consider cultural and comorbidity factors within this, and to ensure that SCD are not being overlooked due to other variables.

The EP is well placed to work with systems in order to advocate for CYP with ASD and SCD. This should include supporting CYP with ASD, increasing the identification of CYP with SCD and reducing the number of CYP experiencing exclusions as a result of ASD or SCD. However, in order to do so, EPs must feel appropriately empowered to approach their EPS, identifying gaps in their own knowledge and stating their training needs.

### **2.3. Rationale for Current Research**

Barnard et al. (2002) identified ‘missing children’ with ASD in the transition from primary to secondary school, stating this was something that needed “further investigation” (Barnard et al., 2002, p. 25). Although researching the presentation of SCD in both genders, Kothari et al. (2013) commented on the need for future research to appreciate the differing presentations of males and females with ASD, stating that research needs to be separated by gender. This was supported by Egerton and Carpenter

(2016). Pellicano, Dinsmore and Charman (2014) identified a lack of research into women and girls with ASD, stating that future research needed to focus upon this population. Furthermore, Shefcyk (2015) stressed that researchers have a responsibility to challenge the public perception of ASD being a male dominated disorder through the output of research into women and girls with ASD.

From investigating EBD in CYP with ASD, Horiuchi et al. (2014) concluded that girls with ASD are “at a greater risk for distress rather than boys with ASD” (Horiuchi et al., 2014, p. 548) and Cridland et al. (2014) reported that “adolescent girls with ASD are more disadvantaged... [than] their male counterparts” (Cridland et al., 2014, p. 1262), suggesting that greater time and resources should be invested into researching the experiences of girls with ASD and the support that professionals are in a position to provide. As well as highlighting the need for more gender specific research into ASD, Cridland et al. (2014) also stressed the importance of research that is stratified by age, stating that “adolescence is a critical period for girls with ASD” (Cridland et al., 2014, p. 1262). This would suggest that this population in particular requires an increased level of support and research. With Cridland et al. (2014) claiming to have produced the first piece of research exploring the perspectives of adolescent girls with ASD and their mothers, the current piece of research hopes to build upon the work that they completed, developing a third perspective on the issues raised, that of the EP.

## Chapter 3. Methodology

### 3.1. Introduction

This chapter addresses the ontological and epistemological position taken by the researcher. It will then go on to explore the aims of the research along with the methods used to conduct the research. Detailed information will be provided around the participants recruited for the research as well as the data collection and analysis that was used during the research.

### 3.2. Ontology and Epistemology

Ontology addresses the meaning of ‘reality’ and theories that surround what is reality (Crotty, 1998). Bhaskar (2008) referred to the development of an ontological position as “[reflecting] upon what must be the case for science to be possible” (Bhaskar, 2008, p. 38).

Establishing the ontological position of this piece of research was important because the exploration of ASD and SCD can fall within a number of different ontological positions and therefore, a number of different methodologies in terms of data collection and data analysis were available to the researcher.

Epistemology addresses how knowledge is known and created (Scotland, 2012). It looks to explore the relationship between the researcher and the ‘reality’ which they wish to explore, through the approaches used.

#### - 3.2.1. *The Ontological Position*

This research took a critical realist stance in terms of ontological position, a perspective which de Souza (2014) believed could be adopted in all disciplines. From this position, it is proposed that the area of SCD (and more specifically, ASD) is socially and historically constructed and so research around this subject is context- and time-dependent (Al-Amoudi & Willmott, 2011). In addition, a critical realist position places an emphasis on science developing theories to explain incidents in the real world. This is important as the research wished to explore the experiences of EPs in the ‘field’, rather than through controlled, laboratory studies. It was therefore vital that the context in which the research was conducted was reflected upon in the research. Although the primary research question asked EPs to recount their experiences, the subsequent questions sought to widen and deepen the focus of the research, including asking questions regarding how and why certain situations had arisen. In order to embrace a critical realist worldview, it was important that the research went beyond simply asking

what is happening (Robson, 2011). The research also acknowledged that although individuals are largely responsible for making meaning of circumstances, some limits of 'reality' do exist (Braun & Clarke, 2006) and de Souza (2014) reports that, while there is a reality as the result of natural and social objects acting independently, it is the social construction of these independent acts that creates human knowledge around such objects.

Creswell (2014) stated that when conducting research from a transformative worldview, "theoretical perspectives may be integrated with... philosophical assumptions" (Creswell, 2014, p. 10). Philosophical assumptions include critical theory, in keeping with this research. However Creswell (2014) also lists a number of alternative theories that could have been applied to this research including feminist perspectives and disability theory. Therefore, this research closely resembled a transformative worldview. However, as the CYP themselves were not included in the methodology of the research, it did not directly empower adolescent girls with SCD. Instead, it was hoped that the EPs would be in a position to advocate for adolescent girls with SCD in mainstream education and hence it was felt appropriate to address this research from a critical realist perspective.

### **- 3.2.2. *The Epistemological Position***

Guba and Lincoln (1994) propose that reality varies between individuals and so it is important to separate the views of the researcher from that of the participants in order to ensure a true interpretation of the participants' realities. In order to do this, the epistemological framework looked to support the researcher and the participants in creating an interaction which produced a rich picture of the current social and political attitudes towards SCD (Guba & Lincoln, 1994). Through this approach, it was hoped that the experiences of the EPs could be explored in order to gain insight into the participants' realities.

As acknowledged by Edge and Richards (1998), it is impossible to remove the researcher from the research. The simple act of selecting an area to research will influence the outcomes of the research. It was important from the critical realist perspective to be aware of this factor throughout the research and take every opportunity to act reflexively in order to produce transparency between the researcher and the research. To achieve this, Scotland (2012) promotes making one's "agenda and value-system explicit from the outset" (Scotland, 2012, p. 12).

Bhaskar (2008) expressed the opinion that critical realism relies upon epistemological relativism to some degree; however critical realism proposes that regardless of our knowledge of the world, certain phenomena still exist. Although this research placed a high emphasis on the social construction of knowledge within the critical realist perspective, Bernstein (2010) warns against ‘bad relativism’ whereby “there is really no truth..., no objective facts, and no universal validity claims” (Bernstein, 2010, p. 109). The researcher was therefore aware of the need to remain mindful of the ‘realities’ uncovered by the data, as proposed by Braun and Clarke (2006) and de Souza (2014).

### **3.3. Research Aims/Questions**

The main research question addressed by this research was:

- What are the experiences of EPs when working with adolescent girls with SCD in mainstream education?

In addition, this research hoped to answer the following questions:

- What is the role of the EP when working with adolescent girls with SCD in mainstream education?
- What support is deemed appropriate and effective for adolescent girls with SCD in mainstream education?
- How can the EPS support EPs and other professionals in providing appropriate and effective support for adolescent girls with SCD in mainstream education?

### **3.4. Purpose of Research**

The research hoped to explore the experiences of qualified EPs within an Outer London Borough EPS and therefore fulfilled the role of exploratory research. Based upon the lack of research revealed by the literature review into the role of the EP when working with adolescent girls with SCD in mainstream education, exploratory research was felt to be most appropriate in order to explore this area in detail and contribute towards the current gap within the research.

### **3.5. Design**

*“[Qualitative research] is the interpretative study of a specified issue or problem in which the researcher is central to the sense that is made.”*

(Banister, Burman, Parker, Taylor & Tindall, 1994, p. 2)

The research design was qualitative. This was felt to be essential in order to gather rich narratives from each participant. Through detailed narratives, it was possible to identify recurring themes and experiences in order to decipher the current role and practice of EPs within the Outer London Borough EPS. Furthermore, qualitative research has an “open-ended, exploratory nature” (Willig, 2008, p. 20) meaning the design and purpose of this research were aligned.

Banister et al. (1994) propose that qualitative research should focus upon “the context and integrity of the material” (Banister et al., 1994, p. 1) being collected and this fits with the research questions being proposed in this research. However, they also appreciate the gap between the object of study and the representation of such object as presented by the researcher. The process of interpretation is considered to influence any results produced by qualitative researchers and as such, the research design is in keeping with the epistemology of this research.

Robson (2011) proposed that qualitative research should present data in a non-numerical format, should focus upon meaning and should involve “inductive logic” (Robson, 2011, p. 19). The research should therefore be driven by the data collected rather than through pre-existing theories and assumptions. Robson (2011) also placed a large emphasis on the importance of gaining the perspective of the participants, whilst acknowledging the impact and involvement of the researcher.

In order to meet the criteria of qualitative research, data was collected through a focus group followed by individual semi-structured interviews. An initial focus group was deemed appropriate as the researcher wished to explore the experiences of EPs without imparting their own experiences on the participants. Therefore, data from the focus group did not contribute to the overall findings of the research; however it was analysed in order to contribute towards the construction of the interview schedule based upon the experiences of the participants. Again, this was in keeping with the critical realist position taken by the researcher and was successful in utilising the qualitative design in order to explore the experiences of EPs when working with adolescent girls with SCD in mainstream education.

### **3.6. Participants and Sampling**

The research was conducted within an Outer London Borough EPS in which the researcher was working as a TEP. Participants were selected using the following inclusion criteria. They were required to be qualified EPs working either full or part

time for the Outer London Borough EPS. They must have had at least six months' experience as a fully qualified EP within the Outer London Borough EPS as the research was concerned with EP practice and experience based within that Local Authority.

Purposive sampling was used to recruit participants, as is usually the case with qualitative research (Morse, 1989). This was deemed appropriate because the research required a sample that matched specific criteria and proportionality was not considered a priority for this research (Evans, 2007).

#### **- 3.6.1. *Focus Group***

In the initial stage of the research, email invitations were sent to all EPs matching the inclusion criteria, inviting them to participate in a focus group in order to capture the scope of experiences within the EPS. Morgan (1998) recommended that six to eight people should participate in a focus group and so the research aimed to follow this advice. Of 19 EPs emailed, a total of eight EPs responded to the email, of which five were available to participate in the focus group. Following analysis of the data collected through the focus group, it was felt that there was a wide enough range of experiences present in the sample to generalise the data to the whole of the EPS, and therefore construct the interview schedule around this data. A second focus group was not deemed necessary.

#### **- 3.6.2. *Pilot Interview***

Following on from the focus group and prior to completing the semi-structured interviews, a pilot interview was conducted. Again using purposive sampling, the participant of the pilot interview fulfilled the criteria as a qualified EP working full time for the Outer London Borough EPS however she did not have at least six months' experience as a fully qualified EP within the Outer London Borough EPS. Therefore, although she was able to answer questions based upon previous knowledge, allowing her to provide important information regarding the validity of the interview schedule, her responses could not be assimilated with the data collected during the semi-structured interviews as it did not relate directly to the context in which the research was being conducted.

As the research was conducted by a novice researcher, it was also felt appropriate to complete a pilot interview in order to "feel at ease [and gather] frank

feedback on the content and process of the interview” (Banister et al., 1994, p. 55) before embarking on the main data gathering stage of the research.

### **- 3.6.3. *Semi-structured Interviews***

Eight participants were interviewed during the second phase of the research. Purposive sampling was used to select EPs who chose to contribute during the focus group as well as those who expressed interest in the research. Again, via email, 19 EPs were invited to participate in the semi-structured interviews. A total of eight EPs responded, all of whom participated in the semi-structured interviews. Robson (2011) reported that qualitative research is often “small-scale” (Robson, 2011, p. 19) in terms of participants and so a sample size of eight participants was deemed appropriate for this research.

Of the initial five participants who contributed towards the focus group, three participants became part of the sample of eight who participated in the semi-structured interviews. Given the small population from which sampling occurred, as with the focus group, all EPs who matched the inclusion criteria were invited to participate in the semi-structured interviews. Through analysing the transcripts produced from the semi-structured interviews, it would appear that there was not a significant difference in the reported experiences of the participants who had contributed to the focus group, compared to those who had not. Therefore, it did not seem necessary to retrospectively control for previous involvement in the research and so all of the semi-structured interviews were included in the final data analysis, regardless of the extent to which the participant had been involved in the research.

### **- 3.6.4. Participant Characteristics**

The characteristics of the EPs who participated in the focus group as well as the interviews were noted and displayed in Table 5. It was felt important to recognise the position of each EP within the EPS during the focus group as this may have interacted with any power imbalance experienced during this activity and hence influenced the construction of the interview schedule that followed (Banister et al., 1994). Further, the length of time working within the Outer London Borough EPS was considered important in order to identify any changes over time.



Table 5. The characteristics of each of the EPs who participated in the focus group, pilot interview and semi-structured interviews.

Participant number	Activity	Position held in the Outer London Borough EPS	Number of years working as a trained EP	Number of years working in the Outer London Borough as a trained EP
P1	Focus Group 1	Maingrade EP	3	1
P4	Focus Group 1	Maingrade EP	2	2
P3	Focus Group 1	Maingrade EP	15	1
P9	Focus Group 1	Maingrade EP	13	13
P10	Focus Group 1	Senior EP	35	25
-	Pilot Interview	Maingrade EP	< 6 months	< 6 months
P1	Interview 1	Maingrade EP	3	1
P2	Interview 2	Maingrade EP	19	1
P3	Interview 3	Maingrade EP	15	1
P4	Interview 4	Maingrade EP	2	2
P5	Interview 5	Maingrade EP	11	11
P6	Interview 6	Maingrade EP	28	28
P7	Interview 7	Senior Specialist EP	12	10
P8	Interview 8	Locum EP	20	2

### **3.7. Strategies for Data Collection**

The qualitative strategy for data collection and analysis for this research was a focus group and individual semi-structured interviews, both of which were analysed through thematic analysis. A focus group was selected as the first strategy for data collection in order to gather a wide range of data in a relatively short period of time. It was hoped that the focus group would provide enough information to guide the content of the individual semi-structured interviews through the construction of the interview schedule. Individual semi-structured interviews were deemed most appropriate for the main data collection strategy because it allowed for focus to be placed on individual experiences. Therefore, the researcher had greater flexibility to explore the narratives being provided by each participant whilst being directed by the information gathered during the initial focus group. Both strategies for data collection were in keeping with the ontological and epistemological position of the research.

#### **- 3.7.1. *Focus Group***

Data from the focus group was collected via the researcher scribing key themes being discussed onto a flip chart in front of the group. This technique was deemed appropriate in order to facilitate the process of member checking during the focus group. The focus group was also audio recorded and transcribed. As the focus group aimed to contribute to the direction taken during the semi-structured interviews, the research was not concerned with the interactions which took place during the focus group and so in-depth visual analysis through video recording was not required.

#### **- 3.7.2. *Pilot Interview***

Although the pilot interview was recorded, it was not deemed necessary or appropriate to conduct data analysis on the information gathered during this stage of the research.

#### **- 3.7.3. *Semi-structured Interviews***

The semi-structured interviews were also audio recorded and transcribed in order to facilitate analysis. The transcriptions were completed by the researcher in order to familiarise themselves with and “immerse” (Braun & Clarke, 2006, p. 87) themselves in the data. Bird (2005) proposes that transcription is a “key phase of data analysis” (Bird, 2005, p. 227), hence it was considered important that this task remained the responsibility of the researcher.

### 3.8. Procedure

In Shefcyk's (2015) editorial for the journal *Autism*, she stresses that simply researching a population does not go far enough to ensure their voices are being heard. Therefore, in order to effectively complete this research, the researcher felt it would be most appropriate to involve EPs in the research process, including the construction of the interview questions.

The research was conducted in two phases: a focus group followed by individual semi-structured interviews. Initially, a homogenous focus group was conducted by the researcher. Focus groups have been found effective in encouraging "participation from people... who feel they have nothing to say" (Kitzinger, 1995, p. 299) and so it was hoped that the use of a focus group would uncover subtleties in EPs' work. Focus groups have been perceived to limit the intimate information contributed by participants due to the open nature of the conversation. For this research, it was not felt that the topic of EPs' experiences of working with adolescent girls with SCD in mainstream education was a particularly sensitive area of discussion; however, it is important to consider that research has suggested that focus groups actually promote the exploration of sensitive topics (Frith, 2001) and so this reduced the level of concern further around the use of a focus group. It is acknowledged, however, that people may have felt unable to contribute during the focus group as a result of the power balance felt between participants (for example, between newly qualified EPs and Senior EPs) hence the researcher used their knowledge of the EPS to attempt to minimise this effect by ensuring a balance in terms of experience and superiority. It was also important to utilise the interpersonal skills, in part learnt through EP training, in order to manage conflict, imbalance of contribution and dominance during the focus group.

During the focus group, the main research questions were presented in order to initiate a conversation around central practices and issues currently experienced by EPs. Following the questions being presented, the researcher acted as a moderator to encourage interaction and conversation without leading the discussion towards their own prior experiences or existing hypotheses (Sim, 1998). A focus group was felt to be most appropriate in this situation as it can be 'a useful method for facilitating qualitative insights into a group's... shared... social and psychological experiences' (Sherriff, Gugglberger, Hall & Scholes, 2014, p. 93) hence feeding into the ontological position of the research. The focus group lasted for approximately one hour.

During the second phases of the research, individual semi-structured interviews were conducted with a purposive sample of EPs. The interview schedule was constructed around the research questions that this research wished to answer, but was also based upon the themes that arose from the focus group. Therefore, the interview schedule was adapted following the focus group to ensure all questions were relevant and likely to produce the most in-depth narratives. The questions aimed to be open-ended in order to avoid the research being led in a particular direction by the researcher and to allow the participants to focus on areas of importance to them (Mertens, 2010; Wilkinson, Joffe & Yardley, 2004). To ensure that information from the focus group was coherently incorporated into the interview schedule, a pilot interview was completed with a participant who did not match the required inclusion criteria in order to participate in the main research.

The use of semi-structured interviews was deemed appropriate as it facilitated greater investigation into perceived gaps and difficulties that were reported during the research. Through the use of semi-structured interviews, freedom was granted to not have to consider standardisation or replicability (Banister et al., 1994), allowing the researcher to move away from the interview schedule when necessary in order to explore specific responses in greater depth. Therefore, the use of semi-structured interviews allowed the meaning held by EPs around the phenomenon that is adolescent girls with SCD to be explored. On average, each interview lasted for approximately one hour, with the shortest interview lasting 30 minutes 35 seconds and the longest interview lasting 1 hour 5 minutes 56 seconds.

### **3.9. Data Analysis**

Data collected from the focus groups was analysed using thematic analysis (Braun & Clarke, 2006; see Appendix 2 and CD attached) and then integrated into the semi-structured interview schedule (see Appendix 3). Thematic analysis was also used to analyse the data collected from the semi-structured interviews.

#### **- 3.9.1. Thematic Analysis**

Inductive thematic analysis (Braun & Clarke, 2006) was chosen as the most appropriate data analysis technique because it fits with the critical realist perspective of this research and provided the opportunity for exploration (Robson, 2011), which was considered important given the purpose of this research.

### **- 3.9.1.1. *Theoretical Background and Aims***

The method of thematic analysis is used for “identifying, analysing, and reporting patterns (themes) within data” (Braun & Clarke, 2006, p. 79). These patterns contribute to themes in the data and are usually identified before, during and after analysis by the researcher (Ryan & Bernard, 2000). Unlike other forms of data analysis, thematic analysis can accompany a range of methods and epistemologies in order to produce meaningful data. Thematic analysis can be conducted in an inductive way or deductive way. For the purpose of this research, inductive thematic analysis was used. Whereas deductive methods seek to provide a more detailed account of specific aspects of the data set, inductive approaches allow identified themes to be generated through the intense analysis of the data collected (Patton, 1990). Given the lack of previous research into the experiences of EPs with regard to adolescent girls with SCD in mainstream education, an inductive data analysis method was regarded as more appropriate as there were no prior assumptions around the possible findings of the research. Further still, based upon the ontology and epistemology of the research, it was important not to impose already assumed knowledge which would have been necessary, to some extent, if using a deductive approach as it requires the researcher to identify specific areas within the data set on which to place a focus.

Based upon the desire for the data analysis to remain data driven, the analysis of the initial data collected through the focus group was incorporated into the interview schedule, altering the structure of the semi-structured interviews in order to be led by the data collected. This resulted in the interview schedule being led by the interests and experiences of the focus group participants, no longer so closely resembling the initial research questions.

Using a semantic approach (Boyatzis, 1998), the researcher was able to identify specific, explicit themes within the data in order to then draw meaning from them through interpretation. A latent approach to analysis of the data was deemed inappropriate as this involves the interpretation of the data based upon assumptions and conceptualisations which is more in keeping with, although not limited to, a constructionist ontological position (Burr, 1995), rather than the critical realist stance taken in this research.

### **- 3.9.1.2. *Advantages of Using Thematic Analysis***

Thematic analysis has been described as a “dynamic research method” (Tang, et al., 2009, p. 15) which has applications with regard to developing theory, aiding clinical practice and, as is the case in this research, supporting the understanding of specific phenomena. Thematic analysis offers the opportunity to “provide a rich thematic description of [an] entire data set” (Braun & Clarke, 2006, p. 83) which is considered useful when investigating a previously under-researched area. Beyond this, the use of inductive analysis provides the opportunity to explore under-researched areas without the necessity of having previous coding frames. In addition, thematic analysis allows one to “[summarise] key features of large amounts of qualitative data” (Robson, 2011, p. 477) which was in keeping with the methodology of this research.

### **- 3.9.1.3. *Different Approaches to Thematic Analysis***

Given the ontological and epistemological position of the research, the use of interpretive phenomenological analysis (IPA; Smith, Larkin & Flowers, 2009) could also have been used. Generally, IPA focuses upon the lived experiences of participants and seeks to explore a particular phenomenon. Usually IPA focuses on areas that are often overlooked or unidentified which appears to fall in line with the description of ASD and SCD in the female population. However, as the data gathered was provided by EPs rather than adolescent girls themselves, it is not possible to interpret the data as the lived experiences of females with ASD. Instead, it is the lived experiences of EPs, something which is less likely to be considered an overlooked phenomenon. It could therefore be argued that the current research does not fully meet the criteria for the use of IPA. Further to this, as the research was conducted by a novice researcher with regard to qualitative data, the use of a data analysis technique that the researcher was familiar with felt more appropriate in order to minimise mistakes or oversights during the analysis process.

Additionally, the use of grounded theory could have been applied to this research. Grounded theory aims to generate a theory based upon the data collected within a study (Robson, 2011). Given the limited information currently available around the role of the EP when working with adolescent girls with SCD in mainstream education, the current research fits the model of grounded theory. However, grounded theory generally adopts an explanatory purpose whereas the current research hoped to fulfil an exploratory purpose, seeking to gain a greater insight into the current practice

of EPs, rather than explaining the current phenomenon of EP practice with regard to adolescent girls with SCD in mainstream education. For this reason, grounded theory was not considered appropriate in this context.

### **3.10. Ethics**

The research was granted ethical approval in February 2016 by the Research Ethics Committee of the School of Psychology, University of East London (see Appendix 4) which is guided by the British Psychological Society (BPS) Code of Human Research Ethics (BPS, 2010).

Shotter (1975) proposed that psychology is a moral science and as such, the researcher considered the ethical aspects of several key areas. Primarily, consent was obtained from the Principal EP at the Outer London Borough EPS to ensure permission had been granted for the Service to participate in the proposed research. In order to conduct this research within the Code of Ethics and Conduct guidelines (BPS, 2009), fully informed consent was gathered from all participants in the form of a briefing sheet (see Appendix 5) accompanied by a signed consent form (see Appendix 6). This included the EPs who volunteered to participate in the focus groups as well as those who completed semi-structured interviews. Within this consent, the opportunity to withdraw from the research was discussed and it was made clear to all participants that they could withdraw from the research up until the beginning of data analysis, and this would have resulted in any data they had contributed being destroyed. To protect the identity of the participants, interview numbers were used when referring to specific extracts within the data and confidentiality and anonymity surrounding individual pupils and schools were maintained by ensuring all interviews remained anonymous throughout.

Flip chart notes from the focus groups were destroyed instantly and audio recordings from the focus groups and semi-structured interviews were stored on a remote hard drive which was kept in a locked cupboard, with only the researcher and research supervisor having access. The audio recordings were destroyed following transcription. In line with the University of East London data protection policies, a paper trail (Flick, 1998), including the transcriptions, will be kept for two years following the completion of the research in order to allow for publication and further cross-referencing of data, as deemed appropriate. Following this, the transcriptions shall be destroyed.

### 3.11. Validity and Reliability

As the data collected was qualitative, it was important for the researcher to remain reflexive throughout the research process in order to pay active attention to the impact of the social, historical and political opinions of the researcher on the interpretation of the data collected. To achieve this, a reflective diary was kept by the researcher, with abstracts from the diary being incorporated into the final thesis, allowing for transparency.

Yardley (2008) argues that it would be inappropriate to apply strict validity and reliability frameworks of quantitative research to qualitative research due to the difference in aims between the two. Quantitative research usually wishes to explore a phenomenon that is wide-spread in order to produce results that can be applied and replicated in a number of different situations. In contrast, qualitative research is usually concerned with subtle interactions which are context-specific. For that reason, qualitative researchers do not wish to produce replicable results as they assume that such events are relatively rare in nature. However, to some degree it should still be possible to achieve a level of generalisability as different contexts usually share similar features. Johnson (1997) therefore refers to ‘theoretical’, ‘vertical’ or ‘logical’ generalisations, rather than the statistical generalisations referred to in quantitative research. To achieve trustworthiness of the research, it was important to demonstrate credibility, transferability, dependability and confirmability (Mertens, 2010). Consideration was made for each of these areas and can be seen in Table 6.

Table 6. A table of the actions and considerations that have been taken in order to demonstrate validity, reliability and trustworthiness of the current research.

Criteria	Research feature
Credibility	In order to ensure the accurate portrayal of the EPs’ views, member checks were used throughout the focus group to ensure that the interpretation of what was being said was in line with the experiences of the EPs. This was achieved by notes being recorded on flip chart paper in front of the group where all members were able to see the information gathered through the research. This was particularly important because



	taking a critical realist worldview meant it was possible that the researcher may have interpreted a situation differently to the participant and so to gain accurate views, the researcher had to work as overtly as possible with the participants to reduce this risk.
Transferability	By conducting semi-structured interviews, deep, rich pictures of EPs' experiences were achieved. As a consequence, it was possible to interpret the data as a complete data set, transferring the findings from the individual EP's experience to that of all those working within the Outer London Borough EPS. In part, it was also possible to transfer elements of the data beyond the Local Authority in which it was conducted due to the depth of information obtained.
Dependability	Through keeping a reflective diary, it was possible to detail each step of the research process, allowing the stability of the research to be measured and monitored over the research period.
Confirmability	Following analysis of the data, the researcher presented the findings to a peer who had not had direct involvement in the research in order to select dominant themes within the data and ensure the conclusions drawn by the researcher were accurate reflections on the data. In this respect, the research used triangulation by comparing researchers' coding to ensure the data was valid (Yardley, 2008).

### 3.12. Reflexivity

*“Reflexivity is the term used for explicit consideration of specific ways in which it is likely that the study was influenced by the researcher.”*

(Yardley, 2008, p. 250)

An identified advantage of thematic analysis is the flexibility that it offers when analysing a data set (Braun & Clarke, 2006), and this flexibility results in the ability of the researcher to determine which themes they believe to be prevalent. Without strict

guidance on what constitutes a prominent theme, Braun and Clarke (2006) report that the researcher plays an “active role... in identifying patterns/themes” (Braun & Clarke, 2006, p. 80). It was therefore vital for a reflective diary to be maintained through the duration of this research in order to preserve transparency with regard to any bias that might have arisen during data collection and analysis. The reflective diary also provided an opportunity to consider the best format for presenting themes based upon their perceived prevalence within the data set (Banister et al., 1994).

Reflexivity can be portrayed as the attempted removal of subjectivity to create a more objective research project. Banister et al. (1994) felt that there was a common misconception within positivist research that, by reducing subjectivity, objectivity naturally increases. They concluded that the researcher simply exposing their position within the research does not remove subjectivity and so researchers should be reflexive and open to their biases in order to view subjectivity as a theoretical and pragmatic resource. Although it is acknowledged that to some extent, the researcher will always guide the identification of themes based upon their interests and motivations, the use of inductive thematic analysis increases the need for reflexivity in this research as the data should be coded without being influenced by the researcher’s preconceptions, hence the need for transparency with regard to these preconceptions (Banister et al., 1994; Yardley, 2008).

### **3.13. Summary**

This chapter presented an overview of the methodology used in this research. The ontological and epistemological position of the researcher was explored and methods regarding data collection and analysis in light of the ontological and epistemological position were discussed. The importance of reflexivity was highlighted and the ethical considerations to be borne in mind when conducting research were also addressed.

## Chapter 4. Findings

### 4.1. Introduction

This chapter aims to present the key themes and subthemes identified through analysis of the qualitative data collected. Details of the interview participants can be found in Chapter 3 and complete transcriptions of the interviews conducted can be found on the CD attached with an excerpt of an interview in Appendix 7. The themes and subthemes will be presented in a thematic map (see Figure 3), followed by a description and interpretation of each theme. The chapter will conclude with a summary of the whole data set. In order to maintain the anonymity of the participants and the Local Authority, names of individuals and service providers have been replaced with generic terms.

### 4.2. Qualitative Analysis

Through the use of thematic analysis (Braun & Clarke, 2006), five themes were identified from the data set. In addition, a number of subthemes were also highlighted, along with features within the themes. The themes, subthemes and features can be seen in Table 7. An example of the coding process is provided in Appendix 8 and full transcripts including coding can be found on the accompanying CD.

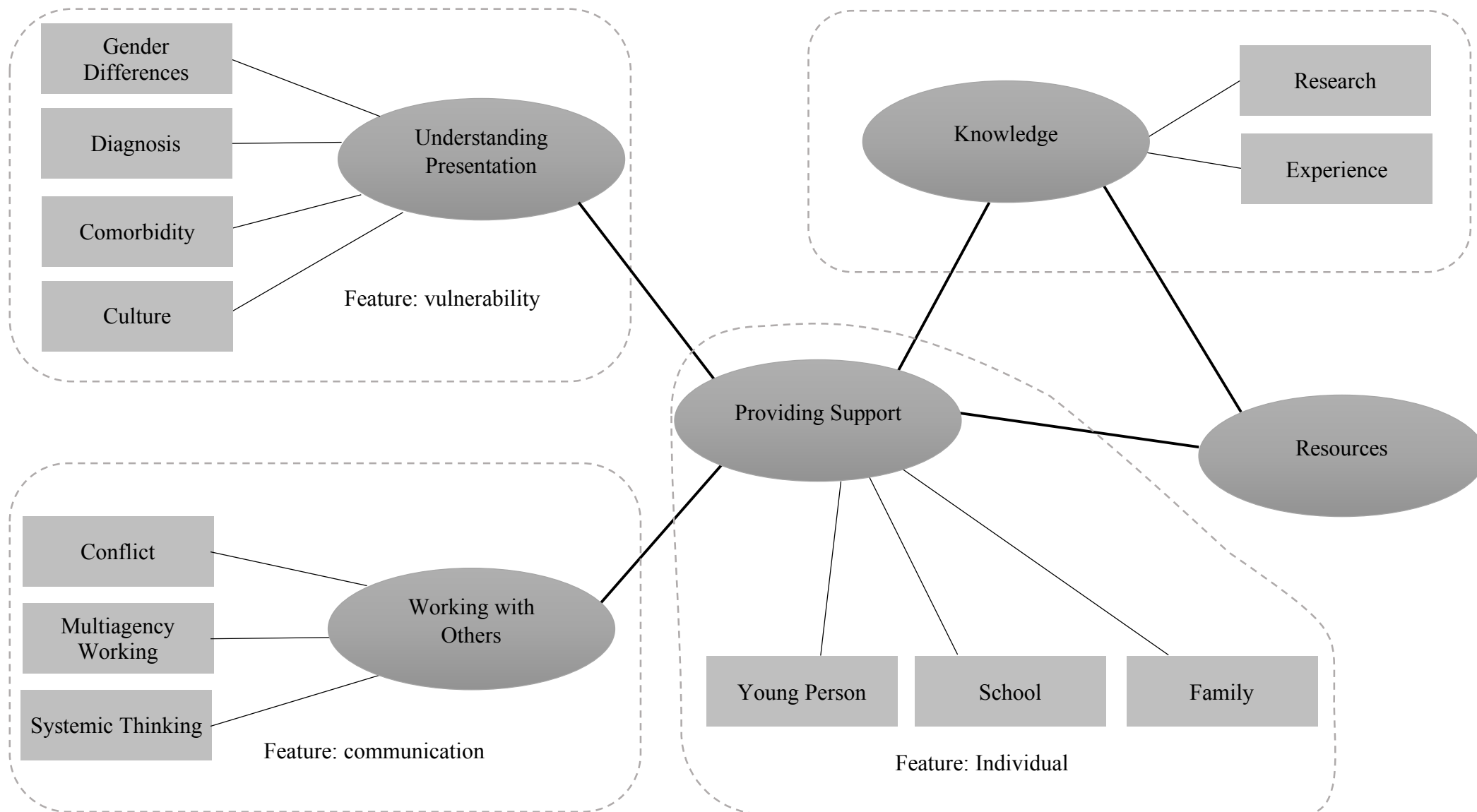
Table 7. The themes, subthemes and features arising from the data collected regarding the experiences of EPs when working with adolescent girls with SCD in mainstream education.

Theme	Subtheme	Feature
Understanding Presentation	Gender Differences  Diagnosis  Comorbidity  Culture	Vulnerability
Providing Support	Young Person  School  Family	Individual

Knowledge	Research Experience	
Resources		
Working with Others	Multiagency Working Conflict Systemic Thinking	Communication

A thematic map was devised to illustrate the themes that emerged from the data set (Figure 3).

Figure 3. A thematic map illustrating the themes and subthemes emerging from the data set.



#### **- 4.2.1. Understanding Presentation**

Understanding the presentation of SCD in adolescent girls was a key theme within the data. Discussions centred around the manifestation of difficulties, with the difference between identifiable presentations and overlooked presentations regularly mentioned. Through deeper analysis of the data, four subthemes emerged; gender differences, diagnosis, comorbidity and culture. Further to this, vulnerability was identified as a feature of the data set and appeared to be an underlying concern for a number of participants.

##### **- 4.2.1.1. Gender Differences**

A number of traits were highlighted by the participants during the interviews. These covered a range of areas including behavioural presentations, social and emotional aspects of SCD and developmental areas of concern. The participants spoke in detail about the identifiable areas of difficulty presented by adolescent girls with SCD in mainstream education.

*“You could see socially that’s where she’s really going to struggle”  
(Interview 2, line 157)*

*“Everyone was quite sure because of the way she was presenting”  
(Interview 6, line 11)*

Some identifiable areas appeared to be in line with the stereotypical presentation of SCD.

*“A girl who was in Year 9 at the time, who was presenting with very  
challenging behaviour in school” (Interview 7, line 11)*

*“She just couldn’t interact with people, she’d hit out and she’d  
scream” (Interview 6, line 17)*

However, other characteristics appeared to relate specifically to girls and, although identifiable to the participants, it was felt that these might not always be identifiable or associated with SCD by other professionals, in particular, to school staff.

*“I didn’t get the sense that she had an awareness of herself”  
(Interview 2, line 205)*

*“The way girls might manifest umm, you know, the need for routine  
and stereotyped behaviours like rigid behaviours umm can be seen  
quite positively in primary” (Interview 3, line 125)*

*“It was really interesting because they weren’t raised with the EP  
when that became known to the school” (Interview 1, line 213)*

Emphasis was placed on social difficulties, including comments relating to the girls experiencing a desire to socialise but lacking the ability, as well as many participants highlighting the negative impact that this had on the girls feeling isolated. It would appear that a number of adolescent girls whom the participants had worked with showed an interest and a longing to interact socially with their peers but did not understand the nuances of social exchanges.

*“She doesn’t like being alone or excluded in any way” (Interview 5,  
line 34)*

*“She’s becoming more and more isolated” (Interview 2, line 24)*

This appeared to be a greater concern than when working with boys with SCD and therefore contributed to highlighting the gender difference with regard to the presentation of SCD.

*“I think they suffer a lot socially because I think often umm girls are  
very umm motivated to be social” (Interview 8, line 191)*

Many participants also linked these concerns to issues of emotional wellbeing and the impact that isolation and loneliness can have on mental health.

*“My key area of concern for her, alongside the sort of social  
communication, was her actual emotional wellbeing because you  
could see she was really, really withdrawing into herself” (Interview  
2, line 100)*

Gender differences were also raised as an explanation for adolescent girls with SCD in mainstream education being missed. This was partly attributed to the fact that the common discourse around SCD and ASD generally focuses on boys, causing people to overlook girls.

*“We have a very... very stereotypical view of the autistic child and that child is more often male” (Interview 3, line 115)*

*“There’s still a lot of misinformation out there and very old fashioned, traditional information about what an autistic person looks like” (Interview 8, line 648)*

Further still, a number of participants proposed the idea that SCD and ASD present differently in girls compared to boys, and that EPs and other professionals are not knowledgeable enough to identify this different presentation.

*“Girls often present very differently to boys” (Interview 8, line 645)*

*“A lot of girls are missed” (Interview 6, line 80)*

Participants also reflected on some of the stereotypical behaviours associated with ASD and how they are commonly perceived as more feminine behaviours, so may not be identified as unusual when presenting in girls, compared to boys displaying the same behaviour.

*“Girls... like to have these interest areas umm and we see it as more normalised, I think, for girls than for boys” (Interview 3, line 128)*

#### **- 4.2.1.2. Diagnosis**

Through exploring the identification of SCD, questions were raised by the participants around the ASD diagnostic process, including the length of time and immediacy of the process, the EP’s role within the process and the other professionals involved in the process. It would appear that the process was often perceived to be too lengthy and the EP role was limited with regard to diagnosis.



*“I understand the process to be very long” (Interview 1, line 375)*

*“The diagnosis process seems to be ages, it seems to be forever”  
(Interview 6, line 386)*

Participants commented on their lack of involvement in the diagnostic process, even though they felt their skill set appropriately matched that required for such a role. A number of participants questioned the reliability of the diagnosis, with comments being made around the unnatural setting of clinics and the large weighting that is placed on parental report. It would appear that there are concerns around the multiagency element of diagnosis and the lack of consideration for context during the process.

*“I sometimes wonder, in [Local Authority], whether the appropriate professionals are... are involved” (Interview 7, line 293)*

*“I’m a bit confused because autism is a developmental disorder, it’s a pervasive developmental disorder so in terms of diagnosis, it would appear to me to fall within the remit of a psychologist to diagnose autism. And I’m confused as to why... why it’s become the domain of psychiatry to diagnose a pervasive developmental disorder”  
(Interview 8, line 472)*

There were mixed opinions with regards to adolescent girls with SCD in mainstream education receiving a diagnosis of ASD. Some participants could not recall working with any girls with an ASD diagnosis whereas other participants felt that all the girls they had worked with had received diagnoses and that a lack of diagnosis was not a problem. The individual difference displayed here may relate to the referral process that a number of participants spoke about. It was regularly commented on that work is, to some extent, dictated by schools and that different schools have different priorities. It is therefore likely that EPs’ experiences are based on the schools which have been allocated to them, meaning they are exposed to a variety of different needs. For the varying participants, their allocated schools’ priorities in terms of SCD may have been drastically different, hence the difference in experience of working with adolescent girls with a diagnosis of ASD.

*“I’ve not had a single girl with an ASD diagnosis” (Interview 3, line 298)*

*“Generally all of them actually have been diagnosed at primary school” (Interview 4, line 8)*

Moving beyond diagnosis, with regard to identification in general and the impact that has on prevalence, there were also opposing views from the participants. Some participants stated that adolescent girls with SCD are often overlooked or misidentified, whereas other participants felt that SCD (and ASD in particular) has become a phrase which is too readily used to explain difficulties being experienced by adolescent girls in mainstream education. There appeared to be an observable divide in opinion based upon the number of years each participant had been qualified as an EP, with the more recently qualified participants feeling that SCD is a very commonly used phrase, whereas those EPs who qualified earlier felt that SCD is still not a prominent discourse within schools.

*“Autism wasn’t picked up” (Interview 5, line 252)*

*“I think sometimes it’s quite explicit that they err away from diagnosis for quite... for as long as they can” (Interview 3, line 579)*

*“I think “ASD” is bounded around possibly a little bit too frequently” (Interview 4, line 242)*

*“Every other child seems to be on the ASD spectrum at the moment” (Interview 6, line 218)*

#### **- 4.2.1.3. Comorbidity**

The complexity of the issues affecting adolescent girls with SCD in mainstream education was a common observation made by the participants in order to explain this cohort being overlooked. A number of participants mentioned SCD coexisting with mental health conditions (such as eating disorders or anxiety) and that these conditions were often viewed as the cause of the girls’ difficulties rather than SCD being identified. In addition, a number of participants mentioned learning difficulties as a remit for their involvement with this population and so, in a number of cases, the EP becoming involved with an adolescent girl in mainstream education with SCD appeared to be the by-product of schools expressing concerns around a lack of academic progress or questions related to social, emotional and mental health.

*“There’s so much going on” (Interview 1, line 92)*

*“You also have the syndrome mix so it’s not always just... sometimes it’s not just autism on its own. It could be autism with something that’s OCD [Obsessive Compulsive Disorder], ADHD [Attention Deficit Hyperactivity Disorder], social anxiety” (Interview 6, line 421)*

*“They’re probably thinking there’s a lot of mental health umm issues with this particular youngster and were putting it down to learning difficulties” (Interview 2, line 22)*

Furthermore, a number of participants reflected on the tendency and ability of girls to mask their SCD by replicating socially desirable behaviour. For this reason, the participants found girls could successfully navigate their way through primary school without the question of SCD being raised until secondary school.

*“They’ve actually been quite verbal, you know, so... so hidden a lot of their needs” (Interview 1, line 345)*

*“She’s actually quite good at masking her difficulties” (Interview 5, line 254)*

*“A key issue is about umm compensatory strategies and about hiding the difficulties” (Interview 8, line 339)*

This could lead to a failure to recognise difficulties related to social communication by the secondary school as there was an assumption that by secondary school, the students’ needs would all have been identified.

*“The general feeling in secondary schools tends to be ‘well surely this would have been picked up at primary’” (Interview 7, line 153)*

#### **- 4.2.1.4. Culture**

Participants also reflected upon cultural factors which they believed contributed to adolescent girls with SCD in mainstream education being overlooked. The need for sensitivity and an ability to reflect upon one’s own culture, and that of the families that EPs work with, featured in the interviews. In the Local Authority within which the

research was conducted, there is a diverse range of ethnicities and cultures, and this was something each participant appeared to be aware of and sensitive to.

*“When a young person is from a background umm with a cultural heritage umm that is diff... different to your own, you have to be so sensitive” (Interview 1, line 94)*

In addition, the construct of ‘disability’ appeared to vary between cultures and it was felt important, as part of the role of the EP, to establish what the view of ‘disability’ was in the culture the EP was working in, in order to fully support the family in understanding and accepting girls with SCD.

*“I always try to do lots of listening to the parents anyway, to get a sense of what this means for them and what parents’ hopes and aspirations are umm which is always guided, I think, by culture anyway, the culture, beliefs and values” (Interview 3, line 158)*

A number of participants reported that the majority of the cases that had been brought to them were related to white European girls, however this is not representative of the ethnic composition of the Local Authority in which the research was conducted. Many participants had not previously considered this observation, and this again seems to relate back to referral routes and methods of identification with regard to adolescent girls with SCD in mainstream education.

*“They’re mostly white, British girls. Umm and I’m sure that there are girls from other ethnicities of similar profiles, but I can’t say I’ve come across them in recent times” (Interview 7, line 99)*

*“Most of the girls who I end up working with who are, in my view, undiagnosed autistic young women, umm are white” (Interview 8, line 89)*

During discussions around the impact of culture upon the identification of SCD, gender was also considered and the power of the voice of women in different cultures became a dominant narrative within one interview.

*“In some other cultures that I work within, girls have less of a voice”  
(Interview 8, line 104)*

It would appear that many cultural issues such as the dominant discourse around ‘disability’, gender stereotypes and acceptance of difference are all impacting on the role that the EP can adopt in supporting adolescent girls with SCD in mainstream education.

*“Cultural factors are always relevant” (Interview 3, line 138)*

Along with cultural factors, the wider political context was discussed, with a general consensus that opinions around SCD have begun to change, with participants acknowledging an increase in acceptance. However, many participants felt this change was not happening fast enough and that more needs to be done to remove the stigma previously associated with SCD. Removing stigma appeared to be the responsibility of society in general, as well as the personal responsibility of EPs working within the community.

*“I think in the last 3/4 years, people have started really talking about this” (Interview 6, line 87)*

*“I would like to think that there’s less of a social stigma” (Interview 8, line 76)*

*“Things are quite slow to move” (Interview 7, line 80)*

*“I can’t think of any change” (Interview 5, line 61)*

*“I think it’s an area we really need to develop our knowledge and practice around” (Interview 3, line 111)*

#### **- 4.2.1.5. Vulnerability**

On a number of occasions, participants referred to adolescent girls with SCD in mainstream education as being particularly vulnerable. As well as their general presentation, emphasis was placed on their stage of life, with a particular focus on puberty and sexual relationships. Another recurring narrative within the interviews was that of permanent exclusion and the risk that adolescent girls with SCD in mainstream education face with regard to this. Again, the risk of exclusion appeared to be related to

the age of the girls, a lack of understanding around their needs and the reduced tolerance demonstrated by secondary schools compared to primary schools.

*“Very, very, very needy and vulnerable” (Interview 6, line 313)*

*“It’s a very difficult time because obviously it’s timing with adolescence” (Interview 6, line 564)*

*“The whole area of sex and relationships and sexualisation is huge in this population” (Interview 3, line 601)*

*“We’re also seeing an increase in adolescent girls being permanently excluded” (Interview 7, line 76)*

*“Secondary schools have very low tolerance for bad behaviour” (Interview 7, line 156)*

#### **- 4.2.2. Providing Support**

The theme of providing support was dominant throughout the data and incorporated a number of areas in which the participants had worked or felt they should work within their roles as EPs.

##### **- 4.2.2.1. Young Person**

The need to support the young person through acting as an advocate for them emerged as a subtheme within the theme of providing support. From reflecting upon previous experience, it would appear that the participants felt they held an important role in gathering and presenting the voices of adolescent girls with SCD in mainstream education. The age of the girls appeared to play a factor in this, with some participants experiencing conflict between respecting the wishes of the young person whilst also ensuring she was in an appropriate setting and accessing appropriate support.

*“It’s important that people are really listening to them” (Interview 5, line 206)*

*“She was older and old enough to have, you know, her own views taken into account and... and even to be included in, you know, all the goal setting tasks” (Interview 3, line 174)*

*“Very articulate about what she’s interested in, not interested in, what she wants to do, doesn’t want to do” (Interview 2, line 200)*

*“She’s so set on what she wants but she so clearly can’t cope with what she thinks she wants and when we attempt it, it’s always gone wrong” (Interview 7, line 113)*

Support for the young person also included the need for appropriate interventions that EPs can implement, or recommend to schools to implement, so as to support adolescent girls with SCD in mainstream education. Given the common belief that SCD and ASD are predominantly male disorders, one participant also reflected upon the impact that accessing support where the other students are all male will have on a girl’s self-perception. This appeared to relate, to some extent, to the need for a shift in perception around ASD being a predominantly male disorder, and a more inclusive approach to addressing the needs of adolescent girls with SCD. Further to this, the participants spoke about the lack of available support for adolescent girls with SCD outside of school. Again, this seemed to link back to self-perception and the lack of opportunity for adolescent girls with SCD to develop a sense of identity within the context of their diagnosis or difficulties.

*“When things are starting to come unglued we could already be starting to look at the presentation and putting the appropriate interventions into place” (Interview 7, line 185)*

*“There isn’t much opportunity to get involved personally in delivering strategies and approaches” (Interview 3, line 346)*

*“What is it like for a girl in a school being in a social communication group with mainly boys? And I wonder what that does for your identity as a girl” (Interview 4, line 246)*

*“I’m not aware of... of very much that’s available locally for education, support, umm even kind of umm social activities” (Interview 8, line 317)*

Moreover, many participants reflected on their role in supporting adolescent girls with SCD and felt they were failing to fulfil this role and that they were letting this cohort down. This appeared to centre mainly around identification and a lack of shared knowledge and awareness. Although it was believed that the role of the EP should incorporate and focus upon supporting young people, the reality appeared to be that this is something EPs struggle to do to the extent which they believe to be appropriate.

*“By not upskilling staff and... and by not giving staff the knowledge to better identify umm the underlying potential causes of the behaviour, I think we’re doing the girls a massive disservice” (Interview 7, line 219)*

*“It’s supposed to be us; it should be us” (Interview 3, line 320)*

#### **- 4.2.2.2. School**

The participants interviewed suggested that, when working in mainstream secondary schools, their role often involved supporting the school. Supporting schools seemed to take a number of different forms. In some cases, imparting knowledge or implementing interventions appeared to be a key role for the EP.

*“[The EP role] should be about... putting together a plan of how... how that assessment is going to inform what you’re going to do to help that young person” (Interview 1, line 127)*

In other cases, problem-solving and providing objective, impartial input appeared to be most useful to schools.

*“I think it’s almost umm a lack of confidence maybe or just that feeling of needing umm an objective eye” (Interview 1, line 41)*

*“It’s being able to offer some kind of supervision to the people that are working very closely with this young person” (Interview 2, line 266)*

In addition, some participants spoke about the need that some schools felt to express their concerns or frustrations without desiring further EP input. Although this did not necessarily fit the perceived role of the EP as reported by the participants, there seemed to be a general acceptance that in some cases this was unavoidable and necessary in order to move conversations forward.

*“[School] need to sometimes, have a platform or to voice their concern” (Interview 4, line 204)*



Whilst discussing the EP role with regard to supporting schools, the need for monitoring and reviewing was also raised. The participants appeared to place importance on reviewing their involvement; however, this appeared to be in conflict with schools who were reported to be less invested in reviewing previous cases.

*“A process of review is actually really key” (Interview 3, line 362)*

*“They’re not motivated when you say ‘I’d like to review Jennifer in 6 months’ time’ you know, it’s not motivating for them” (Interview 8, line 457)*

The ability to review cases was influenced by the amount of resources available as well as the general ethos of the EPS. This appeared to be an area where the participants expressed frustration with regard to their role as EPs.

*“[You have to] have umm procedures where monitoring is just part and parcel of what you do” (Interview 1, line 311)*

Reported experiences appeared to vary between schools. It would appear that the ability of the EP to support schools was heavily dependent on the attitude and understanding of the school itself, with a particular focus on the senior leadership team and individual staff members. As well as the need for cooperation with regard to attitude, many participants also mentioned resources and structures within secondary schools, reporting that some schools did not have the appropriate systems in place to support the work of the EP.

*“Just trying to get your head around the school organisation at the umm at that level is umm really challenging and you know, every school is so different” (Interview 2, line 374)*

*“It will be different depending on which high school they’re at” (Interview 6, line 279)*

#### - 4.2.2.3. *Family*

There appeared to be a difference in perception between providing support for schools and providing support for families. Whereas participants spoke with confidence about their role in supporting schools to understand the needs of adolescent girls with SCD in mainstream education, there was a strong narrative around the lack of support available to families. It would appear that the act of supporting schools fits with the role of the EP, whereas supporting families was felt to be the responsibility of an alternative service, although the participants struggled to identify any services within the Local Authority that existed or had the capacity to fulfil this role. This appeared to apply to support for families in general, but a large emphasis was placed on the lack of specific support for families of young people receiving diagnoses at adolescence.

*“If you get a very, very early diagnosis, you’ve got things like the [ASD support] programme” (Interview 8, line 303)*

*“I’m not sure that there’s anything that’s available, suitable for adolescents’ parents” (Interview 7, line 320)*

*“I just felt it was very confusing for them” (Interview 5, line 243)*

*“There’s not enough support out there. It’s shocking” (Interview 6, line 380)*

Parental influence also featured in a number of the interviews and it would appear that the role of parents is highly important for adolescent girls with SCD. A number of participants felt that it was essential that parents understood the needs of their daughters in order to support them fully. Although general support for families did not appear to fall within the remit of the EP, supporting families with regard to understanding SCD in relation to their daughters came across as a priority for EPs.

*“[Parents are] agents of how things go in the future” (Interview 3, line 164)*

*“Dad didn’t think there was anything wrong and Mum was just fussing” (Interview 6, line 24)*

*“It really is a case of trying to suss out where they’re at in their journey, what would be useful for them to understand and take on board now and what we can just put on the back burner until they’re ready to hear more” (Interview 7, line 137)*

*“It’s about talking through what you think it might be and whether they’re going to accept that there is a possibility that you need a referral from... to a GP or doctor” (Interview 6, line 99)*

#### **- 4.2.2.4. Individual**

A feature running throughout the theme of providing support was the need for intervention and support to be individual and tailored specially to meet the needs of those being supported. This included the individual needs of the adolescent girls but also of the schools and families. A number of participants felt they could not provide generic accounts of their experiences of working to support adolescent girls in mainstream school with SCD because each case was unique and therefore their contribution was unique.

*“It has to be case by case” (Interview 6, line 432)*

*“It’s not a standard umm approach” (Interview 7, line 144)*

*“It’s very bespoke, very individualised” (Interview 1, line 309)*

*“I cannot think of any strategy because I think it’s very much about looking at what there is and tweaking it” (Interview 2, line 396)*

*“It really depends on the school as to how involved you get with those girls” (Interview 6, line 158)*

#### **- 4.2.3. Knowledge**

The importance of having knowledge of SCD featured in every interview. This included the EP themselves expanding their knowledge, but also supporting the knowledge of schools, families and other professionals. Knowledge appeared to be gained through accessing research and from personal experience. Participants appeared to relate knowledge to understanding and the implication appeared to be that through the acquisition of knowledge, a greater understanding could be achieved by the participants as well as by schools and families.

##### **- 4.2.3.1. Research**

All participants valued research as a means of broadening their knowledge and supporting their role as an EP when working with adolescent girls with SCD in mainstream education. However, a number of participants felt there was not enough

research available specific to this cohort. The presentation of SCD in the female population appears to be a developing research area and so, although participants felt research was important to their role as an EP, it was not always available or appropriate when working with this specific population.

*“I think research matters so much being an EP, so much” (Interview 1, line 435)*

*“It’s crucial” (Interview 6, line 466)*

*“I definitely would draw on the research umm but probably not as much as I’d like to” (Interview 5, line 304)*

*“There’s not a whole lot of research out there” (Interview 7, line 374)*

In addition, most of the participants felt that the application of research was difficult to achieve. This was either due to poor dissemination of research, with some participants stating that they struggled to keep up-to-date with the latest research as they were unsure where to look or what to read. Alternatively, some participants stated that research was commonly not generalisable to real life situations. They felt that too much emphasis was placed on scientific rigour and this limited the richness of the research with regard to practical application. Although not verbalised, this appears to reflect the divide between evidence based practice and practice based evidence. In theory, it would appear that all participants valued evidence based practice. However in reality, practice based evidence appeared to provide a greater contribution when supporting EPs in working with adolescent girls with SCD in mainstream education.

*“It should be cascaded down to us in a more relevant and easy way because you know, we don’t even have access to the umm research” (Interview 6, line 474)*

*“There is so much out there and knowing what to actually spend your time looking at and not looking at is equally...” (Interview 2, line 624)*

*“There is a great role but does it get properly disseminated and can we put it into practice? Can it... is... is there a practical bit about it making a difference to our practice that, you know, you know, is it fully utilised?” (Interview 3, line 512)*

*“They’re trying to compete with the scientific subjects and they’re trying to pretend that we are a positivist, scientific subject because there’s some weird hierarchy around that” (Interview 4, line 403)*

Picking up on the suggestions of practice based evidence, a number of participants felt that within the role of the EP, it was also possible to contribute to research, although desire to do so appeared to be limited by personal interest, time constraints and relationships with schools. The participants appeared to identify a gap between EP training, where research is considered extremely important in contributing to the professional doctorate qualification, and EP practice, where research skills are infrequently used and are often forgotten over time.

*“There’s so much we could be doing” (Interview 2, line 256)*

*“Why are all these people coming off doctorates having had to have done big pieces of research then to spend their career never doing any research again?” (Interview 1, line 464)*

*“I wouldn’t necessarily be one of those, I don’t see myself as a very... in that sort of academic umm field” (Interview 6, line 502)*

*“There’s just a feeling of being completely swamped and overwhelmed constantly by workload and backlog, and the idea of having time umm for research is like umm laughable, really” (Interview 8, line 594)*

*“How many times have we seen schools bring in initiatives... and you think... ‘I could do a lovely evaluation for you of that’” (Interview 1, line 471)*

#### **- 4.2.3.2. Experience**

Participants also appeared to rate their knowledge of SCD based upon their personal experiences with regard to individual cases. All participants spoke about the amount of contact they had had with adolescent girls with SCD in mainstream education and this correlated with the level of knowledge they perceived themselves to have regarding this cohort. There also appeared to be an element of personal interest that impacted upon knowledge, with some participants speaking about increasing their knowledge of SCD through self-directed reading and attending specific conferences and training.

*“I don’t have a high school at this moment” (Interview 6, line 266)*

*“Every time I work with umm somebody with autism, I learn more.  
So I’m... I’m learning constantly” (Interview 8, line 547)*

*“I think there’s as much the actual work as opposed to direct  
courses” (Interview 2, line 599)*

*“It’s a real area of interest for me” (Interview 5, line 283)*

*“I would do a fair bit of my own reading and sort of journal articles  
and umm so on and so forth to umm keep constantly updated”  
(Interview 8, line 550)*

There also appeared to be a dialogue around the experience of working with or attending training relating specifically to adolescent girls with SCD and this appeared to relate back to the participants raising concerns around the limited research that is available and the lack of knowledge in general with regard to the specific presentation of SCD and ASD in the female population. Participants did reflect however that they were able to apply more generic experiences and training to the work they completed with adolescent girls with SCD in mainstream education. For some participants, increasing their knowledge did not appear to be a priority, whereas others felt additional input would be useful.

*“I’ve had lots of training over the... over the years umm but nothing  
specific to adolescent girls” (Interview 7, line 355)*

*“I haven’t actually received any specific training about girls on the  
spectrum” (Interview 3, line 455)*

*“Do you want to know about training that isn’t specific to adolescent  
girls because I think I use that when I’m working with any child with  
autism?” (Interview 5, line 284)*

*“I think I’m OK at the moment, but obviously as time progresses I  
might start to need another top up” (Interview 7, line 366)*

*“I personally feel I need more umm need to do more training around  
or reading around or thinking around, to be able to see how it  
actually impacts on the... the wider level” (Interview 2, line 691)*

#### **- 4.2.4. Resources**

An area mentioned in all the interviews was the access to resources. A number of participants spoke about previous EPSs they had worked in where the Local Authority

was organised in such a way that there were specific services providing support for CYP with ASD and SCD. This was viewed positively by all the participants in supporting their role as an EP and increasing their knowledge and opportunities for ways of working with regard to SCD.

*“I think it’s very different in different EPSs” (Interview 8, line 607)*

*“Where I came from, post diagnosis, there was a coffee morning after with other families so you’re not, you know... trying to break the isolation” (Interview 2, line 524)*

*“I’ve been lucky because of, like I said, because of the authority, it was clearly a bit of a thing for them and it was clearly a focus for them” (Interview 1, line 412)*

In addition, funding was mentioned in a number of interviews. This appeared to relate to the funding available to EPSs, creating restrictions on the role of the EP. However, many participants also reflected upon the funding available to schools and how that impacted on their use of EPs. There was a narrative surrounding the need for schools to minimise their spending, however participants also highlighted that early intervention can reduce the spending of schools in the future and that explaining this impact to schools seemed to fall within the remit of the EP.

*“We know how to do it but there are constraints, aren’t there? Budgetary constraints and all that stuff” (Interview 3, line 551)*

*“[Schools] tend to try and direct you towards cases where there might be a financial gain to be made” (Interview 7, line 200)*

*“I think, what [school] might think is a big spend, is actually a really small spend in the long... in the bigger picture” (Interview 2, line 259)*

Budgetary constraints within the EPS were also raised. Linked with the theme of knowledge, many participants felt there was a lack of access to research within the EPS and this was impacting on their ability to utilise the research that was available.

*“We have access to another two, but that’s very limited and there’s not much SEMH [social, emotional and mental health] or mental*

*health stuff umm available to us that's easily accessible" (Interview 7, line 388)*

*"The EPS could certainly, I don't know, fund a little bit of umm journal access maybe" (Interview 1, line 455)*

*"We should have a subscription between us into the most popular journals, umm that we can all access online" (Interview 4, line 452)*

Time appeared to be the most prominent resource to be spoken about. Every participant mentioned that time was a limiting factor when they reflected on the work they were able to complete with adolescent girls with SCD. When discussing time limitations, the participants referred to direct time taken to work with this cohort, as well as indirect time such as keeping up-to-date with research. Although a number of participants were able to reflect on the limitation of time and attempted to provide alternative ways of working to increase their impact within this limitation, responsibility for the management of time appeared to fall to the senior leadership within the EPS.

*"In reality, we don't have enough time" (Interview 4, line 347)*

*"Once you sort of get off that runway at the beginning of the term, I don't feel like I touch the ground again until school closes in July and I become hard pressed to sit down and read a whole article" (Interview 3, line 504)*

*"Although that's not an ideal model, with the limited resources we have, it's the only model that I can see working" (Interview 7, line 340)*

*"That's something for [PEP] to have to answer I think" (Interview 6, line 517)*

#### **- 4.2.5. Working with Others**

It was acknowledged by all participants that EPs do not work in isolation with adolescent girls with SCD in mainstream education. However, participants' experiences of the extent to which they had worked with others, and of the level of success with regard to such working, appeared to vary.

##### **- 4.2.5.1. Multiagency Working**

A desire was expressed for working with other agencies using a multiagency model. Participants frequently raised the subject of multiagency meetings with an



emphasis on identifying the correct professionals to provide support, and then working together to implement interventions that would be effective and appropriate for that young person.

*“We’re the eyes for the other professionals such as paediatricians”  
(Interview 2, line 544)*

*“There’s something about umm being able to actually work with  
somebody and go on a journey together” (Interview 2, line 650)*

*“It’s lovely and easy working with people who are really buying in to  
change and who buy into that. What the... the trick is and the  
important thing is to... to work with people who don’t, and to get  
them to kind of move with you” (Interview 1, line 306)*

The importance of working relationships also emerged from the data collected. A number of participants commented on the relationship they had with the SENCOs in their schools and the impact that this had on the range and quality of work they were able to complete with the students. Establishing a good working relationship where there was a shared understanding of the role of the EP appeared to be essential in order to work efficiently within mainstream high schools. The ability to establish such a relationship appeared to be, to some extent, attributed to luck, with one participant reflecting that she had a positive relationship with one SENCO yet was unable to bring a shared understanding to her work with another SENCO.

*“If you’ve got a good relationship with the school you can... you can  
have some say on the agenda” (Interview 7, line 226)*

*“That SENCO in that school did not see my... the need for my  
involvement at all” (Interview 5, line 161)*

*“I’ve been quite lucky in my SENCOs” (Interview 6, line 178)*

#### **- 4.2.5.2. Conflict**

Whilst discussing working with others, a number of areas of conflict were raised. One specific area of conflict which was raised by a number of participants was how the EP role was understood by schools. In a number of cases, participants reported schools perceiving the role of the EP to be different to how they would like to work. Participants reflected that overall this problem was not specifically related to SCD but

that it was an area of conflict that arose regularly in all areas of SEN when negotiating work with a school.

*“I definitely think there’s a conflict” (Interview 1, line 185)*

*“I think they often give you that information and sometimes think that is going to solve it” (Interview 4, line 171)*

*“So much of it can be about assessment, assessment, assessment umm and it’s frustrating because it has to be about intervention” (Interview 1, line 123)*

*“In an ideal world, I would do far more preventative work” (Interview 7, line 183)*

*“We’re so busy rubber stamping stuff” (Interview 2, line 285)*

Statutory assessment was mentioned in every interview. The participants felt that often EP involvement was requested as a route to obtaining an Education, Health and Care (EHC) Plan. Again, this perceived role as “gatekeeper” (Interview 1, line 187) seemed to contradict the role of the EP held by the participants and contributed to the conflict experienced between EPs and schools.

*“There are the time demands so schools want to use you for statutory work only” (Interview 7, line 199)*

*“They all just want EHC plans” (Interview 6, line 243)*

*“Some of the staff in this high school feel I should be coming in, assessing, statutory assessment and getting her into an alternative placement” (Interview 5, line 123)*

*“I think on the management level, it seems to be a more paper-based task and they often use us much more for going for statutory assessment” (Interview 4, line 175)*

On several occasions, the participants commented on their role in comparison to the role of other professionals when working with adolescent girls with SCD in mainstream education. There appeared to be an element of conflict between roles with regard to responsibility and skillset. Experiences appeared to vary between participants however. Some believed that roles should be flexible and interchangeable between professionals whereas others reported this to be confusing.

*“We do play professional ping pong don’t we, like ‘oh, it’s yours, no it’s mine, no it’s your’” (Interview 1, line 391)*

*“The boundaries are blurred sometimes and that I find a bit tricky”  
(Interview 6, line 180)*

*“I feel that sometimes we’re not being heard” (Interview 2, line 498)*

*“I like fluidity within the roles” (Interview 8, line 516)*

*“Sometimes I’ll say to the CP [Clinical Psychologist] ‘there’s no reason why you shouldn’t do an educational assessment’” (Interview 8, line 369)*

#### **- 4.2.5.3. Systemic Thinking**

Again, with regard to other professionals, but thinking more broadly, a number of participants mentioned the positive impact that thinking and acting systemically can have when working with adolescent girls with SCD in mainstream education. Systemic thinking appeared to include working with the young person’s family, working within the school structure and working cooperatively with other professionals.

*“How effective can you be without involving the group? Because it’s not just about how the child’s behaving, it’s about how others are treating the child and their understanding of what autism is etc, etc., isn’t it?” (Interview 3, line 229)*

Although systemic thinking seemed to be extremely beneficial in the opinions of some participants, they did note that the secondary school structure can cause problems with regard to working with the most influential or most concerned individual, meaning difficulties are not always addressed adequately.

*“In a high school setting you’ve got... yeh, it’s a different thing. You’ve got education and the pastorals and the heads of years”  
(Interview 6, line 290)*

*“Because we’re dealing with somebody in middle management or upper management and TA [teaching assistant] staff, I’m not sure we’re hitting the right people” (Interview 4, line 206)*

*“It’s very much working together because I do insist on speaking to all those people, all the time” (Interview 6, line 191)*

By reflecting on systemic practice, the ability to provide recommendations to school staff that are feasible for them to carry out within the boundaries and limitations of their role, whilst also considering available resources, was also raised as an issue currently being experienced by EPs when working with adolescent girls with SCD in mainstream education.

*“High school’s a little bit more challenging because of the number of people involved and that particular school at that particular time, the systems were not in place” (Interview 6, line 125)*

*“What is possible with the resources on the table?” (Interview 4, line 285)*

Some participants felt that it was important to understand the context of the school and the young person’s current situation prior to making recommendations, in order for the recommendations to be valuable and achievable.

*“Initially it would seem that we were... that we were kind of going to build towards some interventions and making some change, and I think what happens is secondary school life gets in the way and time gets in the way and also you have to have everybody on board” (Interview 1, line 171)*

#### **- 4.2.5.4. Communication**

Communication was identified as a feature within the theme of working with others. In some cases, communication was regarded as the most important thing when working with adolescent girls with SCD in mainstream education. From a number of interviews, it would appear that including all the appropriate professionals had limited impact if hypotheses and strategies were not communicated.

*“The most important thing is about communication” (Interview 1, line 485)*

*“It’s a whole multiagency, you know, discourse, isn’t it really?” (Interview 3, line 438)*

*“Trying to keep... keep that information flowing umm between people, you know, to be able to connect with a range of people... because I think there’s something about hearing it second or third hand that gets lost” (Interview 2, line 389)*

#### **4.3. Summary of Findings**

Overall, the participants placed a high level of importance on their involvement with adolescent girls with SCD in mainstream education. Their perceived roles as EPs appeared to span a variety of areas including completing assessment work, increasing the understanding of others and implementing appropriate interventions whilst working alongside other professionals.

There appeared to be a conflict in opinion around assessment work, with every participant stating that they regularly completed assessments of adolescent girls with SCD in mainstream education. However, this did not appear to be their preferred way of working, suggesting a conflict in opinion between EPs and schools with regard to the role of the EP and assessment. Commonly, assessment work appeared to link with statutory assessment and the production of an EHC Plan, with a number of participants reflecting on the connection between EHC Plans and gaining access to the currently limited amount of resources available.

Resources were mentioned by all participants, with a particular emphasis on specific services, funding and time. Time appeared to be the most limiting factor, influencing how schools chose to allocate work to their EPs as well as impacting on EP practice in general, including report writing, consultation frameworks and accessing research and training. Although the participants were able to suggest a number of solutions with regard to the limitation of time, ultimately they appeared to believe that it was the responsibility of the senior management of the EPS to support the facilitation of activities which required additional time.

Generally it was perceived that there is currently a poor understanding of the presentation and needs of this cohort of students. In terms of identification, the majority of participants spoke about these students being missed and contemplated whether school staff were sufficiently knowledgeable to be able to identify cases of adolescent girls with SCD in mainstream education. The participants also reflected on whether there was enough research conducted and readily available to them in order for them to support schools in increasing their understanding and recognition of adolescent girls

with SCD in mainstream education. A common concern raised by the participants was around the pattern of behaviour they had experienced whereby girls with unidentified SCD transition up to secondary school and shortly afterwards are perceived by school staff as having behaviour difficulties. Linked to this, participants highlighted the vulnerable position that adolescent girls in mainstream education with unidentified SCD can find themselves in, with a number of participants describing cases in which they had been involved previously which had ended with the student receiving a permanent exclusion from their mainstream setting.

Each participant spoke about a number of alternative professionals with whom they felt it was appropriate to collaborate when working with adolescent girls with SCD in mainstream education. However, there appeared to be contradictory opinions around the most effective and appropriate way of forming multiagency working relationships. In some cases, the participants valued the freedom and flexibility that multiagency working can offer, speaking about how overlapping boundaries could allow each professional to fulfil a slightly different, individualised role. In contrast, other participants felt blurred boundaries led to confusion and made multiagency working more difficult. There was a general consensus, however, that communication was the key to ensuring multiagency and systemic work was effective in secondary school settings.

#### **4.4. Summary**

This chapter presented the themes, subthemes and features identified in the data through thematic analysis (Braun & Clarke, 2006). The themes, subthemes and features were then described in detail, with additional interpretation applied to the data in order to produce a detailed analysis of the information gathered. Through the discussion, themes, subthemes and features can be considered in order to answer the research questions presented.

- What are the experiences of EPs when working with adolescent girls with SCD in mainstream education?
- What is the role of the EP when working with adolescent girls with SCD in mainstream education?
- What support is deemed appropriate and effective for adolescent girls with SCD in mainstream education?

- How can the EPS support EPs and other professionals in providing appropriate and effective support for adolescent girls with SCD in mainstream education?

### **5.1. Introduction**

This chapter will begin by relating the data analysed through thematic analysis (Braun & Clarke, 2006) back to the initial research questions, addressing each question in turn. It will go on to consider how the current research connects with the existing literature and research. This will be followed by a critique of the methodology of the current research and hence the limitations of the findings. The focus will then expand to consider the implications for future research as well as how the findings can be applied to the role of the EP. The chapter will conclude with a reflection upon the process of conducting the research.

### **5.2. Relating Key Findings to the Research Questions**

The research wished to address four research questions. Through analysis of the data it was possible to identify themes which related to the research questions and in doing so, answer each question.

#### ***-5.2.1. What are the experiences of EPs when working with adolescent girls with SCD in mainstream education?***

Experiences appeared to vary between participants and were heavily influenced by the number of cases of adolescent girls with SCD that each participant had worked with. When asked about their experiences, it would appear that the presentation of behaviours within each case was seen as significant by the EP. Presentations varied from overt, identifiable behaviours to covert, overlooked behaviours and appeared to be influenced by gender differences and the co-occurrence of SCD with other difficulties. Furthermore, linked to understanding presentation, it would appear that cultural factors and the current socio-political climate also impacted upon the experiences of EPs when working with adolescent girls with SCD in mainstream education.

##### ***- 5.2.1.1. Understanding Presentation***

EPs appeared to describe two presentation styles within the population of adolescent girls with SCD in mainstream education. In some cases, EPs described overt behaviours such as hitting, screaming and withdrawing from social interactions. Based upon the narratives provided by the EPs, it would appear that these behaviours were considered identifiable factors which contributed towards an ASD diagnosis following the involvement of an EP. Although schools were able to use these behaviours to



identify the need for additional input through EP involvement, it would appear that this was not necessarily under the remit of supporting the girls with their SCD and schools were not always able to initially identify ASD traits in adolescent girls with SCD in mainstream education.

In contrast, some presentations appeared to be overlooked by both the school and potentially the EP. The common contributing factor to ASD presentations being overlooked appeared to be the complexity of the cases being presented to the EPs. Discussions were held around the competing hypotheses that EPs are required to consider, including eating disorders, ADHD, OCD and attachment difficulties. In these cases, it was felt that competing hypotheses could mask the identifiable traits of ASD and this could mean that the appropriate professionals were not called upon within a suitable timeframe.

Further masking appeared to arise from the adolescent girls themselves. Another complication mentioned by EPs with regard to adolescent girls with SCD in mainstream education was their ability to mask their difficulties and mimic the behaviour of others. It would appear that this strategy can prove effective at primary level; however, as social interactions become more complex, along with additional complications such as puberty, the ability to successfully mimic behaviour at secondary level drastically decreases. Although this would suggest that ASD traits become increasingly identifiable at secondary level, the participants reported that this was not the case as it appeared to create further confusion for school staff, who appeared to hold the belief that ASD is or should be identified at primary level.

#### **- 5.2.1.2. *Culture and Politics***

Public perception and the social construction of ASD also featured when the participants were asked to discuss their experiences of working with adolescent girls with SCD in mainstream education. This appeared to be most relevant within two domains; that of cultural impact and when considering the current socio-political climate.

When taking into consideration the local context with regard to this research, it was interesting to discover that although over 80% of CYP within the Local Authority are BME (figure obtained through Local Authority records, not referenced, 2012), the majority of participants commented that their experiences were of working with White European adolescent girls. This is out of line with the general population for the area

and suggests that cultural influence is, to some extent, impacting on the rate of referral of BME adolescent girls. Although the EPs were aware of the demographic of the Local Authority with regard to ethnicity, it would appear that this is something that had not been acknowledged or considered previously.

The current socio-political climate was also discussed when considering the EPs' experiences of working with adolescent girls with SCD in mainstream education. Some negative aspects of the current climate were highlighted through discussions (for example, the impact of austerity and the limitations that this appears to be having on the role of the EP), however the general narrative around the socio-political climate appeared to be positive, with many EPs believing that there has been an increase in discussions held around ASD and subsequently, a better knowledge and understanding of ASD within society. It was concluded that although awareness of ASD has increased, the participants felt this could improve further.

#### **- 5.2.1.3. *Summary***

The experiences of EPs when working with adolescent girls with SCD in mainstream education appears to vary between cases and is dependent upon the presentation of the individual young person. The gender differences exhibited by males and females with SCD appears to lead to a mixture of identifiable and overlooked presentations in the female population, which can create difficulties when attempting to increase awareness and understanding of ASD in mainstream settings. In addition, the comorbidity of disorders results in competing hypotheses which add further confusion when working with this population. Broadening the focus from individual girls to society as a whole, it would appear that cultural and political factors impact greatly on the experiences of EPs, as reported by every participant. Although it was noted that the current political climate is working towards creating a greater acceptance of individuals with ASD, it would appear that EPs feel further progress is needed, and through participating in this research, questions were raised around the influence that cultural factors are currently having on adolescent girls with SCD gaining access to EP involvement.

#### **- 5.2.2. *What is the role of the EP when working with adolescent girls with SCD in mainstream education?***

The role of the EP appeared to cover a number of different areas. Providing support to adolescent girls, their families and schools was a key feature of the role of the

EP. Support could be provided in a number of different formats including gaining knowledge and understanding via research, working with others and contributing to the assessment of needs. Whilst fulfilling a supportive role, EPs appeared to strive to achieve a more holistic approach to working with adolescent girls with SCD in mainstream education.

#### **- 5.2.2.1. *Knowledge of ASD and SCD***

Published research was highlighted as being an essential element to the role of the EP; however, the way in which it is presented and disseminated amongst practising EPs appears to present limitations on the impact which research can have. There appears to be a divide between the views and approaches of academic psychologists compared to practising psychologists, creating a lack of transferability of research findings to real life situations.

When working with adolescent girls with SCD in mainstream education, it would appear that EPs feel a responsibility to acquire a better knowledge of current research as well as a responsibility to share that knowledge with other professionals. In addition, within the role of the EP there arose the opportunity to contribute to research and to inform future practice through the study of current cases. As well as large scale research, a number of participants reflected that they were well positioned to provide smaller, evaluative input for their schools; however this was something that was rarely requested by schools. Therefore, although it would appear that the role of the EP relies heavily upon research, both in terms of gaining knowledge and contributing to future knowledge, this role does not appear to be regularly exercised by EPs.

#### **- 5.2.2.2. *A Systemic Approach***

When considering their role, EPs often highlighted the fact that they did not work in isolation when supporting adolescent girls with SCD in mainstream education. A range of other professionals were regularly spoken about and it would appear that multiagency working was felt to be essential in providing comprehensive support to this population. To achieve this level of support, the need for clear communication was raised and it often seemed to fall to the EP to liaise between home and school, as well as between other professionals in order to construct a clear picture of the young person's needs and to decide how best to address them.

Associated with working with others, there was also a strong narrative around adopting a systemic approach when supporting adolescent girls. This approach seemed

to focus strongly on the structure of secondary education and the limitations that this had on the role of the EP when providing support. Limitations included communication between teaching staff, with participants describing having opportunities to discuss CYP with only a small number of staff. It would also appear that often participants felt the staff member with whom they had contact was not the staff member who was in a position to act on their recommendations. Systemic thinking extended beyond the school system however, and included the need for those around the young person (e.g. their parents, teachers, friends and society in general) to gain a better understanding of their needs and for reasonable adjustments to be made to accommodate those needs.

#### **-5.2.2.3. *Assessment***

Just as the participants were in agreement that their role should incorporate research and working with others, it was also commonly accepted that completing assessments was an important component of the role of the EP. The rationale behind completing assessments appeared to vary between gaining more information in order to contribute towards generating appropriate hypotheses, and completing them for statutory purposes. EPs appeared to lay greater emphasis on information gathering, viewing it as an essential strategy in their perceived role of providing effective support for adolescent girls with SCD in mainstream education. In contrast, although statutory assessment clearly featured heavily within the role of the EP, there were mixed views on the motivation behind such assessments, with some participants expressing concerns that they often produced reports containing recommendations that were not actioned by schools. Therefore, although assessment is considered to be a prominent feature in the role of the EP, it would appear that it is not always conducted in a manner that is in keeping with the beliefs and values of the EP.

#### **- 5.2.2.4. *Summary***

The role of the EP appears to be primarily based upon providing support. Support can take a variety of different forms including the dissemination of research, contributing towards research, working with other professionals and providing assessments. Although there was agreement on the current role of the EP, there appears to be a level of dissatisfaction with this role in practice, with many EPs placing an emphasis on being involved in more research and having to conduct fewer statutory assessments when describing their ideal role for the EP.

### ***-5.2.3. What support is deemed appropriate and effective for adolescent girls with SCD in mainstream education?***

The support that was deemed to be appropriate and effective appeared to vary between participants. Some participants were able to identify techniques or interventions that they felt were beneficial in all cases when working with adolescent girls with SCD, whereas others found it difficult to answer this question, highlighting the individualistic feature within the theme of providing support. The theme of providing support linked with all the identified themes, suggesting that appropriate and effective support can be gained through accessing resources, building knowledge and working with others. In addition, a clear understanding of the presentation of SCD was identified as a necessity for providing appropriate and effective support. Through thematic analysis, it was possible to identify that appropriate and effective support took the form of supporting the young person, schools and families.

#### ***- 5.2.3.1. Supporting the Young Person***

A major role for the EP appeared to be to support adolescent girls with SCD in mainstream education through gaining their views and acting as an advocate with regard to their wishes and aspirations. It would appear that these wishes were not always in line with those of the school, family or EP and so part of providing that support was to aid the young person in achieving a better understanding of their SCD in order to create meaningful, achievable goals for the future.

Supporting adolescent girls directly seemed to go beyond the role of the EP and the context of mainstream education. In many cases, it was highlighted that this cohort should be provided with support outside of school in order to increase their social skills and reduce the isolation commonly witnessed by EPs with regard to adolescent girls with SCD in mainstream education. In such cases, the view was expressed that alternative professionals and outside agencies held a responsibility to provide this support. However, it was considered the responsibility of the EP to be aware of what was available and to signpost adolescent girls and their families to that support.

#### ***- 5.2.3.2. Supporting Schools***

As well as directly supporting adolescent girls, it was perceived that providing support to schools was also an appropriate and effective element within the role of the EP. Support for schools included providing space for the school to discuss concerns and assisting in hypothesising around the difficulties being experienced by the girls.

Furthermore, it was felt that support for schools should include upskilling staff and developing their knowledge base of SCD and its associated difficulties and presentations.

Communication was raised as a feature within the theme of working with others and it appeared to be highly relevant when discussing the work of EPs in relation to supporting adolescent girls indirectly through working with schools. Many participants spoke about the structure of secondary schools and the difficulty of disseminating information across the whole teaching staff. In addition, the contact between home and school was seen to reduce at secondary level, presenting yet another barrier to communication.

#### ***- 5.2.3.3. Supporting the Families of Adolescent Girls with SCD***

Families, and in particular parents, appeared to play a major role with regard to supporting adolescent girls with SCD in mainstream education, and as a result, each participant placed a high value on working supportively with families. This work took the form of educating families on how SCD might present in a young person and how to manage more challenging behaviours. However, it appeared that EPs did not feel as able to support families as they did to support schools or the young person themselves. Although the participants were able to identify ways in which they felt the role of the EP incorporated supporting families, it was also suggested that the provision of family support should extend beyond the remit of the EP. It would appear that in practice, there is a lack of support for families beyond the EPS, in part due to services experiencing overwhelming demand. Moreover, there appears to be limited services available within the Outer London Borough Local Authority in order to provide this support.

#### ***- 5.2.3.4. Summary***

In conclusion, it would appear that EPs can support young people and schools through upskilling staff, increasing the understanding of the presentation of SCD in adolescent girls, sharing knowledge and through promoting effective communication at all levels. However, the area of greatest need appears to be in supporting families, an area which does not appear to fall under the remit of the EP and which, in the view of many of the participants, is not being successfully achieved.

***- 5.2.4. How can the EPS support EPs and other professionals in providing appropriate and effective support for adolescent girls with SCD in mainstream education?***

The ability for the EPS to support EPs and other professionals in their practice seemed to be dictated by the available resources within the Local Authority. There were also discussions around working with others and the conflict that this can create between professionals, with the suggestion that the EPS could be more supportive in attempting to reduce this conflict.

***- 5.2.4.1. Availability of Resources***

A number of resources were highlighted as being essential for the EP and others when providing appropriate and effective support for adolescent girls with SCD in mainstream education. These included time, money, access to research and the presence of specific services. Within the theme of resources, it became apparent that there were vast differences between Local Authorities, with some Local Authorities providing a greater number of services than others or placing a greater degree of importance on the different services they provide.

With regard to research, participants appeared to relate the ability to incorporate research evidence into their work (either through accessing research or disseminating research) as being dependent on the actions of the senior leadership team within the EPS. Possible methods suggested by participants in order for the EPS to become more supportive in cases where a lack of resources were perceived to be hindering the EP from appropriately and effectively supporting adolescent girls with SCD in mainstream education included protected time to read and share research, identified research specialists within the team and a termly whole Service focus of interest on one specific research area.

***- 5.2.4.2. Conflict within Roles***

Although working with others (and in particular, the use of systemic thinking) came through as a strong theme when discussing appropriate and effective support for adolescent girls with SCD in mainstream education, there appeared to be some confusion around the specific role of each professional involved. During some interviews, this confusion appeared to relate specifically to the role of the EP as perceived by the EP in comparison to the role of the EP as perceived by others, mainly schools. However, some participants also described the blurred boundaries between

their role as an EP compared to other external agencies such as Clinical Psychologists, Speech and Language Therapists and Occupational Therapists. In some cases, the EP appeared to embrace these blurred boundaries, taking advantage of the flexibility that this offered in terms of different ways of working. Other EPs felt this caused high levels of confusion, with them becoming unsure of what their role was within the work they were completing.

Whether the conflict experienced is specific to the role of the EP and the remit under which they choose to work within schools, or whether it is broader than just the EP role and includes how their remit fits with other external agencies, it is important that the EPS is able to support EPs and other professionals in shaping a clear way of working in order to avoid confusion, conflict and repetition.

#### **- 5.2.4.3. *Summary***

The ability to support EPs in implementing appropriate and effective strategies for adolescent girls with SCD in mainstream education appears to be influenced by the resources available as well as the way in which the role of the EP is perceived by others. With regard to the EPS, it would appear that EPs see it as the responsibility of the senior leadership team to ensure that resources and the understanding of the role of the EP do not create barriers to the EP successfully fulfilling their role. To achieve this, the facilitation of greater resources is necessary as well as a clear dialogue around the role of the EP in order to generate a shared understanding amongst all professionals. It was felt necessary that this should be pursued at a whole Service level, rather than being pursued individually by each EP.

### **5.3. Links to Existing Research**

It is possible to compare the themes that have been identified through this piece of research with those that presented as dominant through the systematic literature review.

#### **- 5.3.1. *The Role of the EP***

Through the systematic literature review it emerged that the role of the EP could be divided into two distinct categories; providing therapeutic input for CYP on an individual level and providing knowledge and support to others at a systemic level (Greig & MacKay, 2005; Williams et al., 2005). It is therefore interesting to compare this description with the feedback provided by EPs with regard to their role when



working with adolescent girls with SCD in mainstream education in order to establish whether that is the case for this specific population. Although individual work was spoken about, it would appear that there is limited opportunity to complete therapeutic work within the role of a Local Authority EP. Instead, EPs mentioned more frequently that they might guide schools in providing therapeutic intervention. This would suggest that EPs identify the provision of therapeutic support as important, however time restrictions make it difficult to incorporate this element into their role directly and so, to some extent, this contradicts the research which suggests that working with CYP at an individual level was a major constituent of the role.

Due to the lack of opportunity to work at an individual level, providing knowledge and support for other professionals working with this population became a dominant theme within the feedback provided by the participants. This finding linked with research conducted by Barnard et al. (2002) who reported an increase in the number of teachers working with CYP with ASD. Greig and MacKay (2005) suggested that this therefore created a greater demand for EPs to target their practice towards supporting school staff. From the current research, it would appear that supporting school staff is a key aspect of the role of the EP and is something that EPs feel particularly comfortable fulfilling. Interestingly, Williams et al. (2005) made a similar observation, predicting that, with increased rates of inclusion in mainstream education, EPs might find themselves becoming more involved in supporting CYP with ASD. The views emerging from the current research differ in that, although every participant spoke about supporting schools in general, there was not a great emphasis on the increase in inclusive practice and how that has impacted on the role of the EP. This may be because they did not feel there has been demand for this, or it may be that the cultural push for inclusion means that the entire population of CYP with SEN has become more included, meaning that the participants did not relate this particular task specifically to supporting adolescent girls with SCD.

#### **- 5.3.1.1. *Where are the EPs?***

It is also interesting to consider that although Barnard et al. (2002) reported 72% of schools mentioning EP involvement with regard to CYP with ASD, no mothers spoke about EP involvement during the interviews conducted by Cridland et al. (2014) which raises the question as to whether mothers recognise this involvement. The results of the current research suggest that EPs spend a considerable amount of time offering support to schools, CYP and families and in doing so, EPs believe that their

involvement is apparent to and valued by the mothers of adolescent girls with SCD. For example, in a number of cases, the participants were able to identify specific mothers with whom they had worked closely. Cridland et al (2014) conducted their research in Australia and so this might highlight a difference in EP practice between Australia and the UK. However, it may be helpful to explore this in further detail within the UK, focusing on parental reports compared to EP reports in order to establish whether there is a disconnect with regard to the prevalence of EP involvement when considering the support provided for adolescent girls with SCD in mainstream education.

### **- 5.3.2. *Using Knowledge and Research***

Throughout the research, the need for an adequate knowledge of ASD was discussed in relation to increasing one's own understanding as well as upskilling and empowering others. The need for a good knowledge base was highlighted by Greig and MacKay (2005) and remains a theme in the current research.

In addition to this, the current research raises the question of how knowledge is gained. A number of EPs reflected that although they might have had some training in ASD, it was usually generic training and did not relate specifically to adolescent girls with SCD. Given the hypothesis that girls can present in different ways to boys, this appeared to be a limitation of the training provided for EPs. Rupasinha (2015) reported that EPs often rely upon experience rather than training to support their knowledge. Although Rupasinha (2015) was reporting on cases of CYP with ASD of BME heritage, it would appear that the same can be said for adolescent girls with SCD. Furthermore, Rupasinha (2015) provided a quote from a participant stating that training was closely associated with the perceived priorities of the EPS, which mirrored the information provided during the current research. Within the current research, one participant reflected that she was fortunate that she had received specific training relating to the female presentation with ASD and attributed that to the fact that it was a particular focus of the EPS at the time.

Considering the link with increasing knowledge further, the role of the EP has previously been reported as that of marrying up research and practice (Hoagwood & Johnson, 2003). The ability to apply research to real life situations was reported by participants in the current research as best practice; however, there appears to be a number of barriers to achieving this. EPs reflected on the difficulty of accessing research and the lack of appropriate structure with regard to disseminating the research.

On a number of occasions, a lack of resources appeared to be presenting a barrier to this happening, however research approaches were also discussed, with the transferability and generalisability of certain research being called into question.

Interestingly, within the theme of knowledge, participants elaborated further on the possibility of fulfilling the role of a researcher within their role as a Local Authority EP. Many participants reflected that they had completed large research projects in order to qualify as an EP, however there appeared to be limited opportunity to conduct research once working as an EP. The role of a researcher was not identified as an area within the EP remit during the systematic literature review and the suggestion made by the current research to incorporate such a role contributes to expanding the findings of Hoagwood and Johnson (2003), highlighting a greater role for the EP than simply sharing academic research with others.

#### **- 5.3.3. *Systemic Approach to Working***

Although working on an individual level was regarded as one of the two categories of work which fell within the role of the EP (Greig & MacKay, 2005; Williams et al., 2005), Farrell et al. (2006) reported a shift from individual assessment to systemic working. This appears to be in line with the current research, whereby EPs reported that time was limited for delivering individual therapeutic intervention. However, an area that remains prominent within the role of the EP is the completion of assessment with the intention of adolescent girls with SCD in mainstream education obtaining EHC Plans. This appeared to be an area of contention amongst the participants, with many feeling that this need for assessment limited the possibilities that their involvement presented. It would appear that although EPs wish to shift towards more systemic ways of working, schools still perceive the role of the EP to be that of an individual assessor, similar to the original model of EP practice as established by Cyril Burt in 1913.

It would appear that the participants wished to persevere in creating a more systemic style of working, with many reflecting on systemic elements of their work when supporting adolescent girls with SCD in mainstream education. For example, a number of participants felt that communication was vital when supporting this population and reported the difficulties faced when attempting to work systemically with large, secondary schools where the structure of the school appeared to prevent systemic thinking. Barnard et al. (2002) found that inclusion was more successful

within primary schools and this is likely to be related to the difficulties reported during the current research with regard to effective communication within secondary schools.

Although reported as a barrier, it would appear that EPs are still able to incorporate elements of systemic work within their role in secondary schools. A number of participants mentioned the need to establish a positive working relationship with particular members of staff within their secondary schools in order to ensure that the work of the EP was appropriately disseminated amongst all staff. For example, one participant spoke optimistically about the relationship she had with a particular SENCo, which had resulted in them organising whole staff training on working with CYP with ASD. This appears to be in line with the research presented by Rupasinha (2015) who placed strong emphasis on the importance of positive relationships in order to implement change.

In addition to issues related to working with school staff systemically, Humphrey and Symes (2010) reported that the system around CYP with ASD should be considered in greater depth, proposing that peer education and coaching is required in order to provide effective and appropriate support for this population. This was briefly touched upon by a small number of participants during the current research but it did not appear to be a strong theme within the data. It is possible that this was viewed as having less of an impact on the success of the EP's role than working systemically with other professionals, hence receiving less coverage. However, it is an important area to consider and may benefit from further research.

#### **- 5.3.4. *Presentation, Identification and Diagnosis***

Discussions around presentation, identification and diagnosis all appeared to overlap and seemed extremely relevant when considering the experiences of EPs when working with adolescent girls with SCD in mainstream education. In support of previous research (Egerton & Carpenter, 2016; Kothari et al., 2013; Shefcyk, 2015), the current research highlights the difference in presentation between boys and girls with ASD and SCD. The presentation appeared to vary between cases however, with some behaviour displaying overtly whereas other behaviour appeared to be commonly overlooked. The array of difficulties as described by Cridland et al. (2014) included diagnostic issues, being surrounded by boys, experiences of high school, complexity of adolescent female relationships, puberty and its related issues and sexual relationships and concerns, all of which were mentioned by participants in the current research.

Furthermore, research published by Vine Foggo and Webster (2017) during the time period in which the current research was conducted suggests that adolescent girls have a desire to be sociable. This is an area which was also highlighted in the current research and supports notions of a difference in presentation between males and females with ASD and SCD. Vine Foggo and Webster (2017) conclude that their research “contradicts stereotypes” (Vine Foggo & Webster, 2017, p. 74) and further adds to the need for professionals to gain specific knowledge in the presentation of ASD in the female population.

The co-occurrence of ASD and SCD with other difficulties (Asberg et al., 2010; Egerton & Carpenter, 2016; Mattila et al., 2010) appears to be particularly relevant to the notion of specific behaviours being overlooked within adolescent girls. The participants in the current research spoke about the complexity of the cases they were involved with, stating a range of additional conditions and hypotheses that they had to take into consideration when working with adolescent girls with SCD in mainstream education. Even without the complication of a diagnosis of an additional condition, many participants reflected that simply the developmental stage of adolescence could create barriers in terms of identifying SCD, with many adults attributing the behaviour of this population to being typical of teenagers.

Interestingly, the literature provides a mixed view with regard to comorbidity and ASD. Whereas Dworzynski et al. (2012) found comorbidity contributed to a greater identification of girls with ASD, Turk et al. (2009) found that having a diagnosis of epilepsy delayed the receipt of an ASD diagnosis for girls. Within the current research, the picture continues to present as mixed. Although it would appear that participants felt comorbidity made it harder to identify ASD, it was often reported that EP involvement was commonly requested under the remit of an alternative diagnosis or concern (for example, providing support for an adolescent girl with an eating disorder) and through this, the EP was able to suggest further assessment with regard to ASD and SCD. Therefore, although comorbidity appears to mask signs of ASD, it can lead to more professionals becoming involved, increasing the probability of ASD being identified. Again, the area of comorbidity and its impact upon identification requires further investigation in order for clear conclusions to be drawn.

In terms of diagnosis, both the current research and previous research report that girls appear to receive a diagnosis of ASD later than boys (Begeer et al., 2013; Bolick, 2001; Egerton and Carpenter, 2016; Shefcyk, 2015; Willey, 2003). This was not

consistently reported however, with some participants reflecting that they had only worked with adolescent girls who had already received a diagnosis. Although this could suggest that the diagnostic process within the Outer London Borough in which the research was conducted is therefore successfully identifying girls with SCD at an early age, this seems unlikely based upon anecdotal reports. Alternatively, it might be that the participants had failed to identify potential SCD in the girls with whom they had worked. Another possible explanation for this observation could be the referral model used within the particular Outer London Borough EPS in which the research was conducted. Referrals are made by school staff and so it is possible that a lack of identification at the school level has therefore resulted in adolescent girls with SCD but without a diagnosis of ASD being overlooked by the school when EP referrals are made. Furthermore, the research did not explore in detail the age at which a diagnosis was received for those girls with a diagnosis, so this does not provide enough evidence to support the hypothesis that girls are not diagnosed as early as their male peers. Based upon the identified difference between girls and boys when presenting with ASD, research suggests the diagnostic process needs to be altered to facilitate the more accurate identification of CYP, and girls in particular, with ASD (Kothari et al., 2013; Rivet & Matson, 2011). The current research provides further support for this.

#### **- 5.3.4.1. *The ‘Missing Children’***

The concept of ‘missing children’ at secondary level has been presented within previous research (Barnard et al., 2002) and this has been linked to high levels of exclusions experienced within secondary education (Barnard et al., 2000). To some extent, this has been reflected in the current data, with participants reporting incidences of adolescent girls with SCD in mainstream education experiencing exclusions, as well as qualitative reports of increased numbers of adolescent girls with SCD being referred to alternative education provisions. However, through analysis of the data, it would also appear that there is a perceived lack of communication within secondary schools and so the current research raises the question of whether it is through a lack of communication or miscommunication from primary school to secondary school that cohorts of pupils are not identified as requiring additional support, girls with SCD being one of those cohorts. Russell et al. (2011) reported that often secondary schools do not have records of the SEN of their new intake, supporting this hypothesis. These research findings may go some way towards contributing to Barnard et al.’s (2002) request for “further investigation” (Barnard et al., 2002, p. 25) into the ‘missing children’.

However, more information is needed investigating the transition period and sharing of information between primary and secondary education in order for the ‘missing children’ to be accounted for.

#### **- 5.3.5. *Providing Support***

The need for providing appropriate support presented as a strong theme throughout the data collected during the current research. The importance of supporting CYP, schools and families was highlighted, along with the ability of EPs to cater for this need. This is in line with previous research (Farrell et al., 2006; Gillham, 1978), although within the current research, the participants appeared to present as more confident when asked to discuss the support they can provide for schools and CYP compared to the support they are able to provide for families. Previous research does not appear to recognise this as a potential area requiring further development within the role of the EP.

However, the lack of support available to families as highlighted in the current research does appear to replicate the findings of Cridland et al. (2014) who interviewed the mothers of adolescent girls with a diagnosis of ASD. These mothers reported a lack of support following diagnosis. A number of EPs within the current research also felt there was a lack of support available for the parents of CYP having just received a diagnosis of ASD, mentioning specifically the lack of support for parents with adolescent daughters having just received a diagnosis.

#### **- 5.3.6. *Culture and Politics***

Research into cultural influences surrounding the identification of SCD and ASD appears to be extremely relevant with regard to the current research. A number of participants reported that the only adolescent girls with SCD in mainstream education with whom they had worked, were of White European heritage. These participants appeared not to have reflected on this fact previously and the published research (figure obtained through Local Authority records, not referenced, 2012) states that this does not fit with the ethnic demographic of the Outer London Borough in which the current research was conducted. This is, however, in line with previous research in which Lindsay et al. (2006) reported that Caucasian CYP are more likely to be identified as having ASD than are CYP of South Asian heritage. Rupasinha (2015) reported strong cultural attitudes towards gender and it might be that the current research goes some way to identifying these. It was hoped that the current research would be able to go

further to explore why this might be, however with limited cases of EPs working with adolescent girls with SCD in mainstream education of BME heritage, this proved difficult. One participant described a situation in which SCD were identified by the EP for a child of Brazilian heritage, and an appropriate support plan was proposed. However, the child was then removed from the school by her mother before the support could be implemented. Given that the mother was described as “culturally very pro-education” (Interview 3, line 155), it is interesting to reflect upon how the Brazilian construct of ASD might have impacted on the mother’s decision to withdraw her daughter from the EP’s involvement. A criticism of current diagnostic methods is that assessment tools used are not culturally fair (Desforges et al., 1995), however the current research would suggest that barriers to identifying ASD in CYP of BME heritage present prior to the assessment phase. In contrast to the view presented by the current research, Russell et al. (2011) found that ethnic origin did not appear to influence the diagnosis of ASD in CYP or the likelihood of CYP displaying ASD traits.

In general, there appeared to be a perception that ASD is becoming more socially acceptable within the British culture, with greater dialogue appearing in the media around ASD and SCD. However, a number of participants expressed frustration that changes are not occurring quickly enough. Although this appeared to be attributed to the current socio-political climate, Rupasinha (2015) proposed that it was the responsibility of the EP to challenge the *status quo* and to bring about change, yet this opinion does not appear to be held by EPs themselves. Shefcyk (2015) believed that it was the responsibility of research to challenge public perception. In support of this view, the current research therefore seeks to increase the awareness of ASD and SCD with regard to the female population, therefore presenting a challenge to the cultural belief that ASD is a predominantly male disorder (Sayal et al., 2006).

#### **5.4. Limitations of the Research**

The research has a number of strengths and limitations with regard to the methodology, specifically relating to the recruitment of participants, the collection of data, the analysis of the data and the influence of the researcher.

##### **- 5.4.1. Recruitment**

It is important to acknowledge that all the participants were recruited from the same Outer London Borough EPS. This was felt necessary in order to combine the accounts of each participant during the analysis process so as to provide a richer picture



of the current practice within that specific EPS. However, this also means that caution should be taken when attempting to transfer the results of this research to alternative EPSs. From analysis of the data, it would appear that there are considerable differences in approaches between EPSs, making it even more important to be aware of the limitations of transferability with regard to this data.

#### **- 5.4.2. Data Collection**

The data collection method of completing a focus group followed by individual semi-structured interviews allowed the research to hone in on the specific areas of interest or concern for the participants, without being influenced by the interests of the researcher. Moving from a focus group of five participants to eight individual semi-structured interviews also enabled the research to broaden and to increase its depth and richness with regard to the information gathered.

However, when considering sample size, the focus group which contributed to the generation of the interview schedule only consisted of five members. Following the advice of Morgan (1998), the researcher's initial aim was to recruit between six and eight participants, with the possibility of conducting a second focus group in order to incorporate roughly 12 participants' views. This was not possible due to time restrictions and the availability of those who volunteered to participate. Had more participants contributed towards the focus group it may have influenced the questions that were then constructed for the interview schedule. However, through analysis of the data gathered during the focus group, it was concluded that the data was sufficiently rich to preclude the need for an additional focus group, the latter being unlikely to produce further information. In addition, the researcher was able to secure a range of levels of authority and years of experience for the focus group so this should have also increased the richness of data, controlling for the limited numbers to some extent.

In contrast to the difficulties experienced when recruiting participants for the focus group, the researcher was able to recruit the target number of participants for the individual semi-structured interviews because this aspect of the research offered greater flexibility in terms of time. Again, the characteristics of the participants appeared to cover a range of levels of authority as well as years of experience, hence producing a varied data set and providing a degree of transferability with regard to the data collected.

The use of participants varied between each phase of the research, with some participants taking part in both phases and others just contributing towards one phase. There were concerns that the participants who had completed the focus group might then, to some extent, be influenced by others (Asch, 1956) and provide accounts during the individual semi-structured interviews that had been adapted to correspond with the *status quo* presented during the focus group. Alternatively, participants who had not contributed to the focus group might have found some questions unusual or out of line with their own thinking.

*“There is a worry that non-focus group participants will not have the necessary background information to fully contribute to the interviews, but also focus group participants may now provide more conformist answers having already discussed these questions in a social group.”*

Reflective diary entry, 1<sup>st</sup> August 2016

Given time and sample size constraints, it was decided that the researcher should interview all the participants who volunteered, regardless of which phase of the research they had previously contributed to, whilst remaining conscious of any differences this produced in the data. Through analysis of the data, prior contribution did not appear to have influenced the responses produced by the participants and there did not appear to be significant differences between the responses of those who had been present for the focus group and those who had not. However, it is important to consider the opportunities that participants had to discuss the research away from the focus group. It may have been that a lack of difference between responses was due to private discussions occurring between those who had participated in the focus group and those who had not. However, given the culture of the EPS in which the research was conducted, with the majority of EPs regularly working from home and minimal space to engage in social interactions within the office, it was deemed appropriate to assume that these conversations were unlikely to have taken place and so were unlikely to impact upon the data collected through the individual semi-structured interviews. Therefore, it was possible to include all data gathered from all the interviews, regardless of the level of involvement experienced by each participant. However, it still remains important to acknowledge that this may have had an impact on some of the participants however, and should be taken into consideration when exploring the findings in greater depth.

#### - 5.4.3. Data Analysis

Through the use of thematic analysis (Braun & Clarke, 2006), it was possible to analyse the quantity and range of data collected during the interviews. However, it could be argued that thematic analysis only provides surface level information regarding the experiences of the participants and data such as tone of voice, hesitation and body language are lost. Although this would have added to the richness of the data, it was not deemed appropriate in this instance as this research wished to gather an overview of the experiences of EPs due to it being the first research of its kind. A more thorough analysis technique might be considered necessary if the research were to be repeated or expanded upon.

A further criticism of thematic analysis is that, even when completed using inductive methods, an element of the researcher will always appear in the data and influence the results. The individual semi-structured interview schedule was based upon the analysis of the discussion held during the focus group, in order to remove some bias that the researcher might have exercised when constructing the interview questions. However, the focus group discussion was generated by the presentation of the four research questions and so immediately ideas such as support, other professionals and the possible contribution of the EPS would have been raised and were likely to have influenced the discussions that followed. Again, through the maintenance of a reflective diary, the researcher attempted to reduce the impact that this had on the data, being open about her position and closely following the six phase process of thematic analysis.

*“Phase 1 – familiarise √ Phase 2 – initial codes √ Phase 3 –  
searching for themes → today’s job”*

Reflective diary entry, 3<sup>rd</sup> February 2017

*“I... feel I’ve completed phase 3 appropriately... and can now move  
on to phase 4: reviewing themes”*

Reflective diary entry, 3<sup>rd</sup> February 2017

*“Starting on phase 5 but I feel I haven’t fully completed phase 4 e.g.  
there’s too much overlap within my themes. I’m tempted to collapse  
‘presentation’ so it only has ‘identifiable’ and ‘overlooked’ but will I  
lose the detail regarding cultural differences and diagnosis?”*

Reflective diary entry, 10<sup>th</sup> February 2017

#### **- 5.4.4. Reflexivity**

This research was influenced by the researcher's own interest in ASD and her personal experience of girls being less frequently identified as well as her awareness that adolescence is a particularly difficult period of time for any young adult, let alone someone who has additional needs. The passion felt by the researcher around this subject appeared to contribute towards encouraging EPs within the Service to participate in the research, as it was possible to argue a genuine need for the research. However, it is important to reflect upon the fact that, as all the participants knew the researcher to some extent, they may have been influenced by their knowledge of the researcher's past experiences and therefore motivated to provide accounts of experiences that were in keeping with those of the researcher's.

Throughout the research, the researcher kept a reflective diary to record and acknowledge moments when she became aware of her own biases and how they might be impacting on the data. Identified areas of vulnerability with regard to the researcher influencing the research included during data collection, and the impact that the researcher had on the participants, as well as during data analysis, during which the researcher consciously monitored her coding to ensure it was a true representation of the original transcript, rather than an interpretation shaped around what the researcher felt or believed.

*"I'm becoming increasingly aware of my own thoughts and feelings on the topic and how I am (almost unconsciously) incorporating my own views into my codes by being selective about how much of the transcript I take as my code."*

Reflective diary entry, 22<sup>nd</sup> December 2016

#### **5.5. Implications for Future Research**

The research findings build on, to some extent, the research conducted by Cridland et al. (2014), in that it presents an additional voice to those of adolescent girls and their mothers. However, as Cridland et al.'s (2014) research was conducted in Australia, it would be beneficial if the current research could be extended to incorporate adolescent girls and their families within the Outer London Borough in which the research was conducted. Not only would this provide an account of the experiences of this population within the UK but it would also facilitate the triangulation of data by reporting the experiences of adolescent girls, their families and the EP. In addition, the views of secondary school staff might also be helpful in expanding the research further,

with a particular focus upon future support for adolescent girls with SCD in mainstream education.

Over and above this, it might be informative to reproduce the current research within another Local Authority EPS. As a number of participants reflected on the difference between EPSs, it would be useful to explore the impact that that would have on the overall data analysis. In so doing, it might be possible to conclude that the current research has greater transferability than it is currently assumed to have. However, it is also important to acknowledge that the EPS in which the research was conducted placed a large focus on the requirement of specific diagnoses in order to access particular support. This appeared to be reflected in the narratives provided by the participants during the current research. It is therefore likely that the emphasis placed on diagnosis might reduce if the research were to be conducted in an alternative Local Authority EPS.

#### **5.6. Application to the Role of the EP**

From the research, it is possible to conclude that working with adolescent girls with SCD in mainstream education definitely falls within the remit of the role of the EP. However at present, it is felt that not enough is being done by EPs and EPS to fulfil this role and to fully support this population.

One area highlighted by the research was the frequency at which girls appeared to be overlooked with regard to SCD and ASD. It would appear that EPs often have the greatest knowledge of the presentation of SCD in the female population and this knowledge needs to be disseminated across other professions. For that reason, the current research suggests that EPs should become more vocal in expressing concerns regarding overlooked girls. This could include delivering training on the presentation of adolescent girls with SCD. In addition, EPs could become more proactive on a day to day basis, by raising questions regarding the identification of SCD during planning meetings with schools and through conversations with other professionals.

The research also looked beyond the role of the EP and considered implications for EPSs and Local Authorities. There appeared to be discrepancies around the services and support on offer between Local Authorities, with EPs placing greater value on the Local Authorities that were able to provide specific support for those with SCD and ASD. The importance of research in guiding practice was also spoken about by participants and it would appear that access to research is essential for EPs, although not

always available. Responsibility for accessing research appeared to fall to the senior leadership team within the EPS and so this is an area that should receive greater attention in the future from Principal and Senior EPs.

### **5.7. Reflection**

Through the research process, the researcher has been able to develop her reflexive skills. This has been achieved through the active completion of a reflective diary, encouraging regular reflections on the work that was being undertaken as well as the impact that that was having on the researcher as well as those around them. Not only did this allow the researcher to become more aware of the impact that she was having on participants and vice versa, but through the recognition of this, the researcher has been able to develop greater reflexivity within her role as a TEP, becoming more sensitive to the reactions and responses of the CYP, parents and school staff that she worked with on a regular basis.

Furthermore, the research has brought to the forefront the importance of raising awareness with regard to the female population and SCD/ASD. It would appear that although EPs are aware of this population and the support they require, other professionals are often less so. As a practising TEP, the researcher could reflect upon the number of occasions on which she had been able to promote the recognition and support for adolescent girls with SCD and subsequently endeavoured to discuss this cohort to a greater extent within her role.

### **5.8. Conclusion**

This research aimed to explore the experiences of EPs when working with adolescent girls with SCD in mainstream education in order to guide future EP practice. Through the completion of a focus group and individual semi-structured interviews, it would appear that there were five key themes within the role of the EP that contributed towards supporting adolescent girls with SCD in mainstream education; namely understanding presentation, providing support, knowledge, resources and working with others.

The themes identified as being instrumental in working with adolescent girls with SCD in mainstream education appeared to relate closely to that of previous research. Although the current research is the first of its kind to focus specifically on EPs' experiences of working with adolescent girls within mainstream school, it is possible to compare the findings to research conducted through interviews of adolescent

girls with ASD and their mothers (Cridland et al., 2014) as well as research on the role of the EP in relation to other difficulties (Rupasinha, 2015). The current research therefore allows for a triangulation of data and supports previous findings.

Limitations to the current research include its transferability. In order to analyse all the interviews as one data set, it was important that the participants reflected upon experiences within the Outer London Borough EPS in which the research was conducted. However, through analysis, it became apparent that there are large variations between EPSs and so, had a range of Local Authority EPSs been involved in the research, themes might have presented differently.

Furthermore, although the current research aimed to advocate for adolescent girls with SCD in mainstream education to some extent, it was unable to meet the criteria for emancipatory research as the young people themselves were not directly involved in the research. Although the research aims to make inferences on the experiences of adolescent girls with SCD in mainstream education through the exploration of the experiences of EPs, it is important to remember that the findings are that of the EPs' experiences rather than the girls themselves. However, as previously mentioned, the ability to triangulate findings with those of previous research would suggest that the conclusions drawn from the current research do fall in line with the experiences of adolescent girls as reported in person. Further research may be beneficial however, focusing upon the views of adolescent girls themselves, in order to identify the similarities and differences between the experiences of EPs and that of the young people.

Although the research is unable to provide an accurate account of the experiences of adolescent girls themselves, it is important to acknowledge that the research does provide a detailed analysis of the experiences of EPs when working with adolescent girls with SCD and this allows for implications to be made around the future practice of EPs. Implications for future practice include the continued need to raise the profile of adolescent girls with SCD in order to support earlier identification. This should involve targeting educational professionals and upskilling staff members through increasing their knowledge of SCD, as well as expanding the role of EPs to include considering the socio-political climate, in an attempt to influence the current *status quo* with regard to ASD and SCD.

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## **Appendices**

# Appendix 1.

A table summarising the research papers included in the systematic literature review, along with an analysis of their strengths and weaknesses.

Research paper	Description	Strengths	Weaknesses
*Egerton, J., & Carpenter, B. (2016). <i>Girls and Autism: Flying under the radar. A quick guide to supporting girls with autism spectrum conditions</i> . Staffordshire: Nasen.	A published guide on supporting girls with ASD.	<ul style="list-style-type: none"> <li>• This paper highlights the necessity for information to be provided that is gender specific to girls.</li> <li>• The guide provides practical advice that can be applied to real life situations and therefore has face validity.</li> <li>• Further areas of research are identified in order to increase knowledge of ASD in the female population.</li> </ul>	<ul style="list-style-type: none"> <li>• As a published guide, information regarding the methodology and literature review search criteria are missing from the information provided.</li> <li>• Occasional case studies are provided as examples of girls with ASD. These lack generalisability.</li> </ul>
Rupasinha, J. (2015). Addressing an imbalance? Educational psychologists' considerations of	An investigation into the ways in which EPs consider ethnic minority	<ul style="list-style-type: none"> <li>• Findings were triangulated with analysis of the local demographic statistics and</li> </ul>	<ul style="list-style-type: none"> <li>• The multiple embedded case study consisted of a sample size of three EPs, only one</li> </ul>

ethnic minority cultural factors in assessments for autistic spectrum condition. <i>Educational and Child Psychology</i> , 32(2), 77 – 88.	cultural factors in the identification of ASD.	<p>Local Authority procedures for ASD assessments.</p> <ul style="list-style-type: none"> <li>• The study indicates a gap between psychological knowledge and practice, highlighting opportunities for future research.</li> </ul>	<p>of which worked within a Local Authority EPS, reducing the generalisability to the current research.</p> <ul style="list-style-type: none"> <li>• There is an element of overlap between the themes identified, with some themes appearing to cover a broad range, applicable beyond ethnic minority cultural factors.</li> </ul>
Shefcyk, A. (2015). Editorial. Count us in: Addressing gender disparities in autism research. <i>Autism</i> , 19(2), 131 – 132.	An editorial for <i>Autism</i> , focusing upon gender differences with regard to ASD.	<ul style="list-style-type: none"> <li>• The editorial draws on a range of published research to illustrate key points.</li> </ul>	<ul style="list-style-type: none"> <li>• The editorial has been written with the purpose of encouraging its audience to continue reading the journal, hence there is an element of emotive language within the article.</li> </ul>
Cridland, E.K., Jones, S.C., Caputi, P., & Magee, C.A. (2014). Being a	A study exploring the experiences of adolescent	<ul style="list-style-type: none"> <li>• The research appropriately identifies a clear rationale for</li> </ul>	<ul style="list-style-type: none"> <li>• The research is based in Australia. Therefore,</li> </ul>

<p>girl in a boy's world: Investigating the experiences of girls with autism spectrum disorders during adolescence. <i>Journal of Autism and Developmental Disorders</i>, 44, 1261 – 1274.</p>	<p>girls with ASD through interviewing adolescent girls with ASD and their mothers.</p>	<p>the study, supported by evidence.</p> <ul style="list-style-type: none"> <li>• The research focuses entirely on the female population and provides an in-depth account of the difficulties experienced by girls.</li> <li>• Consideration was taken with regard to reducing the anxiety of the participants through conducting the interviews within the participants' homes, meaning more detailed accounts were likely to be presented.</li> <li>• The research team conducted credibility checks throughout the data analysis process.</li> <li>• The research identifies areas of need for further research.</li> </ul>	<p>findings cannot be generalised to the UK population.</p> <ul style="list-style-type: none"> <li>• Each girl had a formal diagnosis of ASD and so caution must be taken when generalising the findings to adolescent girls with SCD.</li> <li>• Based upon the chosen research method, the voices of the mothers were stronger than the voices of the girls themselves.</li> <li>• Although the researchers identified a lack of research around the female presentation of ASD, hence providing a rationale for this study, they did not have a matched group of male</li> </ul>
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			<p>participants, meaning that any differences reported had to be through speculation and via the support of previous research.</p>
<p>Horiuchi, F., Oka, Y., Uno, H., Kawabe, K., Okada, F., Saito, I., Tanigawa, T., &amp; Ueno, S. (2014). Age- and sex-related emotional and behavioral problems in children with autism spectrum disorders: Comparison with control children. <i>Psychiatry and Clinical Neurosciences</i>, 68, 542 – 550.</p>	<p>Research into the influence of age on EBD when co-occurring with ASD, drawing comparisons between the male and female population.</p>	<ul style="list-style-type: none"> <li>• The research takes into consideration gender and age as well as incorporating a control sample within the study.</li> <li>• The researchers identify the appropriate steps needed with regard to future research in order to combat the main limitations of their study.</li> </ul>	<ul style="list-style-type: none"> <li>• The sample contained participants with a clinical diagnosis of ASD hence this research does not directly relate to the current research.</li> <li>• Sample sizes were small; particularly with regard to adolescents with ASD and female participants.</li> <li>• EBD behaviour was rated based upon a questionnaire completed by parents where perceptions can be</li> </ul>

			influenced by previous experiences.
Domellöf, E., Hedlund, L., & Ödman, P. (2014). Health-related quality of life of children and adolescents with functional disabilities in a northern Swedish county. <i>Quality of Life Research</i> , 23, 1877 – 1882.	Research into the health-related quality of life for CYP with a variety of disabilities including intellectual disabilities, ASD, movement disorders and hearing disabilities.	<ul style="list-style-type: none"> <li>• The research used a questionnaire which had been vigorously tested to ensure reliability and validity.</li> </ul>	<ul style="list-style-type: none"> <li>• The research is based in Sweden. Therefore, findings cannot be generalised to the UK population.</li> <li>• The sample size with regard to female participants was extremely small.</li> <li>• The data collection method relied on self-report which can prove inaccurate if participants do not fully understand what is being asked of them.</li> <li>• Data was collected in the absence of a researcher so participants could not seek clarification. In some</li> </ul>

			instances, parents were encouraged to answer on behalf to their child, reducing the reliability of the data collected.
Kothari, R., Skuse, D., Wakefield, J., & Micali, N. (2013). Gender differences in the relationship between social communication and emotion recognition. <i>Journal of the American Academy of Child and Adolescent Psychiatry</i> , 52(11), 1148 – 1157.	An investigation into emotion recognition in CYP with and without SCD, stratified by gender and age.	<ul style="list-style-type: none"> <li>• This research has applications to real life practice.</li> <li>• A control sample of boys with and without ASD was recruited in order for direct comparisons to be made.</li> <li>• A longitudinal study allows comparisons to be made over time without attempting to recruit a matched sample.</li> <li>• Participants within the ASD sample showed traits of ASD, rather than having obtained a formal diagnosis, increasing the generalisability of</li> </ul>	<ul style="list-style-type: none"> <li>• Cultural and socioeconomic factors were not taken into consideration in this research.</li> <li>• Parental report was used to determine whether each participant was displaying traits of ASD, which can be an unreliable method.</li> </ul>

		findings to the current research.	
Stampoltzis, A., Papatrecha, V., Polychronopoulou, S, & Mavronas, D. (2012). Developmental, familial and educational characteristics of a sample of children with Autism Spectrum Disorders in Greece. <i>Research in Autism Spectrum Disorders</i> , 6, 1297 – 1303.	An exploration of gender ratio, age of diagnosis, educational setting and comorbidity in a sample of CYP with an ASD diagnosis.	<ul style="list-style-type: none"> <li>• The research provides statistics in relation to the specific area in which the study was conducted, which can then be directly compared to research produced from other areas of the world.</li> <li>• An application to real life practice is highlighted through the figures produced.</li> </ul>	<ul style="list-style-type: none"> <li>• The research is based in Greece. Therefore, findings cannot be generalised to the UK population.</li> <li>• The sample contained participants with a clinical diagnosis of ASD hence this research does not directly relate to the current research.</li> <li>• Variables such as cognitive level, language skills and social adaptability were not measured or taken into consideration.</li> <li>• The researchers overlooked the influence of societal norms on the findings.</li> </ul>



<p>Russell, G., Steer, C., &amp; Golding, J. (2011). Social and demographic factors that influence the diagnosis of autistic spectrum disorders. <i>Social Psychiatry and Psychiatric Epidemiology</i>, 46, 1283 – 1293.</p>	<p>An examination of the impact of social and demographic factors during the ASD diagnosis process.</p>	<ul style="list-style-type: none"> <li>• Further research has been conducted, supporting these findings.</li> <li>• A control group was provided which encompassed children of similar severity but who had not received a diagnosis of ASD.</li> <li>• The researchers were able to report a degree of reliability within their data with regard to ASD diagnosis.</li> </ul>	<ul style="list-style-type: none"> <li>• The research overlooks the impact that depression rates would have on the male population as well as the female population.</li> <li>• The participants of the study were not matched in terms of diagnosed and undiagnosed ASD and overall, there was an extremely small female sample.</li> <li>• Comorbidity of disorders was also not acknowledged or accounted for.</li> </ul>
<p>Asberg, J., Kopp, S., Berg-Kelly, K., &amp; Gillberg, C. (2010). Reading comprehension, word decoding and spelling in girls with autism spectrum disorders (ASD) or</p>	<p>An investigation into the literacy abilities of girls with ASD and ADHD</p>	<ul style="list-style-type: none"> <li>• The research highlights the necessity to focus specifically on the female population.</li> <li>• The research used a matched control group.</li> </ul>	<ul style="list-style-type: none"> <li>• The research is based in Sweden. Therefore, findings cannot be generalised to the UK population.</li> </ul>

attention-deficit/hyperactivity disorder (AD/HD): performance and predictors. <i>International Journal of Language and Communication Disorders</i> , 45(1), 61 -71.	compared to the typically developing population.	<ul style="list-style-type: none"> <li>• Measures for ADHD were obtained through teacher and parent report.</li> <li>• The participants did not have to have received a formal diagnosis of ASD in order to participate.</li> </ul>	<ul style="list-style-type: none"> <li>• The sample size with regard to girls with a diagnosis of ASD was small.</li> <li>• The girls displayed a mixed presentation, with traits of ADHD also displaying in the girls with ASD.</li> <li>• The research was unable to use the same testing method for all ages, bringing into question validity to some extent.</li> </ul>
Assoline, S.G., Foley Nicpon, M., & Doobay, A. (2009). Profoundly gifted girls and autism spectrum disorder: A psychometric case study comparison. <i>Gifted Child Quarterly</i> , 53(2), 89 – 105.	A case study investigating the relationship between extreme giftedness and social difficulties when comparing profoundly gifted girls with and without ASD.	<ul style="list-style-type: none"> <li>• The research wishes to have practical applications in terms of bridging the gap between clinical and educational practices.</li> <li>• Data was gathered from a variety of different sources,</li> </ul>	<ul style="list-style-type: none"> <li>• Using a case study methodology, only two girls participated in the research, reducing generalisability.</li> </ul>

		providing a more detailed account of experiences.	
Turk, J., Bax, M., Williams, C., Amin, P., Eriksson, M., & Gillberg, C. (2009). Autism spectrum disorder in children with and without epilepsy: impact on social functioning and communication. <i>Acta Paediatrica</i> , 98, 675 – 681.	Research on the developmental and psychological functioning of CYP with ASD, with and without epilepsy.	<ul style="list-style-type: none"> <li>• The research used a between-group design and matched participants based upon age and verbal ability.</li> <li>• This is the first study of its kind to compare CYP with ASD, with and without epilepsy and so appropriately contributes to a gap within the literature.</li> <li>• It also successfully highlights areas of exploration with regard to future research.</li> </ul>	<ul style="list-style-type: none"> <li>• The sample size was relatively small, especially with regard to female participants.</li> <li>• Participants within the ASD group had a formal diagnosis of ASD and so results cannot be directly compared to the cohort being discussed in the current research.</li> <li>• The participants attended a range of different educational provisions so results cannot be generalised to experiences of mainstream education.</li> </ul>

			<ul style="list-style-type: none"> <li>• The research does not explore gender differences specifically and therefore fails to make links between the later diagnosis within the ASD plus epilepsy group and the higher proportion of female participants.</li> </ul>
<p>MacKay, T., Knott, F., &amp; Dunlop, A. (2007). Developing social interaction and understanding in individuals with autism spectrum disorder: A groupwork intervention. <i>Journal of Intellectual and Developmental Disability</i>, 32(4), 279 – 290.</p>	<p>An investigation into groupwork as an intervention for promoting social skills in CYP with ASD.</p>	<ul style="list-style-type: none"> <li>• All participants were attending mainstream education, hence relating to the current research.</li> <li>• Project leaders were required to meet regularly, ensuring intervention fidelity between groups.</li> <li>• The research has practical applications to real life and is structured in a way that other</li> </ul>	<ul style="list-style-type: none"> <li>• The sample contained participants with a clinical diagnosis of ASD hence this research does not directly relate to the current research.</li> <li>• The female sample within this research was extremely small.</li> <li>• The researchers set an arbitrary cut off of participants having attended</li> </ul>

		intervention leaders can be guided by.	<p>50% of the sessions in order to contribute data.</p> <ul style="list-style-type: none"> <li>• Follow up interviews were held with the parents but not the participants themselves.</li> <li>• The research was unable to provide a control group.</li> </ul>
Soppitt, R. (2006). Clinical observations in children with autistic spectrum disorders. <i>Autism</i> , 10(4), 429.	An open letter discussing the observations of the researcher with regard to CYP with ASD.	<ul style="list-style-type: none"> <li>• The letter draws attention to the specific difficulties experienced by girls with ASD.</li> </ul>	<ul style="list-style-type: none"> <li>• Minimal research is offered in order to support the claims of the letter.</li> </ul>
Greig, A., & MacKay, T. (2005). Asperger's Syndrome and cognitive behaviour therapy: New applications for educational psychologists. <i>Educational and Child Psychology</i> , 22(4), 4 – 15.	A case study exploring the use of Cognitive Behaviour Therapy with a secondary school boy with Asperger's Syndrome.	<ul style="list-style-type: none"> <li>• Data was gathered through a variety of methods.</li> <li>• The research allows for a flexible intervention to be evaluated, with the possibility of an application to future practice for EPs.</li> </ul>	<ul style="list-style-type: none"> <li>• This study has limited generalisability as it is a single participant case study.</li> <li>• The participant used for the study was male and only just entering adolescence, hence unrelated to the population</li> </ul>

		<ul style="list-style-type: none"> <li>• The research has been supported by previous research, using groups of CYP rather than through a single case study methodology.</li> <li>• The research suggests a number of alterations that may be made to the role of the EP in light of the research in order to promote positive practice.</li> </ul>	<p>focused upon in the current research.</p> <ul style="list-style-type: none"> <li>• As the research took place over a number of sessions and without the presence of a control group, it is difficult to attribute any changes to the intervention alone.</li> </ul>
Williams, S.K., Johnson, C., & Sukhodolsky, D.G. (2005). The role of the school psychologist in the inclusive education of school-age children with autism spectrum disorders. <i>Journal of School Psychology, 43</i> , 117 – 136.	A review into best EP practice with regard to providing support for CYP with ASD in inclusive education.	<ul style="list-style-type: none"> <li>• The paper provides a range of areas in which CYP with ASD require support and specifies exactly how that support should look if provided by an EP.</li> <li>• The paper therefore has practical implications for the</li> </ul>	<ul style="list-style-type: none"> <li>• The research is based in America and so discusses the role of the school psychologist. Therefore, caution must be taken when drawing comparisons between this research and</li> </ul>

		role of the EP with working with CYP with ASD.	<p>the role of the EP within the UK.</p> <ul style="list-style-type: none"> <li>• A methodology is not provided so it is not possible to know how the review was conducted and which search terms were used.</li> </ul>
<p>*Barnard, J., Broach, S., Potter, D., &amp; Prior, A. (2002). <i>Autism in schools: Crisis or challenge?</i> London: The National Autistic Society.</p>	<p>An expansion on previous research (Barnard, Prior &amp; Potter, 2000), gathering the views of teachers with regard to CYP with ASD.</p>	<ul style="list-style-type: none"> <li>• The researchers received a high response rate for a postal survey.</li> <li>• The research looked beyond need to consider support available.</li> <li>• The research identifies a need for EP involvement and hence provides a clear rationale for the current research.</li> </ul>	<ul style="list-style-type: none"> <li>• The survey did not specifically focus on the female population.</li> <li>• Recommendations made featured the role of the EP but were not specific to the role of the EP.</li> </ul>

<p>*Barnard, J., Prior, A., &amp; Potter, D. (2000). <i>Inclusion and autism: Is it working?</i> London: The National Autistic Society.</p>	<p>A survey into inclusion as seen by parents of school aged children with ASD, parents of adults with ASD and the CYP themselves.</p>	<ul style="list-style-type: none"> <li>• The researchers received a high number of responses.</li> <li>• The research highlights a difference in provision between primary and secondary education, supporting the need for further research in this area.</li> <li>• Participant details are provided when related to specific quotes in order to establish the position held by the participant and the level of severity of ASD in that circumstance.</li> <li>• A pilot study was completed prior to the survey being sent out to ensure the questions were appropriately targeting inclusive practice.</li> </ul>	<ul style="list-style-type: none"> <li>• The research does not explore the female population specifically.</li> <li>• Little emphasis is placed on the role of the EP or recommendations for shaping EP practice.</li> <li>• Very few responses were from the CYP themselves and those that were only incorporated high functioning CYP.</li> </ul>
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<p>Gross, J. (1994). Asperger Syndrome: A label worth having? <i>Educational Psychology in Practice</i>, 10(2), 104 – 110.</p>	<p>A review of the impact of receiving a diagnosis of Asperger's Syndrome, with a specific focus on the involvement of EPs.</p>	<ul style="list-style-type: none"> <li>• A detailed account is provided for the presentation of Asperger's Syndrome in a variety of contexts.</li> </ul>	<ul style="list-style-type: none"> <li>• The paper does not investigate the female population specifically.</li> <li>• This paper is now extremely outdated, especially since the removal of the diagnosis of Asperger's Syndrome from the DSM 5 (APA, 2013).</li> </ul>
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## Appendix 2.

The excerpt of the transcription of the focus group.

- 235 P3: In... in the ones that I've known. But this was in my previous job where they'd more  
236 likely feature for me because I was linked to social care umm. And it does become external,  
237 extreme defiance in class, will get physical and fights with peers, physical fights with peers.  
238
- 239 P9: Yes, I've had a few of those. More of those than of the int... you know, internalising.  
240
- 241 P3: Yeh, yeh, I... it's always been mor... But then I wonder if there's a developmental  
242 pattern. That would be very interesting.  
243
- 244 P10: I've had more anx... anxious girls umm that have been pushed into sort of extremes  
245 of anxiety so... and... and then when they become extreme in their anxiety then they  
246 become a concern to the school. But they've had to become quite extreme to be, you  
247 know...  
248
- 249 P4: Register on the...
- 250
- 251 P10: Yeh, yeh.  
252
- 253 P1: I think that's probably been my... That's kind of captured my experience in terms of  
254 why so many girls have been raised with me in this short time that I've been qualified, and  
255 the question of ASD... social communication difficulties is... has been raised, is it stemming  
256 from anxiety? And often I've wondered about... sometimes about the usefulness of saying  
257 ASD because... because there have been other things and other factors around their anxiety  
258 and their expressions of anxiety and their experiences of anxiety than simply... And I've  
259 found it's maybe has become a little bit comfortable to just pin it and peg it onto something,  
260 rather than going "wow, OK what is actually this about" because this... this goes... And this  
261 is about lots of different things that we need to explore.  
262
- 263 P10: I find the girls that I've been working with have their own internal template of how  
264 the world should be and they become much more anxious at the more the world differs  
265 from their template. And it... it seems to happen more in adolescence because things  
266 become much less certain, the conversations among their peers become faster, they use  
267 shorthand don't they, and it becomes...  
268
- 269 P1: The peers become much more relevant than the parents and that...
- 270
- 271 P10: Yeh. And their templates sort of go to fit it's... it's really challenged and they become  
272 anxious and... Because things are not how they should be.  
273
- 274 P3: Yeh. And that's the developmental bit I wonder about. Because in primary, at the  
275 end of the day there's... there's a lot more that's... that's within control, I guess. You know,  
276 the... it's pretty much the same routine and structure every day, you've got 1 class teacher  
277 and you go to high school and there's a number of relationships you have to...  
278
- 279 P10: ... Manage.  
280

## Appendix 3.

The interview schedule constructed for use during the individual semi-structured interviews.

### Introductory comments

“Thank you for being willing to take part in a follow up interview to the previous [focus group]. Can I first of all assure you that you will remain completely anonymous and no records of the interview will be kept with your name on” (Robson, 2011, p. 286).

This interview wishes to explore in more detail some of the areas of interest that were raised during the focus group and shall take roughly one hour. In order to protect the identity of schools and individuals, please can you avoid using names during the interview. Pseudonyms may be used instead.

### Questions

#### **Lived experiences**

1. Tell me about a time when you have worked in mainstream education with adolescent girls with unidentified social communication difficulties.
  - In what way did these girls present behaviourally and socially?
  - Can you give me an example of the remit given by the school when you were asked to work with these girls?
  - Since qualifying as an EP, have you noticed any changes in the common discourse around adolescent girls and social communication difficulties?
2. What cultural factors did you feel you had to consider when embarking on this work (e.g. parental consent, school systems, CYP views)?
  - Did anyone feel differently to you about the situation?

#### **Role of the EP**

3. How do you feel your role as an EP fits with cases of adolescent girls with social communication difficulties in mainstream education?
  - Do you believe this is a view held by other professions (including school staff)?
4. Tell me about the ideal role of the EP with regard to adolescent girls with social communication difficulties in mainstream education and how this differs from real life practice.
  - Have you ever experienced a conflict between the ideal and real life role of the EP with regard to this cohort of girls?
  - Do you feel this is specific to adolescent girls with social communication difficulties or does it extend further with regard to the role of the EP?
5. Are there specific needs of adolescent girls with social communication difficulties in mainstream education that you feel the role of the EP currently fails to address?
  - Are there any other professionals who you feel hold a position whereby they should also address these areas of need?

#### **Appropriate and effective support**

6. Tell me about strategies that you have used to appropriately and effectively support adolescent girls with social communication difficulties in mainstream education.
  - How were you able to identify that your strategies were appropriate and effective?
  - What was it about your strategies that meant this support was appropriate and effective?
7. Which other professionals/agencies do you believe should be involved in supporting adolescent girls with social communication difficulties in mainstream education?
  - What is your experience of the diagnostic process and the support offered to families following diagnosis?
  - Have any other professionals been involved in providing support (at any stage) in the cases that you have mentioned?
  - Whose responsibility do you think it should be to incorporate all appropriate professionals/agencies in providing support to adolescent girls with social communication difficulties in mainstream education?

### **Support provided through the EPS**

8. What training have you received on supporting adolescent girls with social communication difficulties in mainstream education?
  - How was this training arranged/how did this training come about?
  - What impact did you find the training had on your practice?
9. In what way do you feel research contributes to your role as an EP when working with adolescent girls with social communication difficulties in mainstream education?
  - In what ways, if any, do you feel the EPS could be more supportive of accessing research?
  - In what ways, if any, do you feel the EPS could be more supportive of contributing to research?
10. What do you think is most important when working to support adolescent girls with social communication difficulties in mainstream education?
11. Do you have any questions or additional comments you would like to add?

### Closing comments

Thank you for volunteering to participate in my research. Your answers have been extremely useful and will hopefully contribute to a shift in perception regarding adolescent girls with social communication difficulties in mainstream education.

Your data will remain anonymous and shall be stored securely. If you wish to withdraw from the research you have the right to request that your data is destroyed up until I begin data analysis which shall commence in August 2016.

Once again, many thanks.

**School of Psychology Research Ethics Committee**

**NOTICE OF ETHICS REVIEW DECISION**

**For research involving human participants**  
BSc/MSc/MA/Professional Doctorates in Clinical, Counselling and Educational Psychology

**REVIEWER:** John Turner

**Course:** Professional Doctorate in Educational and Child Psychology

**STUDENT:** Amy Such

**SUPERVISOR:** Tina Rae

**Title of proposed study:** What are the lived experiences of educational psychologists when working with adolescent girls in mainstream education with social communication difficulties? An exploratory study.

**DECISION OPTIONS:**

1. **APPROVED:** Ethics approval for the above named research study has been granted from the date of approval (see end of this notice) to the date it is submitted for assessment/examination.
2. **APPROVED, BUT MINOR AMENDMENTS ARE REQUIRED BEFORE THE RESEARCH COMMENCES** (see Minor Amendments box below): In this circumstance, re-submission of an ethics application is not required but the student must confirm with their supervisor that all minor amendments have been made before the research commences. Students are to do this by filling in the confirmation box below when all amendments have been attended to and emailing a copy of this decision notice to her/his supervisor for their records. The supervisor will then forward the student's confirmation to the School for its records.
3. **NOT APPROVED, MAJOR AMENDMENTS AND RE-SUBMISSION REQUIRED** (see Major Amendments box below): In this circumstance, a revised ethics application must be submitted and approved before any research takes place. The revised application will be reviewed by the same reviewer. If in doubt, students should ask their supervisor for support in revising their ethics application.

**DECISION ON THE ABOVE-NAMED PROPOSED RESEARCH STUDY**  
(Please indicate the decision according to one of the 3 options above)

APPROVED

## Appendix 5.

The briefing sheet given to the participants prior to participating in the research.

### UNIVERSITY OF EAST LONDON

School of Psychology  
Stratford Campus  
Water Lane  
London E15 4LZ

#### **The Principal Investigator**

Amy Such

Contact details: [work email] and [work phone number]

#### **Consent to Participate in a Research Study**

The purpose of this letter is to provide you with the information that you need to consider in deciding whether to participate in a research study. The study is being conducted as part of my Professional Doctorate in Educational and Child Psychology at the University of East London.

#### **What are the experiences of educational psychologists when working with adolescent girls with social communication difficulties in mainstream education? An exploratory study.**

The main purpose of this research is to explore the lived experiences of educational psychologists (EPs) when working with adolescent girls with social communication difficulties in mainstream education. The research stems from increased concern regarding adolescent girls' vulnerability to exclusion from mainstream education as a result of social communication difficulties which present themselves as behavioural difficulties (Barnard, Prior & Potter, 2000). The research hopes to explore practice within [Local Authority] Educational Psychology Service (EPS), hence you have been invited to participate in the research as a practicing EP within [Local Authority] EPS.

#### **What does the research involve?**

1. Initially you will be asked to participate in a focus group with between six and eight other [Local Authority] EPs. The focus group will focus on experiences you have had working with adolescent girls in mainstream school with social communication difficulties. Information gathered from the focus groups will contribute towards an interview schedule.
2. Between eight and ten participants will then be selected to participate in semi-structured interviews with the researchers. Participants will be selected based upon experience and availability.

Although there is no direct benefit to you for participating, it is hoped that by feeding back the findings of the research, [Local Authority] EPS will reevaluate its approach to working with adolescent girls with social communication difficulties in mainstream education and implement changes to ensure this population of students is being identified and supported as early as possible, reducing their vulnerability to exclusion and subsequently their vulnerability heading into adult life.

## **Confidentiality of the Data**

Data will be collected through audio recordings which will then be transcribed. Audio recordings and transcriptions will be kept on a remote hard drive and stored in a locked cupboard with only the researcher and research supervisor having access. Following the transcription of the audio recordings, they shall be destroyed. Transcriptions shall be kept for up to two years, in keeping with Data Protection policies, to allow for publication and further cross-referencing of the data, as is deemed appropriate. Following this, the transcriptions shall be destroyed.

To protect the identify of the participants, pseudonyms will be used when referring to individual semi-structured interviews and confidentiality and anonymity surrounding individual pupils and schools will be maintained by ensuring all interviews remain anonymous throughout.

## **Location**

The research shall be conducted within the Local Authority of [Local Authority], either within [name of office] or [name of office], depending on availability and preference of the participant.

## **Disclaimer**

You are not obliged to take part in this study and should not feel coerced. You are free to withdraw at any time. Should you choose to withdraw from the study, you may do so without disadvantage to yourself and without any obligation to give a reason. Should you withdraw, the researcher reserves the right to use your anonymised data in the write-up of the study and any further analysis that may be conducted by the researcher.

Please feel free to ask me any questions. If you are happy to continue you will be asked to sign a consent form prior to your participation. Please retain this invitation letter for reference.

If you have any questions or concerns about how the study has been conducted, please contact the study's supervisor, Dr Tina Rae, School of Psychology, University of East London, Water Lane, London, E15 4LZ. Email: [t.m.rae@uel.ac.uk](mailto:t.m.rae@uel.ac.uk).

**or**

Chair of the School of Psychology Research Ethics Sub-committee: Dr Mark Finn, School of Psychology, University of East London, Water Lane, London, E15 4LZ. Tel: 020 8223 4493. Email: [m.finn@uel.ac.uk](mailto:m.finn@uel.ac.uk).

Thank you in anticipation.

Yours sincerely,



Amy Such  
1st February 2016

Appendix 6.

The consent sheet given to the participants prior to participating in the research.

UNIVERSITY OF EAST LONDON

**Consent to participate in a research study**

**What are the experiences of educational psychologists when working with adolescent girls with social communication difficulties in mainstream education? An exploratory study.**

I have read the information sheet relating to the above research study and have been given a copy to keep. The nature and purposes of the research have been explained to me, and I have had the opportunity to discuss the details and ask questions about this information. I understand what is being proposed and the procedures in which I will be involved have been explained to me.

I understand that my involvement in this study, and particular data from this research, will remain strictly confidential. Only the researcher involved in the study will access to identifying data. It has been explained to me what will happen once the research study has been completed.

I hereby freely and fully consent to participate in the study which has been fully explained to me. Having given this consent I understand that I have the right to withdraw from the study at any time without disadvantage to myself and without being obliged to give any reason. I also understand that should I withdraw, the researcher reserves the right to use my anonymous data in the write-up of the study and in any further analysis that may be conducted by the researcher.

Participant's name (BLOCK CAPITALS)

.....

Participant's signature

.....

Researcher's name (BLOCK CAPITALS)

.....

Researcher's signature

.....

Date: .....



## Appendix 7.

An excerpt of the transcription of one of the interviews in order to provide an example of the content.

47 won't speak to anybody. Umm she's not contributing. She's not answering... asking  
48 questions so yeh.

49

50 R: I think you've kind of covered it already but what was the remit that was given to  
51 you by the school when you first become involved?

52

53 P5: Umm yeh, I think they very quickly could see that difficulties she was having  
54 managing in a mainstream and they wanted to go down statutory assessment route so that  
55 was... so I suppose the priority but then also, they are interested in how best to include her  
56 as she moves through the school.

57

58 R: And since qualifying as an EP, have you noticed any change in the common discourse  
59 around adolescent girls and social communication difficulties?

60

61 P5: Umm interesting question. Not really, not that I can... [pause] No. I can't... I can't  
62 think of any change in... I... I suppose... for me, the... the key thing is... I... I worked in a high  
63 school... in a different high school up until about 2 years ago, which was a difficult high  
64 school to work in, and I feel there, children or girls with social communication difficulties  
65 would not have been highlighted to me, unless there were significant behaviour issues. So  
66 umm that's not answering your question at all but... So I'm trying to think, has there been a  
67 change in terms of... No, I don't feel that there has been a huge change, no.

68

69 R: OK. Umm, when you were working with this... this girl, what cultural factors did you  
70 feel you had to consider? Umm so I'm thinking things to do with kind of parents, parental  
71 consent, parental views and then also kind of the school system as a whole but then also the  
72 young person's views.

73

74 P5: Umm this... this situation is really complex because Mum has significant heal...  
75 mental health difficulties. Umm and there are lots of cultural issues as well. Umm the  
76 father is from an Indian heritage and Mum, White British. Umm, the more I've worked with  
77 Mum, the more I think she has social communication needs that have now developed into  
78 mental health issues. Umm I haven't managed to meet with Dad. Umm so the cultural  
79 issues haven't been something I've had to really deal with face-to-face but the... the home  
80 circumstances have been a big issue in working with this family. Umm and then you asked  
81 me... Can you...?

82

83 R: You're talking about kind of parents and home values. Then also kind of the school  
84 environment I suppose. Was there anything that you had to do, kind of thinking about  
85 people feeling differently to you or people kind of being on the same wavelength?

86

87 P5: Yes, umm the SENCo in my... in this high school, umm I have a really good working  
88 relationship with. She's incredibly pro inclusion and therefore makes it very easy to work  
89 with her. So she and I are about to do training for the whole staff next week on autism  
90 because of this pupil and a few others who I'm working with at the moment. Umm the  
91 others are all male. Umm so there's definitely problems within the school system,  
92 understanding autism and how it can present in the classroom. Umm so we feel like we're  
93 having to do a lot of supporting people to shift their views. So yeh.

## Appendix 8.

An excerpt of the coding of one of the interviews in order to provide an example of the process.

Initials	Transcript	Extract	Code	Theme (subtheme)
R	So please can you tell me about a time when you've worked with adolescent girls in mainstream education with an unidentified social communication difficulty?			
P4	[Pause] There have been a couple. So umm... I've worked with a few individuals and then a few in a group, but not a social communications group, a sort of more of a resiliency group umm and it wasn't all girls. Umm so with individuals, generally all of them actually have been diagnosed at primary school. So it was more about how to cope with their needs at the moment. Umm [pause] and I felt, I could be wrong, but less acceptance from the staff that a child could behave in this way; that a girl... I felt that between dealing with a boy with social communication issues and a girl with social communication issues, the girl was seen as weird where a boy was seen... seen as annoying umm in the discrepancy between a girl and a boy umm... Do you want me to just carry on? What sort of detail do you want?	<p>I've worked with a few individuals and then a few in a group, but not a social communications group, a sort of more of a resiliency group umm and it wasn't all girls. (P4:6)</p> <p>generally all of them actually have been diagnosed at primary school. (P4:8)</p> <p>more about how to cope with their needs at the moment (P4:9)</p>	<p>1) Prevalence</p> <p>1) Diagnosis</p> <p>1) Support (school)</p>	<p>Presentation (identifiable)</p> <p>Presentation (identifiable)</p> <p>Support (school)</p>