# An investigation into the diagnostic bias in primary school teachers against girls with Autism Spectrum Disorder

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#### Thesis declaration form

I confirm that the work presented in this thesis is my own. Where information has been derived from other sources, I confirm that this has been indicated in the thesis.

Signature:

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#### **Overview**

This thesis comprises of three parts, with an overall focus on the diagnostic bias against females with autism.

Part one provides a conceptual introduction to the topic through a narrative review and synthesis of the previous relevant literature. It considers the pertinent theories aimed at explaining the higher rates of autism diagnoses in males, before focusing on one specific theory – the presence of a female autism phenotype – in more detail. It presents a synthesis of the key literature which has investigated and evidenced this presentation, and attempts to deduce the 'true' higher male prevalence from possible diagnostic bias. It outlines current gaps in research, before providing a rationale for the empirical study of the thesis, and a justification for the methodology used.

Part two is an empirical paper examining whether primary school educational staff, in their role as gatekeepers to autism diagnosis, show a bias against females with the condition through an over-recognition in males and a lack of understanding of the female presentation. Primary education staff were presented with vignettes depicting children with different mental health conditions, including both the male and female autism presentations, and asked to rate the likelihood of the child having the different diagnoses and the likelihood of them seeking support for that child. Gender was also manipulated on the vignettes, with half of the respondents receiving female-gendered vignettes, whilst the other respondents received identical male-gendered vignettes. Results indicated that respondents showed a bias against females with autism; female-gendered vignettes received lower estimations of autism and support seeking than male-gendered, regardless of the presentation described, and the female autism presentation received significantly lower estimations of autism and support seeking than the male autism presentation. The findings have potential implications for the recognition of females with autism in the future, as well as training for education staff in this area.

Part three provides a critical appraisal of the research process overall. It reflects on the challenges faced and an evaluation of the decisions taken in regards to methodology and respondents. Finally, a reflection is provided on the experience of engaging in a joint project.

This was a joint project with fellow DClinPsy student Kate Fulton (Fulton, 2019). See Appendix A for a breakdown of contributions.

#### **Impact Statement**

Autism is a neurodevelopmental condition which affects an individual's social and cognitive functioning. If the condition is left unrecognised, it can cause long-term adverse effects on the wellbeing of those affected, as well as an absence of any support or information which would come with a diagnosis. Research investigating the large male-to-female ratio of diagnosed autism has evidenced that many girls with autism are being missed, and there is seemingly a bias against girls with the condition. It is unclear as to how or why this is occurring, but this project provides evidence for one possible mechanism for this bias. It demonstrates that professionals in the educational system, who act as gatekeepers to an autism assessment, display a bias against girls depicted in vignettes by not recognising the differing autism presentation in females, and displaying a higher sensitivity to recognising autism in males.

By evidencing one possible cause for the diagnostic bias against females with autism, the current project provides an avenue for improving our recognition of girls with the condition. Through the provision of increased awareness and training to those in our educational system on autism in females, it may improve the recognition of the condition and thus prevent the long-term adverse effects currently observed.

Furthermore, this research contributes to the increasing literature investigating the differing prevalence rates of autism diagnoses in males and females. It provides suggestions for future investigation, including the replication of the study with other populations who also act as gatekeepers to autism diagnosis. In addition, through the use of vignettes, this study provides a valid and ethical methodology for such investigations, as well as for similar research in the literature investigating gender disparities in other mental health conditions.

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## **PART 1: Conceptual Introduction**

A review of the gender ratio in diagnosed autism and the bias against females with the condition

#### Abstract

Aim: To consider and summarise the key research and theories on the gender differences in rates of diagnosed autism and the diagnostic bias against females with the condition.

Method: Through consultation with relevant experts and a search of the database PsycINFO, a comprehensive list of literature relevant to the gender bias was identified.

Results/Conclusions: Despite a number of theories aimed at explaining the high male-to-female ratio in autism diagnosis, there is a clear bias against the diagnosis of females. Furthermore, the literature would suggest the mechanisms of this bias are currently unclear, but it is likely - at least in part - due to the under-recognition of the female autism phenotype amongst professionals. An outline of the aims of the research project developed from this are presented, as well as a justification for the project's methodology.

#### Introduction

This project intends to increase knowledge about the observed gender difference in rates of diagnosed autism by investigating whether primary school educational staff show a diagnostic bias in the identification of the condition. It has been consistently shown that more males than females are diagnosed with autism, with prevalence studies estimating a male-to-female ratio of 4.5:1 for those formally diagnosed (Loomes, Hull, & Mandy, 2017). There is further evidence to support the theory that, compared to boys, girls are at higher risk of their autism being missed, with the true male-to-female ratio being lower than prevalence studies estimate (Loomes et al., 2017). Although the research would support the notion that there is a diagnostic bias against females, the mechanisms that drive this are yet to be determined. It is suggested that it could be due to a lack of understanding of how autism presents in females, but as research currently stands, it is unclear if this is the case, nor where in the diagnostic process it could occur.

The aim of this study is to contribute to the existing literature by investigating if this bias occurs at what is the beginning of the diagnosis pathway for many individuals: at the level of primary school educational staff in their role as professional gatekeepers to referral for assessment. More specifically, using an experimental design, the project will determine whether educators are more likely to identify autism in males when presented with identical male and female vignettes, and investigate their sensitivity to a description of a female-typical phenotype in comparison to a male-typical phenotype. It is intended that this work will contribute to the understanding of the gender bias in autism and potentially lay ground for the additional training of teachers in the recognition of a utism in females. This literature review will consider the key research and theories upon which the current study is founded. An outline of the gender differences in rates of diagnosed autism will be presented, before a discussion of three key theories which aim to explain the bias in autism. The review will go on to discuss one of these theories - the presence of a female autism phenotype – in more detail, presenting the key literature which has investigated and evidenced its existence as well as outlining the current gaps in research. Finally, the review will outline the aims of the current study before providing a justification for the methodology used.

#### Gender differences in rates of autism diagnosis

Autism Spectrum Disorder (hereafter autism) is a neurodevelopmental condition defined by difficulties in social communication, social reciprocity, sensory processing, and flexibility (American Psychiatric Association [APA], 2013). Alongside this, those with the condition are at higher risk of experiencing a range of additional difficulties, including difficulties with employment, further physical and mental health comorbidities, poorer quality of life, and difficulties with social relationships (Howlin & Moss, 2012). Nevertheless, it has been shown that a timely diagnosis can alleviate some of these long-term consequences; a diagnosis can enable access to services, provide support to family members, and identify individual needs and interventions (Bryson, Rogers, & Fombonne, 2003). In comparison, those individuals whose autism goes unrecognised often report more adverse consequences, including experiences of bullying, isolation, and feelings of 'not fitting in' or being misunderstood (Portway & Johnson, 2005; Bargiela, Steward, & Mandy, 2016; Punshon, Skirrow & Murphy, 2009; Portway & Johnson, 2003). Since the very origin of the condition, there has been a predominance of males diagnosed with autism (Asperger, 1944; Kanner, 1943). For example, in 1943 Kanner described 11 cases of autism, and eight of these were boys. Similarly, Asperger (1944) highlighted the gender disparity he had observed in his seminal paper, and noted that many girls seemingly had traits but this was not as fully formed as in boys; he states that the girls he came across had 'contact disturbances' reminiscent of those seen in boys, yet these tended to be the only observed traits. Since this time, there has been much variability in the reported male-to-female ratio of children diagnosed with autism, with the estimates from prevalence studies ranging from 2:1 to 7:1 (Halladay et al., 2015), yet ultimately the discrepancy remains with 4:1 being the most frequently reported ratio based on an average of multiple studies across the world (Halladay et al., 2015). The reason for the discrepancy in prevalence between the sexes is as yet unclear, resulting in a number of possible theories aimed at explaining this. Some of these theories assert that there is a real sex difference in vulnerability to autism that needs to be explained, such as the Multifactorial Liability Model and the Extreme Male Brain theory, whilst others argue that the male-to-female ratio, at least in part, is an artefact of diagnostic biases against females. These three most dominant theories are explained briefly below.

It is also worthy of note at this point that, similar to others in the literature (Lai, Lombardo, Auyeung, Chakrabarti, & Baron-Cohen, 2015), this review has utilised the definitions of 'sex' and 'gender' from the World Health Organisation (WHO, 2011), such that sex is understood as the biological characteristics which define males and females, whilst gender refers to the socially constructed roles and behaviours associated with men and women. Because these terms are often used

interchangeably in the literature, unless otherwise specified, this review will do so also.

#### The Multifactorial Liability Model

One of the first suggestions put forward is the 'threshold' or 'multifactorial liability' model. This theory posits that all individuals have some liability to develop autism, but they do not develop the condition unless this liability exceeds a certain value (i.e. the threshold; Tsai, Stewart & August, 1981). It is argued that biologically, males have a lower threshold for autism and therefore lower genetic 'liability' is required for a male to develop the condition (Tsai et al., 1981; Tsai & Beisler, 1983). Nevertheless, the evidence for this 'female protective effect' is mixed. Using behavioural scales of autism, it is understood that everyone in the general population can be measured somewhere on a continuum of autism traits. Based on this it is argued that family members of individuals with autism show a larger average number of autistic traits than those family members of individuals without autism (Robinson, Lichtenstein, Anckarsäter, Happé, & Ronald, 2013). Consequently, if greater 'genetic liability' is required for girls to develop autism, then their family members should display more traits than family members of boys with the condition. Following this, Robinson et al. (2013) examined siblings from two large nationally representative samples and found that siblings of females had significantly more autistic impairments than siblings of males, suggesting females require greater etiologic load to develop the condition. However, others have failed to find an increased risk of autism in relatives of females with autism (Goin-Kochel, Abbacchi, & Constantino, 2007), nor differences in autism severity in males based on whether they had a brother or a sister with the condition (Banach et al., 2009). As a result, it

is possible that a 'female protective effect' exists, however the current evidence does not seem sufficient at this time to fully explain the disparity between the sexes in autism diagnoses.

#### The Extreme Male Brain

Another dominant theory in the field is that of the Extreme Male Brain (EMB), first put forward by Baron-Cohen in 1997 (Baron-Cohen & Hammer, 1997). This is an extension of his Empathising-Systemising theory, in which he argues that, on average, males are natural systemisers (they have a stronger ability to analyse and construct systems) and females empathisers (a stronger ability/drive to understand another's emotions and thoughts, and respond appropriately; Baron-Cohen, 2002). He went on to argue that autism is an extreme form of the male pattern of neurodevelopment, such that empathising is hypo-developed and systemising is hyper-developed (Baron-Cohen, 2002). It follows that, according to this theory, males in the general population are more vulnerable to autism than females; the average male will already show the pattern of stronger systemising and weaker empathising seen in autism, whilst females would require a larger deviation from the average neurodevelopmental pattern of their sex in order to develop the condition.

Foetal testosterone has been seen as the mechanism underpinning EMBT. It is argued that foetal testosterone is involved in the masculinization of the brain and levels of testosterone correlate with autistic traits (Baron-Cohen et al., 2011). Furthermore, it has been evidenced that higher levels of foetal testosterone occur alongside a higher frequency or severity of autism characteristics (Baron-Cohen et al., 2011). As higher levels of androgens such as testosterone have been shown to differentiate the foetus as male (Finegan, Bartleman, & Wong, 1989), this would support the notion that males are more vulnerable to autism than females.

A number of scholars have been critical of EMBT however. Krahn and Fenton (2012) argue that Baron-Cohen and colleagues provide an unconvincing gendering of skills or capacities in the human population, and thus could be disadvantaging both males and females with the condition. The authors contest the theory's position that males and females are biologically predisposed to be better systemisers and empathisers respectively, and there is a disregard for the social and cultural factors which undoubtedly impact on skills and characteristics. This further relates to the moral objections put forward, whereby individuals argue that theories such as EMBT, which posit psychological sex differences as 'hard-wired', can result in stereotypes and promote inequality (Fine, 2008).

Moreover, empirical research has contradicted aspects of EMBT. For example, it has been shown that exposure to high levels of prenatal testosterone can be associated with poorer systemising abilities in females (Finegan, Niccols, & Sitarenios, 1992; Hines et al., 2003), rather than the increased performance EMBT would predict. Similarly, Alarts, Swinnen, and Wenderoth (2016) used fMRI to look at brain connectivity in males and females both with and without autism, and found that autism profiles show typical sex differences rather than females with autism showing masculinization of the brain. As such, as it currently stands, there is mixed evidence for the Extreme Male Brain theory and it remains unclear the extent to which the discrepancy in male to female ratio can be explained by these claims.

#### A diagnostic bias

Although there may be some evidence for the above theories, the variability in prevalence ratios would suggest that, even if the condition is objectively more common in males, the traditional reported male-to-female ratio of diagnosed autism may be much smaller. This leads onto the third theory dominating the literature, and the focus of this study and literature review; the presence of a diagnostic bias. This argues that the high male-to-female ratio of diagnosed autism is, at least in part, due to under-diagnosis of females with the condition. This anti-female diagnostic bias is thought to arise because there is a distinct 'female autism phenotype' that does not fit the current diagnostic criteria, which were largely derived from male cases (Lai et al., 2015). This has led to empirical interest in the putative 'female phenotype' of autism, suggesting that autistic females, on average, show different and/or less repetitive stereotyped behaviour and externalising problems, and more emotional difficulties in comparison to their male counterparts (Mandy et al., 2012). This arguably results in a stereotype that the condition is more common in males, in addition to being objectively harder to recognise or diagnose in females – both of which would increase the likelihood of girls not receiving an autism diagnosis in comparison to their male counterparts.

#### Literature review of the diagnostic bias in autism

Although not a systematic review, the current literature review used a comprehensive and rational process to identify literature relevant to the gender bias. The following steps were taken: (1) experts in the field recommended key papers, including reviews, and these were read and their reference sections searched; (2) a database search was conducted to identify additional relevant papers. The database search was

conducted on PsycInfo (September 10, 2018) using the following search terms: ("autism spectrum disorder" or autism? or Asperger\* or ASD) AND ("gender bias" or "female phenotype" or "diagnos\* bias"). 512 results were returned, of which 48 were deemed relevant, and from the references of these, an additional nine articles were found, resulting in a total of 57 reviewed results. This included 47 empirical papers, seven reviews, and three meta-analyses. Overall, the research in this area can largely be divided into two areas: those that investigate the existence of a diagnostic bias in autism and, those which investigate the gender differences in autism and the possibility of a 'female phenotype'.

#### Is there a diagnostic gender bias in autism?

As it stands, a number of different lines of evidence converge on the idea that there is a bias against autistic females being diagnosed. The literature largely supports the existence of two types of bias: (1) females are less likely to get an assessment than males, and (2) if they are assessed, girls are less likely to meet criteria compared to males with equivalent levels of traits.

The existence of the first type of bias can be seen most prominently in a thorough meta-analysis of autism prevalence studies conducted by Loomes et al. (2017), in which a comparison is made between clinically diagnosed samples and those receiving an assessment regardless of whether they had been seen by services. The authors found that in the 34 studies which looked at children with a pre-existing clinical diagnosis, the male-to-female ratio was 4.5 to 1, yet in the 20 studies which sought all cases of autism regardless of whether they had received a diagnosis, the male-to-female ratio was significantly lower at 3.2 to 1. Similarly, Zwaigenbaum

and colleagues (2012) examined siblings of children with autism – therefore noted as 'high-risk' – and identified a number of undiagnosed children, of which the male-tofemale ratio was significantly lower than expected at 1.65 to 1. This would suggest that there are a number of females meeting criteria for autism, but not reaching the stage of assessment to gain a formal diagnosis.

Further support for this type of bias can be seen in the literature which indicates that girls generally receive their diagnosis later than their male counterparts, despite similar, or even earlier, ages of first concern. For example, Rutherford et al. (2016) conducted a retrospective analysis of 150 adults and children recently diagnosed, and found a significant difference in the average age of referral and diagnosis between the genders, with girls receiving these later than boys. Their analysis showed that the duration of assessment was largely the same between the sexes, suggesting that the delay in diagnosis occurs at the stage of referral. Similarly, Begeer et al. (2013) examined data from over 2000 individuals diagnosed with autism, and found that girls both under and over 18 years of age were identified later than their male counter-parts. Seemingly, girls are being referred later than boys (Aggarwal & Angus, 2015), despite concerns for their development often being raised earlier (Horovitz, Matson, Turygin, & Beighley, 2012).

Qualitative research further supports the existence of this bias. Bargiela et al. (2016) investigated the experiences of fourteen late-diagnosed women with autism, and found that many reported experiences of pursuing a diagnosis with their GP but were not offered an assessment. Additionally, these women reported that a variety of professionals dismissed their concerns or failed to notice difficulties and provide an assessment.

The other notable type of bias seemingly occurs even if girls are able to get an autism assessment, with the literature indicating that girls with high levels of autistic symptoms are less likely to meet autism diagnostic criteria compared to males. Russell, Steer and Golding (2011) utilised secondary data analysis to investigate autistic traits in a large sample of UK children and examined the role of social and demographic factors in diagnosis. Their analyses revealed that even when symptom severity is held constant there is a gender bias towards diagnosing boys i.e. girls were less likely to be identified with autism even when their symptoms were equal in severity. Further to this, Ratto et al. (2018) found that girls with autism show more severe levels of autistic traits and poorer skills of daily living than diagnosed males, suggesting that girls may require a stronger presentation of autism in order to receive a diagnosis. Admittedly such findings were based on parent ratings, and the authors acknowledge the possibility that parents may respond differently for each gender with parents expecting girls to be more socially competent for example. However, not only are the measures used in this study sex-normed, reducing the likelihood of this, but the suggestion that a more severe presentation is required in females is further supported by Salomone, Charman, McConachie, and Warreyn (2016). These authors found a significant interaction between gender and verbal ability on age of diagnosis, such that female children with more advanced verbal ability were diagnosed later than males who had the same levels of verbal ability. Similarly, Dworzynski, Ronald, Bolton, & Happé (2012) analysed data from over 15,000 twin pairs in England and compared girls who met diagnostic criteria for autism with undiagnosed girls who scored highly on trait measures. They found a lower diagnosis rate amongst girls in comparison to boys, and found that girls with a diagnosis tended

to have a more severe presentation with lower cognitive ability and/or additional behavioural problems.

Together, the literature indicates the existence of a diagnostic bias against females with autism; females are less likely to receive a diagnosis, often require a more severe presentation to meet diagnostic criteria, and receive their referrals and diagnosis later than their male counterparts.

#### The Female Phenotype

The existence of a diagnostic bias has led onto research attempting to understand the possible mechanisms that could explain this, one of which is the 'female autism phenotype'. The literature indicates that this female phenotype differs from the male presentation in four key domains; (1) the existence/presentation of restricted and repetitive behaviours or interests (RRBIs), (2) social behaviour and communication, (3) the use of camouflage, and (4) co-occurring difficulties. This review will go on to consider and explain each of these in turn.

#### 1. Restricted and repetitive behaviours or interests

One of the most replicated findings in the literature thus far is the difference in RRBIs between the genders. Tillman et al. (2018) investigated a large sample of over 2000 individuals from across Europe, and found that females tended to show a lower frequency of RRBIs on commonly used measures of autism in comparison to their male counterparts. Not only can this distinction not be accounted for by measurement differences (Frazier, Georgiades, Bishop, & Hardan, 2014), but it has also been replicated by studies using parent report, direct observation, and clinician judgements (Mandy et al., 2012; Jamison, Bishop, Huerta, & Halladay, 2017; Sipes, Matson, Worley, & Kozlowski, 2011). Additionally, Van Wijngaarden-Cremers and colleagues (2014) conducted a meta-analysis of 22 studies which examined gender differences in autism, and one of their main findings was the difference in RRBI's, whereby boys tended to show more than girls from the age of six upwards. Although most research has focused on childhood and adolescence (Tillman et al., 2018; Van Wijngaarden-Cremers et al. 2014), this finding has also been replicated in adults with autism, regardless of severity of symptoms (Wilson et al., 2016; Hattier, Matson, Tureck, & Horovitz, 2011).

Seemingly the research for younger children is mixed, with some authors replicating this finding amongst toddlers (Hartley & Sikora, 2009), whilst others failing to find a significant difference between the two genders in this domain (Harrop, Gulsrud, & Kasari, 2015; Van Wijngaarden-Cremers et al., 2014). This may suggest that the differences in RRBIs between males and females are not observed until later, although the literature is unclear as to when or how this may develop. As one of the key requirements of an autism diagnosis (DSM-5), if females show less of this impairment, this could begin to explain why many females go unidentified, particularly when many clinicians can be reluctant to consider a diagnosis without the presence of these behaviours (Mandy et al., 2012).

More recently however, it has been suggested that females with autism are not engaging in less RRBIs than males, but rather these manifest differently in girls (Hiller, Young & Weber, 2014). The literature indicates that the restricted interests seen in girls tend to involve people or animals, rather than objects or things (Lai et al., 2015), with both carers of children with autism and adult

females with the condition, reporting that girls seem to show more 'normative' interests (Hiller, Young, & Weber, 2016; Bargiela et al., 2016). As such, this would suggest that girls are still meeting the diagnostic criteria in this regard, but it is simply manifesting differently and therefore harder to identify.

#### 2. Social behaviour and communication

In addition to differences in RRBIs, the literature has also focused on potential gender differences in the social domain of autism. At first glance, the research appears mixed, with some authors reporting clear differences in this area (Lai et al., 2015; Sun et al., 2014), whilst in their thorough meta-analysis and review, Van Wijngaarden-Cremers et al. (2014) concluded that there are no differences between the sexes in social behaviour and communication. Even so, it appears that both conclusions are somewhat true; if one defines and measures the social domain in terms of how the DSM-5 describes the core symptoms of autism, the literature indicates that you will not find consistent differences; however, if one uses more subtle and diverse measures of social behaviour, differences seemingly appear (Hiller, Young, & Weber, 2014).

Studies such as that conducted by Tillman et al. (2018) for example, have found that boys and girls show comparable levels of impairment on measures such as the Autism Diagnostic Interview Revised (ADI-R), which are based on the broad social criteria of the DSM. Similarly, in the meta-analysis conducted by Van Wijngaarden-Cremers and colleagues (2014), gender differences in the core triad of impairments, including social behaviour and communication, were reviewed in 22 publications that used various diagnostic measures of autism, which led to the conclusion that the sexes do not differ in this domain.

Nevertheless, in research that looks more closely at this criterion and uses more subtle measures, there does appear to be differences between the genders. Firstly, males and females seem to differ in regards to their social motivation, with girls tending to show more of an interest in friendships and relationships than their male counter-parts. For example, using a mixed-methods design, Sedgewick, Hill, Yates, Pickering and Pellicano (2016) looked at the social motivation and friendship experiences of adolescents with autism, and found that females with autism showed comparable levels of motivation and friendship quality to girls without autism, whilst boys with autism were qualitatively different to both their non-autistic counterparts and females with the condition. Similarly, Head, McGillivray, & Stokes (2014) used the Friendship Questionnaire (FQ) to assess friendships and social function, and found that females with autism displayed higher FQ scores than their male counterparts (indicating better social skills), and similar scores to typically developing boys. Reports from carers in Hiller et al. (2016) corroborate this, stating that girls had a strong desire to fit in with their peers in comparison to boys.

Further to this, Backer von Ommeren, Koot, Scheeren, & Begeer (2017) investigated social-emotional reciprocity, a key criterion for the diagnosis of autism, and found that overall children with autism show limitations in reciprocal behaviour in comparison to typically developing peers, however girls with autism showed significantly higher reciprocity scores than boys with autism. This supports the conclusion made by Dean, Harwood and Kasari (2017) that social challenges seen in girls are both different and less obvious than those seen in boys. In their observations of both typically developing children and children with autism, these researchers found that, unlike their male counterparts, girls with autism spent some time in joint engagement with peers, suggesting both higher social motivation and less isolation. Notwithstanding, the authors observed that these girls primarily 'flitted' between social groups and peers, and still spent a significant amount of time alone, particularly in comparison to typically developing girls. As such, although their social difficulty may be more subtle, the research would indicate it is nevertheless genuine in girls with autism.

#### 3. The use of camouflage

A third factor defining the female phenotype in the literature, and related to social behaviour, is the notion that many females attempt to 'camouflage' their difficulties during social situations. This refers to individuals trying to mask or compensate for tendencies linked to autism, which results in a less prototypical presentation (Hull, Mandy et al., 2017). Examples of this in the literature include using pre-prepared topics or jokes in conversation, imitating facial expressions and gestures, and forcing oneself to make eye contact during social interactions (Lai et al., 2017). Related to the increased social motivation previously discussed, camouflaging is likely driven by a wish to 'fit in' and form social relationships (Hull, Petrides, et al. 2017).

Research on this phenomenon has tended to come from literature investigating autism in females. For example, in a qualitative study on the experiences of late-diagnosed females with autism, Bargiela et al. (2016), found that women gave accounts of camouflaging, often referred to as 'pretending to be normal', which included taking on a particular persona or engaging in social mimicry. Similar findings were reported by Tierney, Burns and Kilbey (2016) from interviews with ten adolescent females. These girls reported a motivation to develop and maintain friendships but they were often faced with difficulties arising from this, and so they reported developing strategies such as masking and imitation in order to manage these relationships. This also appears to be the case regardless of culture; Sunagawa (2015) interviewed girls in Japan and found that they also reported the use of superficial social adaptation skills to 'veil' their difficulties.

Although this finding is largely based on qualitative self-report with females, it is noted that the tendency to engage in camouflage is not restricted to this gender; Hull, Petrides et al. (2017) conducted a qualitative study with a large sample of adults diagnosed with autism, and found that both males and females reported engaging in camouflaging behaviours to some degree. But more recent research indicates that girls engage in more camouflage, or do so more successfully, than their male counterparts. For instance, in their interviews, Hull, Petrides et al. (2017) found that a significantly large proportion of males reported that their camouflaging techniques were often unsuccessful, and although this was also reported by some females, the gender ratio suggested that this was more often the case for males in comparison to females. Similarly, Dean et al. (2017) used concurrent mixed methods design to examine the social behaviours of almost 100 school children. Their results supported the qualitative reports, such that girls with autism were observed using compensatory behaviours such as staying in close proximity to peers and weaving in and out of activities, which enabled them to mask any social challenges. In comparison, the authors report the 'male landscape' makes it easier to notice the social difficulties of boys with autism, such that they are often playing alone during school breaks. Further to observations and self-report, Lai et al. (2017) created a measure which attempted

to operationalise camouflaging in adults with autism, and using this with both males and females with the condition, found that females scored significantly higher than males i.e. women showed more camouflaging than their male counterparts.

#### 4. Co-occurring difficulties

Further to differences in RRBIs, higher social motivation, and the occurrence of camouflaging in females, the research has also investigated whether the male and female autism phenotypes differ in regards to co-occurring difficulties. Overall, males and females with autism show comparable frequencies of co-occurring difficulties, and they tend to have more than neuro-typically developing individuals (Posserud, Hysing, Helland, Gillberg & Lundervold, 2018; Pisula et al., 2017). However, although the overall number of comorbidities may be comparable, the types of difficulties each gender experiences tend to differ. Boys with autism tend to show more externalising problems than girls, such as behaviour difficulties and inattention. For example, May, Cornish and Rinehart (2016) examined children aged 7-12 years and found boys were reported to have more inattention and more elevated levels of hyperactivity-impulsivity. Similarly, using data from a longitudinal child study of over 9000 children, Posserud et al. (2018) found less Attention Deficit Hyperactivity Disorder (ADHD) in females compared to males with autism, based on teacher and parent reporting. This is further corroborated by teacher reports in both Hiller et al. (2014) and Mandy et al. (2012), in which girls with autism are reported to have fewer externalising problems than their male counterparts. There is some preliminary evidence that this finding is generalisable across cultures, since Amr, Raddad, El-Mehesh,

Mahmoud, & El-Gilany (2011) examined children from three Arab countries and found that boys with autism exhibited more delinquent behaviour problems than girls, as measured by a behaviour checklist.

It is noted that Hiller et al. (2016) had contradictory findings, such that in an online survey conducted with carers of children with autism, carers rated externalising behaviour as a greater concern for girls rather than boys. However, this tended to be related to the child's desire to control play activity, rather than elevated levels of inattention or hyperactivity. Similarly, as noted by the authors, the findings could also be impacted by expectations of how boys and girls should socialise and behave; it is possible that people are less tolerant of bad behaviour in girls as they expect it less or have differing cultural expectations for girls in comparison to boys.

Further to the reduced prominence of externalising difficulties in females, the research indicates that girls with autism tend to show more internalising difficulties. Rynkiewicz and Lucka (2015) investigated co-occurring psychopathology in adolescent girls and boys with autism, and found that girls were more likely to experience anxiety, depression, suicidal ideation, and psychiatric hospitalisation. Similarly, in the study of over 9000 children conducted by Posserud et al. (2018), they also found that eating disorders and Obsessive-Compulsive Disorder (OCD) were more common in girls with autism than boys. Interestingly, in this study, the girls' problems were also rated as less impairing than boys by both teachers and parents. The authors concluded that there was a strong contribution of disruptive behaviour to levels of rated impairments and contact with health services, suggesting that the internalising

problems more common in girls with autism can be underestimated and overlooked by adults surrounding the child.

Although the area is still in its infancy, the literature would indicate that eating disorders are one of the main internalising difficulties often observed in females with autism (Kirkovski, Enticott, & Fitzgerald, 2013). Researchers have commented on the observation that many females with anorexia nervosa often show impairment in social function and flexibility, which could be indicative of autism (Mandy & Tchanturia, 2015). For example, in their study of cognitive ability in anorexia, Gillberg, Rastam, Wentz & Gillberg (2007) noted the significant proportion of females in the sample with both autism and anorexia. Furthermore, in a direct investigation of this, Mandy and Tchanturia (2015) used gold-standard assessment measures of autism on women receiving treatment for an eating disorder. Their results showed that seven out of the ten sampled women were estimated to have autism based on the measures used, and reported these difficulties to have onset prior to the eating disorder. It is noteworthy that only one female in this sample had a childhood diagnosis of autism, suggesting that a significant proportion of the sample likely met criteria for autism but this had been missed during childhood.

Despite most of the literature focusing on differences in the core symptoms of autism, research has begun to emerge which investigates possible cognitive differences between the genders in regards to autism, which could also shed light on the above difficulties seen. For example, Lehnhardt et al. (2016) aimed to investigate the possible 'protective' cognitive processes that enable females with autism to develop the socio-communicative adaptations discussed above. The researchers

looked exclusively at individuals diagnosed later in life – with the suggestion that these are individuals whom have adapted more successfully – and using a range of cognitive tests found that males with autism showed higher verbal abilities whilst females with autism showed higher processing speed and executive functions. The authors concluded that this pattern of strengths might be a prerequisite for establishing the 'camouflaging' seen in high-functioning females with autism. Even so, although others have also found cognitive differences between the sexes in autism, they are not sufficient to pinpoint a gender specific cognitive profile for autism as of yet (Kiep & Spek, 2017).

In summary, the current research would support the existence of different gender phenotypes within autism. As discussed, girls with autism tend to show less restricted and repetitive behaviours and more socially focused interests, in addition to higher social motivation and the tendency to camouflage their difficulties. Seemingly, they are also more likely to suffer from internalising comorbidities and have fewer problems with inattention and hyperactivity in comparison to their male counterparts.

#### Typical sex differences

Nevertheless, authors in the field have begun to suggest that due to the influence of sociocultural factors, this pattern of differences reflect those seen in typically developing males and females (Kreiser & White, 2014). As noted by Goldman (2013), gender is a social construct and socialisation differs by sex and culture. That is, individuals will attend to behaviour and emotions of a child differently depending on the cultural expectations of that sex, which will in turn influence how the child

responds and develops. A mother will do this with their child from birth, prior to any confirmation or indication of the presence of autism, demonstrating that individuals with autism are subjected to the same socialisation influences as their typically developing peers; these children are taught to interact and play in accordance with the gender-based rules of their culture and family (Goldman, 2013). It would therefore follow that like their typically developing counterparts, males and females with autism will also show differences in behaviour based on their gender and the differing socialisation they have been subjected to.

This could also help explain the observed gender differences discussed. For instance, Kreiser and White (2014) hypothesise that due to gender expectations, females may experience more severe adverse consequences for disruptive or socially insensitive behaviour. Consequently, those girls with autism may present with less severe social difficulties or externalising problems than boys because they are motivated to avoid such consequences and therefore engage in the coping methods discussed, i.e. camouflaging. Similarly, peer groups may further influence females with autism, such that females tend to have smaller friendship groups with an expectation that conversations should have an interpersonal focus. Consequently, exposure to this likely strengthens the social skills and empathising ability amongst females with autism (Kreiser & White, 2014).

To evidence the similarities in gender differences in typically developing individuals, Hull, Mandy and Petrides (2016) conducted a meta-analysis of articles that compared cognitive and behavioural characteristics in males and females with and without autism. In the thirteen studies that looked at core symptoms of autism, the authors found that the observed gender differences were comparable between autism and typically developing samples. That is, any gender differences observed in

measures of social impairment, communication difficulties, and RRBIs, were similar for both individuals with autism and those typically developing, indicating that individuals with autism are inherently similar to their typically developing peers in regards to their gender variation. This would suggest that the current diagnostic criteria do not reflect typical sex differences, and instead are biased towards males, further explaining the under-representation of diagnosed females. Nonetheless, the researchers also reviewed studies which investigated additional autism symptoms, such as play behaviours and externalising and internalising problems, and found that patterns of sex differences were different between autism and typically developing samples for certain traits. Consequently, it is suggested that the diagnostic criteria should account for typical sex differences, but there should still be an awareness of potential autism-specific gender phenotypes.

#### Where is the bias occurring?

If, as suggested by the reviewed literature, there is the presence of at least a mild diagnostic bias against females with autism, and this is potentially the result of the differing presentation in this gender, it also raises the question as to where in the diagnostic process this bias occurs, and thus where we can intervene to improve the recognition of females with autism. Rutherford et al. (2016) began to investigate this by examining data from a representative sample of adults, adolescents, and children diagnosed with autism, to determine where the observed gender differences occur – prior to or during the diagnostic process. Results showed a significant difference in the age of referral and diagnosis between males and females – with females receiving both later – yet a similar duration of assessment, indicating that the bias may occur during the period of referral. This would suggest that it is the professionals

responsible for referral to assessment services who are potentially missing the signs of autism in girls.

There are many individuals who can raise the initial concern for those with autism. However, if we aim for early recognition, then arguably the key gatekeepers for a child's referral include the child's family, their General Practitioner (GP) and/or their school teacher/another relevant education professional. The literature suggests that many children with autism are first recognised and/or diagnosed during the school age period (Ratto et al., 2018). This is in addition to the finding that many of the previously discussed sex differences are most commonly observed during this time (Jamison et al., 2017). This would indicate that there is a need for professionals in the education system to have knowledge of autism in both males and females and the ability to detect its signs in children.

Nevertheless, it would seem that currently this may not be the case, with children tending to receive earlier diagnoses from non-school settings in comparison to schools (Daniels & Mandell, 2014). Although at this time the research is limited, the literature would indicate that teachers may have difficulty in recognising autism, particularly in females. In comparison to both clinicians and parents, teachers tend to report fewer concerns for girls. For example, Posserud, Lundervold and Gillberg (2006) utilised parent and teacher reports to assess autistic features in over 9000 children and examined the impact of age and gender on symptom reports, as well as the level of agreement between the raters. The results showed a boy to girl ratio of 2.1:1 for parent-reported autistic difficulties - which is comparable to the ratios found in population-based studies. By contrast, for teacher ratings of the same children, the

male-to-female ratio was much higher, at 5.1:1. The implication is that teachers, compared to parents, underreport autistic symptoms in girls.

It can be noted that the low agreement between raters could be due to teachers having difficulty recognising these problems in females, but could just as likely be due to parents overrating symptoms in their children – particularly their daughters. Nonetheless, Hiller et al. (2014) utilised both clinician and teacher reporting to examine sex differences in children diagnosed with autism, and similarly found that teachers tended to report significantly fewer concerns for girls than boys in comparison to the clinicians. As this study did not include parent ratings, yet teachers were still shown to be underreporting difficulties in females, it would indicate that teacher's likely struggle to recognise these problems in girls rather than parents overrating symptoms. The results of this study showed that boys with autism tend to present as more disruptive in school environments than girls, suggesting boy's difficulties are more noticeable to teachers. This would imply that teachers are less likely to recognise difficulties in girls and thus refer to assessment services.

Qualitative studies have also indicated that those in the education system may have difficulty in recognising autism in females. Bargiela et al. (2016) interviewed fourteen women who experienced a late diagnosis (adulthood or late adolescence) of autism, and many of these women reflected that teachers were one of the significant professionals in their lives who had little knowledge of how autism presents in females. They recalled that their behaviour was often misinterpreted as being 'shy' and that their passivity was seen as socially acceptable for girls and therefore often went unnoticed. They noted that if they had been more disruptive, they may have received support sooner. Seemingly, the presentation of females may not allow for as

easy detection by teachers. For example, Mandy et al. (2012) found that, unlike the parent ratings, teachers reported greater externalising difficulties and social problems in males with autism than females, which suggests their behaviour is more likely to be noticed by the educational system. Furthermore, as previously mentioned, Dean et al. (2017) found that the social landscape of girls enables them to camouflage any social difficulties more easily, suggesting that if teachers look for the typical social isolation on the playground when identifying children with potential autism, they are unlikely to detect females.

As demonstrated, the very nature of females' autism presentation makes it harder to detect the condition, and gender stereotypes further impede on any signs of autism being viewed as concerning. In addition to this, it is possible that teachers hold limited and/or stereotypical views of autism which further makes diagnostic bias more probable. Dunne (2008) found that teachers held a number of misconceptions about autism, including the belief that children with autism have special abilities or talents, and that most children with autism have a learning disability. Surprisingly, these misconceptions did not correlate with the number of years spent teaching nor the number of children with autism they had had contact with. The combination of these findings has led to the suggestion that better educated providers are one of the key barriers preventing timely diagnosis (Elder, Brasher, & Alexander, 2016) and that training in the female phenotype may improve both teachers and clinicians' recognition of autism in girls (Bargiela et al., 2016).

#### The current study

It is acknowledged that teachers and those in the education system play a vital role in the referral and diagnostic process of autism (Dunne, 2008). Still, although implied by the current research, there has been no direct investigation into whether these professionals display a potential diagnostic bias against females with autism, and thus possibly explaining some of the disparity in the male to female ratio. As such, this leads onto the purpose of the current study. The aim of this study is to directly test whether professionals in the education system show a bias towards the male gender by being more likely to identify autism in cases of children identified as male, regardless of the information presented. Similarly, it will test whether these professionals also show a bias by being unable to detect the female presentation of autism, regardless of the gender in which it is presented. If shown, then this would provide evidence to support the need for more appropriate training to those in education on detecting autism, particularly in females, and therefore potentially reducing the observed late diagnosis in this gender.

#### Use of vignettes to explore the diagnostic bias

One of the likely reasons this topic has yet to be directly tested is due to the difficulty in manipulating the variables. Quite clearly it is impossible to directly manipulate which children have autism and how they present, and similarly it would be unethical to delay diagnosis to observe potential biases. In order to reliably investigate this topic, one must be able to present educational staff with potential cases, manipulating the gender and presentation, whilst still controlling for potential influencing factors. In this study it is proposed that an appropriate methodology for this is a vignette experiment, otherwise known as a factorial survey (Steiner, Atzmüller, & Su, 2016). Vignettes are short descriptions of fictional situations containing information assumed to be important in the decision-making of respondents (Alexander & Becker, 1978; Poulou, 2001). As explained by Alexander and Becker (1978), one of the advantages of vignettes is the ability to systematically vary the characteristics used in the description to investigate the effect on respondent's judgements or responses. Consequently, a vignette experiment involves the presentation of a number of vignettes that systematically vary in terms of subjects or situations with the aim of eliciting respondents' attitudes, behaviour or beliefs (Steiner et al., 2016). This approach is being increasingly used by a variety of disciplines. For example, vignettes have been used within marketing research to understand consumer behaviour and influences on product sales (Wason, Polonsky, & Hyman, 2002), within psychology to test theories related to learning (Barrera & Buskens, 2002) and understanding of mental illness (Thurman, Lam, & Rossi, 1988), and in sociology to understand attitudes towards immigration (Steiner & Atzmüller, 2006). The research largely focuses on investigations into attitudes, judgements and perceptions (Poulou, 2001; Bauman & Del Rio, 2006), particularly for topics which are difficult to study empirically (Bauman & Del Rio, 2006). In regards to this study, such methodology would enable educational staff to be presented with the same situational description of a child, whilst directly manipulating the gender and/or presentation, and observing the impact on the decision to refer the child for further support or assessment.

As suggested by Alexander and Becker (1978), topics such as these could be investigated through direct questioning; for example 'would you be more likely to raise concerns for a boy showing difficulties with social interaction in comparison to a girl?' Yet the vignette has several advantages over this method. Firstly, it enables the researcher to reduce the possibility of socially desirable responses, which the above example would likely elicit. Further to this, individuals are often influenced by unconscious biases, and may not be aware of factors which impact their judgements or decisions (Pronin, 2007), thus their responses to direct questioning are less likely to represent their behaviour in real-life situations e.g. teachers may believe and hope they would treat each gender equally, however in practice this may not be the case.

Another advantage of this method, put forward by Steiner et al. (2016), is that due to vignettes being representations of situations, the follow up questions are embedded in a context that makes them more realistic and less abstract than typical survey questions. As previously mentioned, the use of vignettes also enables flexibility in investigating multiple simultaneous factors, yet arguably provides a more interesting task for respondents in comparison to the potential monotony of multiple survey questions (Steiner et al., 2016; Schoenberg & Ravdal, 2000). Researchers also note the high internal validity, construct validity, and reliability of such techniques (Steiner et al., 2016; Bauman & Del Rio, 2006).

As mentioned, vignettes have been used for a wide variety of topics; however their use is particularly common in social and educational research (Bauman & Del Rio, 2006). For example, Bauman and Del Rio (2006) used this methodology to investigate teachers' responses to bullying, whilst Poulou (2001) explored teachers' perceptions of children with behavioural and emotional difficulties. Both researchers present an exploration of possible methods that could be used to investigate these topics, before validating the use of vignettes. It is worth noting the disadvantages raised in these reviews, including the questionable external validity of such a

technique; although vignettes can include complexity, it is impossible for them to account for all possible environmental or personal factors which could or can influence decisions in the real-life situation (Poulou, 2001; Steiner et al., 2016). Consequently, in regards to this study, the use of vignettes still raises the possibility that the teachers would react differently if presented with the hypothetical children in real-life, and perhaps show more or less of a bias than shown by this experimental technique. Although the characteristics of vignettes may restrict the external validity however, they ensure improved construct validity and internal validity by measuring what is intended. Furthermore, they are likely the closest method of gaining externally valid results in this study due to the difficulty of measuring such factors empirically.

Vignettes can also be problematic if not constructed properly; they must be realistic and consistent, ensuring researchers do not inherently bias their presentation (Poulou, 2001). Consequently, with sufficient piloting and care taken in the construction of the vignettes, such difficulties can be avoided. Schoenberg and Ravdal (2000) note that there is no perfect methodological tool, and instead researchers must use the best methodology available to them. In relation to this, Poulou (2001) concludes that vignettes are seemingly the most appropriate method for understanding teachers' cognitive and emotional decisions and responses, and therefore this methodology is likely to be the most effective in investigating potential biases teachers' show in autism.

To conclude, the aim of this research study is to contribute to the limited literature on potential barriers to the recognition of autism in females. More specifically, it aims to investigate whether primary school educational staff - gatekeepers to referral for autism assessment – show a bias against females in their recognition of autism. It will test two hypotheses: 1) when presented with vignettes of both females and males with autism, which are identical except for the gender of the individual described, teachers will be more likely to identify autism if the individual described is male, and 2) teachers will be more sensitive to the male-typical phenotype compared to the female-typical phenotype of autism, regardless of the gender of the child described.

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# **Part 2: Empirical Paper**

# An investigation into the diagnostic bias in primary school teachers against girls with Autism Spectrum Disorder

#### Abstract

**Aim**: To contribute to the limited literature on potential barriers to the recognition of autism in females by focusing on primary school education staff in their role as gatekeepers to referral for autism assessment. More specifically, to investigate two types of bias; (1) whether these professionals are more likely to recognise autism in males as a result of gender stereotyping, and (2) whether they are able to identify the female presentation of autism.

Method: Using an internet-based survey, respondents were presented with two vignettes describing children with male-typical and female-typical autism respectively, as well as two 'distractor' vignettes describing children with other mental health conditions. Gender was also manipulated such that all vignettes were randomly presented as either male or female. Respondents rated the likelihood of the child described having autism, and the likelihood of seeking support for the child. **Results:** Responses from a total of 289 primary school educational staff showed a significant main effect of both gender and presentation (male-typical vs. femaletypical) on estimations of the child in the vignette having autism, with respondents showing a bias against girls and the female autism presentation. There was also a significant interaction: female gender had a larger effect on the female presentation than the male. When these estimations of autism were controlled for, there were no significant effects of gender or presentation on the likelihood of respondents seeking support for the child in each vignette.

**Conclusions**: The findings of this study support the experiences reported by latediagnosed women by providing evidence that primary educational staff show a diagnostic bias against females with autism through a lack of recognition of the female presentation and a higher sensitivity to autism in males.

#### Introduction

Autism Spectrum Disorder (hereafter autism) is a neurodevelopmental condition defined by difficulties in social communication, social reciprocity, sensory processing, and flexibility (American Psychiatric Association [APA], 2013). Since its first description, the frequency of males with a diagnosis of autism has been significantly higher than the frequency of females (Asperger, 1944; Kanner, 1943). Although prevalence studies show that the male-to-female ratio of autism diagnosis varies between studies ranging from 3:1 to 7:1 (Halladay et al., 2015) the rates of diagnoses amongst males seemingly always exceeds those of females (Halladay et al., 2015).

The literature supports the notion that the high male-to-female ratio of diagnosed autism is, at least in part, due to under-diagnosis of females with the condition. For example, in a thorough meta-analysis of prevalence studies, Loomes, Hull, & Mandy (2017) found that in studies which reported on samples of children with a pre-existing clinical diagnosis, there was a reported male-to-female ratio of 4.5 to 1. By contrast, in those studies which assessed all children for autism within a given population, regardless of any prior assessment or concerns, the reported ratio was significantly lower at 3.2 to 1. This would suggest that a significant proportion of females are not receiving an assessment and subsequent diagnosis.

The bias against girls with autism is further evidenced in the literature: females frequently receive their diagnosis later than boys, despite similar ages of first concern (Rutherford et al., 2016; Begeer et al., 2013), and girls are less likely to receive a diagnosis despite similar levels of autistic traits (Russell, Steer, & Golding, 2011). A number of studies have shown that girls diagnosed with autism often

display more severe levels of autistic traits than boys, suggesting that in order to get a diagnosis, girls may require a more clear-cut presentation (Ratto et al., 2018; Salomone, Charman, McConachie & Warreyn, 2016).

The existence of a diagnostic bias against females is important due to the adverse consequences which can occur when a child goes undiagnosed. It has been shown that individuals whose autism goes unrecognised often report experiences of social isolation, bullying, and feelings of being misunderstood or 'not fitting in' (Portway & Johnson, 2003; Portway & Johnson, 2005; Punshon, Skirrow & Murphy, 2009; Bargiela, Steward, & Mandy, 2016). Furthermore, an autism diagnosis often enables access to services, leads to the identification of individual needs and interventions, and can result in the provision of support to family members (Bryson, Rogers, & Fombonne, 2003). As such, if females do not receive a diagnosis, or are delayed in receiving this diagnosis, they are at significant risk of adverse life consequences and lack of support.

Although the literature indicates the existence of a diagnostic bias against females with autism, the mechanisms of this bias are currently unclear. To begin understanding this, Bargiela et al. (2016) conducted a qualitative study with 14 latediagnosed women, investigating why these individuals believe their condition was not identified in childhood and/or adolescence. The researchers identified an important factor which may be key to the gender bias discussed: the attitudes and knowledge of professionals who are gatekeepers to autism services and thus diagnosis. In this study, all participants reported that during their childhood, professionals had been aware that they experienced difficulties, but had failed to

associate these with autism. Furthermore, many of these women had sought help from teachers and/or general practitioners (GPs), but these professionals had missed their autism-related difficulties. The participants attributed the professionals' inability to detect their autism to two key factors:

- Gender stereotypes participants perceived that GPs and teachers often missed the signs of autism in females because they held a mistaken belief that autism is a male-only condition, and unlikely to occur in females.
   This reduced their sensitivity to autism symptomology in females.
- (2) The female autism phenotype participants reported that there was a lack of understanding amongst professionals about how autism presents in females – the female autism phenotype – and therefore misinterpreted these symptoms.

The female autism phenotype is the female-specific profile of autism that is increasingly recognised in the literature (Lai, Lombardo, Auyeung, Chakrabarti & Baron-Cohen, 2015). This presentation is not specific to all females with autism and no males with the disorder, however it has been shown to be more prevalent in the former. The current literature suggests four key features of the female autism phenotype:

 Higher social motivation – in comparison to their male counterparts, females with autism tend to show more interest in friendships and relationships (Hiller, Young, & Weber, 2014; Sedgewick, Hill, Yates, Pickering, & Pellicano, 2016).

(2) Camouflaging – research has indicated that many people with autism attempt to 'camouflage' their difficulties, and this is seemingly more common

in females. This refers to individuals trying to mask or compensate for their autism tendencies, and can include practising gestures and facial expressions, and forcing themselves to make eye contact (Bargiela et al., 2016; Hull et al., 2017).

(3) Gender-specific co-occurring difficulties – individuals with autism can often experience comorbid emotional and behavioural difficulties, and there is emerging evidence that these may be partially influenced by gender. Seemingly males may be more likely to show problems with behaviour, whilst females are more likely to develop emotional difficulties like anxiety or anorexia (Mandy et al., 2012; Westwood et al., 2016).

(4) Differences in restrictive and repetitive behaviours/interests (RRBIs) – the literature indicates that RRBIs manifest differently between girls and boys (Hiller et al., 2014). The restricted interests seen in boys tend to focus around mechanics and mathematics, whilst their female counterparts tend to have more socially-focused (e.g. other girls, novels) and/or more normative interests (e.g. animals, pop stars) (Bargiela et al., 2016; Hiller, Young, & Weber, 2016).

As suggested by the women interviewed in the Bargiela et al. study (2015), it is plausible that this female autism phenotype is contributing to the observed diagnostic bias, due to a potential unawareness of its existence amongst professionals' key to the diagnosis pathway.

In line with the findings of Bargiela et al. (2015), it has been shown that many children with autism are first diagnosed during the school age period (Ratto et al.,

2018) and the bias against girls seemingly occurs at the stage of referral (Rutherford et al., 2016). This indicates that educational staff are important gatekeepers to assessment for autism and diagnosis, and thus there is a need for these professionals to have sufficient knowledge of autism in both genders to be able to detect its signs in children. Research suggests, however, that this is not the case, and teachers may have difficulty recognising autism, particularly in females. In addition to the findings of Bargiela et al. (2015) previously mentioned, Posserud, Lundervold and Gillberg (2006) examined both parent and teacher reports in over 9000 children, and found in parent-reports there was a boy-to-girl ratio of 2.1:1, whilst teacher ratings of the same children showed a higher male-to-female ratio at 5.1:1. This implies that teachers were not noticing the same autism-related symptoms in girls that parents were, and were much more likely to raise concerns for boys in comparison to girls. This has been further corroborated in comparisons between teachers and clinicians (Hiller et al., 2014) illustrating that this is unlikely to be a case of parents overreporting symptoms in their daughters, and instead indicative that teachers are underreporting autistic symptoms in girls and have less autism-related concerns for this gender.

Despite the key role teachers play in ensuring early diagnosis, research is yet to investigate this topic area and whether a potential decision bias is contributing to the observed differences between males and females in prevalence rates of diagnosed autism. Consequently, this study aims to employ an experimental design to investigate this potential barrier to diagnosis in order to further our understanding and ultimately improve professionals' recognition of autism in females.

The key aim of this study is to contribute to the limited literature on potential barriers to the recognition of autism in females. Due to their role as one of the professional gatekeepers to referral for autism assessment, the study will specifically focus on teachers. The study will test two hypotheses:

- Gender stereotyping when presented with vignettes of both females and males with autism, which are identical except for the gender of the individual described, teachers will be more likely to (a) identify autism if the individual described is male, and (b) seek support if the individual described is male.
- Female autism phenotype regardless of the gender of the individual described, teachers will be more likely to (a) identify autism in the maletypical phenotype compared to the female-typical phenotype, and (b) seek support for the male-typical phenotype compared to the female-typical phenotype.

# Method

This study was part of a joint project with Fulton (2019). Two separate studies were developed, which used the same data and ethical approval, but had different aims. For more information, a joint thesis statement can be found in Appendix A.

#### **Participants**

This study used opportunity sampling through social media (Facebook and Instagram) adverts to recruit 'primary school educational staff'. This was defined as any individual who had experience of working in an educational capacity within a primary school and had some form of primary education training. Under this inclusion criteria, respondents could be currently working in a primary school, have previously worked in a primary school, or still training to become a primary school teacher. This led to the inclusion of teaching assistants, Special Educational Needs Co-Ordinators (SENCOs), and more senior staff such as Headteachers or Deputy Heads. Any individual who worked in a school but in a non-educational capacity (i.e. Data Manager, Administration staff etc.) was excluded, as well as those that did not complete the entire survey.

A total of 353 respondents began the survey, with 55 dropping out prior to responding to all four vignettes. A further 8 people ended the survey before completing the demographics information, and were therefore also excluded. As demographic information was collected at the end of the survey it is unclear if there were systematic differences in those that dropped out in comparison to those who completed the survey, however there was no significant difference in vignettes presented. Consequently, a total of 290 individuals completed the survey, and one further respondent was excluded due to working in a non-educational capacity. This led to 289 respondents in total.

# Ethics

Ethical approval for the study was gained from University College London Ethics committee (see Appendix B). Respondents were provided with information sheets at the beginning of the questionnaire which they were able to print off if they wished. Informed consent was required before the respondent proceeded with the survey. Both the information sheet and consent can be seen as part of the questionnaire in Appendix E.

# Design

The study used an experimental design delivered via the internet. The main aspect of the design was four short written vignettes about fictional children. The content of these vignettes varied to manipulate the two independent variables: (1) gender and (2) type of autism presentation ('male autism phenotype' vs. 'female autism phenotype'). In total there were four vignettes, listed below:

- A child with the male autism phenotype
- A child with the female autism phenotype
- A child with separation anxiety
- A child with Attention Deficit Hyperactivity Disorder (ADHD)

A description of these vignettes, including how they were developed, will be presented before a further explanation of the design is provided below.

#### Vignette Development

Due to their importance in this study, considerable time was taken prior to recruitment to develop vignettes that were carefully matched in terms of overtness of disorder and the number of symptoms reported. The vignettes were standardised as much as possible; each vignette referred to a seven-year-old pupil and was 180-200 words in length. We decided on five disorder-specific pieces of information for each condition. These were derived from the diagnostic criteria for each disorder and the detailed descriptions of the female autism phenotype in the literature. In order to make the focus of the study less evident, we also structured each vignette to include information alluding to one co-morbidity, and one physical health concern. Further to this, effort was made to ensure the information included in each vignette was as gender-neutral as possible. For example, we referred to a restricted interest in Harry Potter in the vignette for the male autism phenotype, which is known to be enjoyed by both boys and girls alike (which was agreed with both autism experts and respondents involved in our pilot), rather than stereotypical interests more commonly associated with males, such as trains or cars. This enabled us to change only the name and gender pronouns for each disorder-specific vignette, whilst keeping the remainder of the vignette unchanged. Table 1 shows a comparison of all the vignettes to demonstrate the standardisation used.

Table 1	
Symptoms included in each vignette	

Vignette Type	Word Length	Disorder Symptom 1	Disorder Symptom 2	Disorder Symptom 3	Disorder Symptom 4	Disorder Symptom 5	Physical Health Symptom	Co-morbid condition
Female Autism Phenotype	180	Difficulty socialising, but higher social motivation "best friends with another girl in the class, Mia, although Chloe does not seem to be friends with any of the other children	Camouflage/ Mimicking "Chloe will also copy a lot of Mia's behaviours"	Socially acceptable restricted interest "Chloe loves meerkats, and has pictures of them over her books, and will often reference them in her creative writing"	Hyper-sensitivity to touch "you are required to put cream on her during the summer months, which Chloe becomes very distressed about"	Disordered eating "she is a fussy eater and will leave a fair amount of her food every lunchtime"	Mild eczema "she suffers from mild eczema"	Anxiety "she is generally quite nervous and will worry a lot about her work"
Male Autism Phenotype	195	Difficulty socialising "He tries to join in with the other children but tends to be ignored"	Restricted interest "if there is any free time in the classroom, Johnny will spend it playing with his Harry Potter cards."	Difficulty with change "He likes the routine of the classroom, but you have noticed that he can struggle moving from playtime back to the classroom"	Inflexible adherence to routines "you have observed that he responds well to quite strict rules and boundaries"	Deficit in emotional regulation & social communication "He has been involved in a couple of arguments and fights with his peers"	Dietary concerns "you have noted that his lunch lacks healthy options like fruit"	Anxiety "he is quite a nervous child who will worry a lot about things going wrong"
ADHD	193	Difficulties with concentration "He can find it difficult to focus during class"	Easily distracted "will often distract peers or interrupt you when you are giving instructions"	Excess energy "it is difficult to manage James in the classroomhe prefers to be out of the	Impulsive "he can become boisterous with his peers, which has led to other children being hurt accidentally"	Restless & fidgety "will often fidget in his seat"	Dietary concerns "you have noticed that his lunch lacks healthy options"	Disruptive behavioural disorder "It has become difficult to manage James in the classroom and he has

				classroom and engages well in PE"				become one of the more challenging pupils in the year group"
Separation Anxiety	182	Refusal to go to school	Distress leaving caregiver	Physical anxiety symptoms	Fear of event which would lead to separation	Excessive fear of being alone	Mild eczema "She suffers	Low mood "Becky is often
		"arrives late to your class every day"	"you have had to physically coax Becky from her Mum when they enter the classroom"	"Becky will often complain of sickness, such as nausea or headaches"	"she will refuse to go to the far end of the playground, stating that she is scared of being taken by a stranger near the gates"	"she became very tearful at the prospect because she did not want to walk around the school alone"	from mild eczema"	tearful and withdrawn"

During this process, seven autism experts were consulted to provide their opinions on the vignettes. This included researchers who worked in the field, clinicians, and adult females with a diagnosis of autism. This was primarily to assess the ambiguity of each vignette, their accuracy in depicting the disorder, and equality between vignettes in terms of severity of symptoms presented and the extent of information provided. These experts were asked to comment on each of the above aspects, and the vignettes were redrafted a number of times based on their feedback. When all of these experts were satisfied with each vignette, the drafts were used in the pilot and respondents were further asked to comment on the suitability of each vignette. The respondents in the pilot were also satisfied, and therefore these became the final eight vignettes seen in Appendix C.

### Design of experiment

Respondents were asked to complete an online survey, which involved reading the four vignettes described above, before answering questions based on their content. After each vignette, respondents were asked to rate how likely the child depicted in that vignette had: (1) autism, (2) an anxiety disorder, (3) ADHD, and (4) a disruptive behavioural disorder, such as conduct disorder or oppositional defiant disorder. They were then asked how likely they would be to seek additional support for the child depicted, from three different sources: (1) within the school (e.g. the school SENCO), (2), an Educational Psychologist, and (3), a medical professional (e.g. a GP). Consequently, after each vignette they were asked to complete a total of seven Likert scales, ranging from 0-100, with 0 representing 'Extremely Unlikely' and 100 representing 'Extremely Likely', before proceeding onto the next vignette.

There were two independent variables in the experiment: (1) gender, and (2) type of autism presentation ('male autism phenotype' vs. 'female autism phenotype'). The type of autism presentation was a within-person variable, such that every respondent received both the female autism phenotype and the male autism phenotype, along with the two distractor vignettes mentioned previously (ADHD and separation anxiety). Gender was a between-person variable; for each vignette the gender was randomised, with approximately half of the respondents reading the vignette presented as a female, and the other half reading the vignette presented as a male. The only difference in vignette content was the protagonist name and genderspecific pronouns. To clarify, we did not separate the respondents into two groups, with one half receiving all male-gendered vignettes and the other half receiving all female-gendered vignettes. Instead, each vignette was independent, and respondents were therefore randomised to one gender for each vignette separately. This enabled respondents to receive a mixture of male and female gendered vignettes. This resulted in an experiment which used 'Balaam's design' with each respondent randomly assigned to one of four possible sequences. These sequences can be seen in Table 2.

### Table 2

Design/Sequence	Male Autism Phenotype	Female Autism
		Phenotype
Sequence MF	M (male name)	F (female name)
Sequence FM	F (female name)	M (male name)
Sequence MM	M (male name)	M (male name)
Sequence FF	F (female name)	F (male name)

#### Balaam's design for current experiment

#### Procedure

The experiment was delivered via the internet, using the survey software 'Qualtrics'. For this study the respondents were not told they were participating in an experiment focused on autism and gender. Instead the information sheet framed the experiment more generally, and explained that it focused on mental health in children. To ensure this claim was convincing, and further conceal the true focus of the study, we included the additional vignettes – on ADHD and separation anxiety – previously outlined, and the Likert scales on other mental health difficulties. The purpose of this was to prevent priming our respondents and thus improve the external validity of our results.

After completing the seven Likert scales for each presented vignette, respondents were asked to answer a number of demographic and experience related questions. At the end of the questionnaire, as an incentive to participate, respondents were provided with the chance to donate £5 to one of three possible charities. It was explained that the researchers would donate to the respondents chosen charity on their behalf.

# Questionnaire

The primary outcome of the experiment was the level of likelihood expressed for the child having autism. To measure this each respondent was asked 'How likely is it that this child has autism' after being presented with the vignette. The same question was asked for ADHD, anxiety disorder, and disruptive behavioural disorder respectively. As previously mentioned, responses were given on an anchored Likert scale from 0 (Extremely Unlikely) to 100 (Extremely Likely). On similar Likert scales, each respondent was also asked to indicate the likelihood of them seeking

support from (1) within the school e.g. a school SENCO, (2) from an Educational Psychologist, and (3) from a medical professional such as a GP. These questions were forced response, such that respondents could not move on with the questionnaire without providing an answer.

Following these questions, the respondents were asked a number of demographic and experience related questions. This included age, gender, and profession, as well as experience and training in regards to the different mental health difficulties discussed. The questionnaire was manipulated to filter respondents based on their responses i.e. if they reported being a current teacher, they were asked about the school they taught in and the number of children with particular conditions in their class, whilst those that did not report being a current teacher were not presented with these questions.

# Pilot

Once developed, the questionnaire was piloted on four members of primary school staff (two qualified teachers, one teaching assistant, and one SENCO) using cognitive interviewing techniques. This involved asking respondents to state their thoughts aloud as they completed the survey, in addition to the interviewer utilising a semi-structured interview schedule in order to gain the opinions of respondents on particular areas of interest. This was recorded and a copy of the interviewing schedule used can be seen in Appendix D. The purpose of the pilot was to ensure usability of the questionnaire, clarifying if there were any terms or questions that needed to be reworded, and ensure the vignettes represented primary school aged children.

Feedback from this pilot further confirmed the usability of our vignettes, with respondents reporting that each pupil described was representative of a seven-yearold child. Similarly, initial results showed that participants gave different responses for each vignette, and suggested results confirming our hypotheses.

Nonetheless, small changes were made to the questionnaire based on the feedback received. This was mainly in regards to wording: the term 'vignette' was not understood and therefore changed to 'fictional case' throughout, and similarly the term 'refer' led to some confusion and was consequently changed to 'seek support'. Further to this, the original questionnaire referred to Conduct Disorder, however only one interviewee knew of this diagnosis, and she was a trained SENCO. Consequently, questions relating to this disorder were changed to 'disruptive behavioural disorder' instead, as this was a more commonly understood term. A copy of the final questionnaire can be seen in Appendix E.

#### Analyses

For all analyses, the software IBM SPSS Statistics, version 25, was used. Autism Vignettes

To test the hypotheses, whilst accounting for the Balaam's design that included both within and between subject factors, multilevel modelling (MLM) was used. This approach allowed us to account for the fact that Vignette Phenotype is a withinsubjects factor, with every respondent taking part in both conditions (female and male phenotype), whereas Gender is a between-subjects factor, with each respondent only participating in one condition (male or female name). This between-subjects factor is 'nested' within vignette phenotype. That is, due to the randomisation process used, a respondent could have been presented with one gender for the male phenotype (e.g. a boy displaying the male autism phenotype) and the opposite gender for the female phenotype (e.g. a female displaying the female autism phenotype), resulting in some respondents taking part in both conditions for the gender variable. As such, not all observations are independent of one another. This therefore violates the assumption of other possible statistical tests, such as a mixed ANOVA, which require observations to be independent of one another. MLM can accommodate this 'nesting' element of our Balaam's design, allowing us to test the effect of each independent variable on our dependent variable.

MLM was used to analyse all outcome variables separately; the likelihood of the child described having autism, and the likelihood of seeking support for that child from three different sources. For the support seeking outcome variables, two separate analyses were conducted; (1) a MLM analysis, and (2) a repeat of this analysis, whilst controlling for the ratings provided by respondents for the likelihood of the child depicted having autism, ADHD, or disruptive behavioural disorder. The reason for this was to examine whether Gender and/or Vignette Phenotype had an independent effect on the likelihood of respondents seeking support, regardless of how likely the respondent rated the child to have a mental health condition. This provided an indication as to whether primary educational staff show a more general bias against seeking support for females and/or the female presentation, regardless of whether they considered the child to have a mental health difficulty.

#### Distractor vignettes – ADHD and separation anxiety

For the 'distractor' vignettes, there was only one independent variable – Gender. Each respondent participated in one condition (male or female gender), and therefore the observations are independent of one another. Consequently, for each vignette, an independent t-test was conducted to test the impact of gender on respondent's likelihood ratings for the relevant diagnosis (i.e. anxiety disorder and ADHD). Similarly, t-tests were carried out for the effect of Gender on likelihood of seeking support for each vignette also.

#### Results

#### **Sample characteristics**

Of the 289 respondents, 17 were male (5.9%) and 272 female (94.1%). The age ranged from 20 to 64 years, with a mean of 34.5 years (SD = 10.7). The majority of respondents were current teachers (n=217, 75.1%), however the sample also included 11 (3.8%) trainee teachers, 14 (4.8%) teachers not currently practising, and 47 (16.3%) members of educational staff that were not teachers (i.e. teaching assistant, SENCO etc.). The number of years practising as a teacher ranged from less than a year to 42 years (M=8.81, SD=7.7). Table 3 shows the amount of experience respondents have had with autism, anxiety disorder, and ADHD, based on the number of children currently in their class with these diagnoses, and the number of children with these diagnoses they have worked with throughout their career, in addition to any training received by respondents in these conditions.

# Table 3

		Disorder	
	Autism	Anxiety Disorder	ADHD
Children currently in class			
N (%)	234 (81.0)	225 (77.9)	232 (80.3)
$\leq 0$	106 (36.7)	166 (57.4)	147 (50.9)
1	75 (26.0)	38 (13.1)	65 (22.5)
≥2	53 (18.3)	21 (7.3)	20 (6.9)
Mean (SD)	1.03 (1.5)	0.45 (1.0)	0.62 (1.4)
Children with diagnosis throughout career			

Experience of and training in the different mental health diagnoses in children

N (%)	283 (98.0)	279 (96.5)	279 (96.5)
$\leq 0$	8 (2.8)	90 (31.1)	34 (11.8)
1	11 (3.8)	58 (20.1)	37 (12.8)
2	23 (8.0)	36 (12.5)	52 (18.0)
3-5	89 (30.8)	58 (20.1)	74 (25.6)
6-10	69 (23.9)	18 (6.2)	52 (18.0)
11-15	30 (10.4)	5 (2.0)	15 (5.2)
≥16	53 (18.3)	14 (4.8)	15 (5.2)
Mean (SD)	9.58 (8.5)	3.35 (5.9)	5.15 (5.9)
Professional experience of mental health	125 (43.3)	40 (13.8)	87 (30.1)
difficulty prior to training* N (%)			
Personal experience of mental health	119 (41.2)	128 (44.3)	68 (23.5)
difficulty* N (%)			
Training received since qualification* N (%)	158 (54.7)	45 (15.6)	65 (22.5)
Note $\Delta DHD - Attention Deficit Hyperactivit$	v Disorder		

*Note*. ADHD = Attention Deficit Hyperactivity Disorder

\*Number of respondents who reported 'Yes' to these questions

# Multi-level modelling

For the autism vignettes, the scores expressing the likelihood of the described child

having autism, and the scores expressing the likelihood of seeking support for that

child, can be seen in Table 4.

## Table 4

Descriptive statistics for main effect of Vignette Phenotype, Gender Name, and Interaction for all dependent variables.

	Vignette Phenotype		Gender Name		Interaction				
	Male P	Female P	Male N	Female N	Male P Male N	Male P Female N	Female P Male N	Female P Female N	
Likelihood*									
Mean	70.24	60.44	68.32	62.45	70.61	69.89	66.08	54.85	
SD	20.11	25.72	21.44	25.20	19.13	21.06	23.33	26.83	
95% CI	67.81-72.57	57.46-63.42	65.82-70.82	59.55-65.34	67.43-73.80	66.47-73.31	62.23-69.92	50.44-59.25	
N	289	289	285	293	141	148	144	145	
School**									
Mean	75.16	68.42	74.24	69.42	75.78	74.57	72.72	64.15	
SD	23.44	25.51	22.25	26.71	22.34	24.50	22.13	27.90	
95% CI	72.45-77.88	65.47-71.38	71.64-76.83	66.35-72.49	72.06-79.50	70.59-78.55	69.08-76.37	59.57-68.73	
N	289	289	285	293	141	148	144	145	
Psychologist**									
Mean	51.70	48.10	52.25	47.61	50.06	53.25	54.39	41.85	
SD	28.10	29.06	28.51	28.59	28.78	27.45	28.17	28.67	
95% CI	48.44-54.95	44.73-51.46	48.93-55.57	44.32-50.89	45.27-54.86	48.79-57.71	49.75-59.03	37.14-46.55	
Ν	289	289	285	293	141	148	144	145	
Medical**									
Mean	48.92	47.78	50.30	46.45	47.57	50.21	52.98	42.61	
SD	27.98	29.74	29.14	28.50	29.06	26.95	29.07	29.60	
95% CI	45.68-52.16	44.34-51.22	46.90-53.70	43.17-49.73	42.73-52.41	45.83-54.59	48.19-57.77	37.76-47.47	
Ν	289	289	285	293	141	148	144	145	

*Note.* SD = Standard Deviation. CI = Confidence Interval. P = Phenotype. N = Name. \*Estimated likelihood of child having autism, scale 0-100. \*\*Estimated likelihood of seeking support for child from within school/psychologist/medical professional

#### Likelihood of having an autism diagnosis

## Table 5

*Coefficients and significance levels for estimated likelihood of child having an autism diagnosis* 

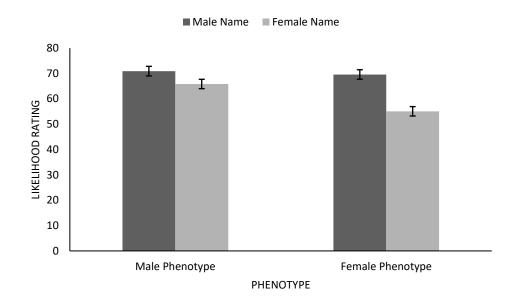
	Coefficient (β)	SE	Ζ	Sig.	95% C.I.
Fixed effects					
Constant	55.07	1.86	29.53	p < .001 ***	51.41 - 58.72
Male phenotype	14.53	2.50	5.84	p < .001 ***	9.65 - 19.41
Male name	10.79	2.61	4.13	p < .001 ***	5.67 - 15.91
Interaction	-9.47	3.74	-2.53	p=.011*	-16.792.15
Random effects					
Between subjects SD ( $\sqrt{\psi}$ )	10.50	1.48	-	-	7.97 – 13.84
Within subjects SD ( $\sqrt{\theta}$ )	20.13	0.84	-	-	18.55 - 21.84
Interclass correlation coefficient	0.21	0.06			0.12 - 0.34

*Note*. Significant \**p*<.05, \*\*\**p*<.001.

As can be seen from Table 5, there was a main effect of Vignette Phenotype (Coefficient = 14.53, p<.001), Gender (Coefficient = 10.79, p<.001), and a significant interaction effect between these two factors (Coefficient = -9.47, p=.011). In regards to Vignette Phenotype, being presented with a male phenotype resulted in an average 14.53 increase in likelihood rating in comparison to the female phenotype, controlling for the other predictors in the model. Similarly, for Gender, compared to the female gender, being presented with a male gender resulted in an average 10.79 increase in likelihood rating, controlling for the other predictors.

The significant interaction showed that the effect of Gender is larger for the female phenotype in comparison to the male. That is, for the male phenotype, the average likelihood ratings between male and female gender were similar (Z=0.5, p=.614) whilst there was a large, significant difference between the average likelihood ratings for the female phenotype for male gender (M = 66.1) and female gender (M = 54.9) (Z=4.13, p<.001). This can be seen more clearly in Figure 1. This

suggests that there is a bias against the vignettes presenting females with autism generally, but particularly if they present with the female phenotype.



*Figure 1*. Graph to show interaction between Vignette Phenotype and Gender for autism likelihood rating.

## Likelihood of seeking support

## Table 6

## Coefficients and significance levels for estimated likelihood of seeking support for child from three different sources

	Non-controlled					Controlled				
	Coefficient	SE	Ζ	Sig.	95% C.I.	Coefficient	SE	Ζ	Sig.	95% C.I.
School										
Constant	64.57	1.92	33.61	p<.001***	60.81 - 68.34	21.86	3.17	6.89	<i>p</i> <.001***	15.64 - 28.08
Male phenotype	9.38	2.38	3.93	<i>p</i> <.001***	4.70 - 14.05	3.10	2.03	1.53	<i>p</i> =.13	-0.88 - 7.08
Male name	7.73	2.58	3.00	<i>p</i> =.003**	2.57 - 12.78	2.41	2.09	1.15	<i>p</i> =.25	-1.69 - 6.51
Interaction	-5.24	3.72	-1.41	<i>p</i> =.16	-12.53 - 2.06	-0.94	2.99	-0.31	<i>p</i> =.75	-6.79 - 4.92
Psychologist										
Constant	42.00	2.16	19.44	<i>p</i> <.001***	37.77 – 46.24	7.28	3.95	1.84	<i>p</i> =.07	-0.46 - 15.02
Male phenotype	10.92	2.54	4.30	<i>p</i> <.001***	5.94 - 15.89	4.07	2.44	1.67	<i>p</i> =.09	-0.72 - 8.86
Male name	12.23	2.78	4.40	<i>p</i> <.001***	6.78 - 17.68	7.71	2.54	3.04	<i>p</i> =.002**	2.74 - 12.68
Interaction	-14.74	4.03	-3.66	<i>p</i> <.001***	-22.646.85	-11.64	3.63	-3.21	<i>p</i> =.001**	-18.754.53
Medical										
Constant	44.10	2.18	20.24	p < .001 * * *	39.83 - 48.37	8.38	4.08	2.05	p=.04*	0.38 - 16.38
Male phenotype	6.42	2.52	2.55	<i>p</i> =.011*	1.48 - 11.37	0.84	2.50	0.34	<i>p</i> =.74	-4.07 - 5.75
Male name	7.39	2.78	2.66	<i>p</i> =.008**	1.95 - 12.83	3.90	2.60	1.50	<i>p</i> =.13	-1.19 - 8.99
Interaction	-10.67	4.02	-2.65	p<.001***	39.83 - 48.37	-8.41	3.71	-2.26	<i>p</i> =.02*	-15.691.13

*Note*. Significant \**p*<.05, \*\**p*<.01, \*\*\**p*<.001.

#### Multi-level modelling without additional controls

When the three 'support seeking' outcome variables were analysed, without controlling for the estimations of each mental health difficulty, a number of significant results were found. A main effect of Vignette Phenotype was found for all forms of support seeking, with the male phenotype vignette resulting in higher ratings than the female phenotype for seeking support from within the school (Coefficient = 9.38, p<.001), from an Educational Psychologist (Coefficient = 10.92, p<.001), and from a medical professional (Coefficient = 6.42, p=.011).

Similarly, a main effect of Gender was found for all forms of support seeking; the male gender resulted in higher likelihood ratings than the female gender for seeking support from within the school (Coefficient = 7.73, p=.003), from an Educational Psychologist (Coefficient = 12.23, p<.001), and from a medical professional (Coefficient = 7.39, p=.008).

Furthermore, a significant interaction was found between Vignette Phenotype and Gender for ratings of support seeking from an Educational Psychologist (Coefficient = -14.74, p<.001), and from a medical professional (Coefficient = -10.67, p<.001) – an explanation of this interaction is provided below.

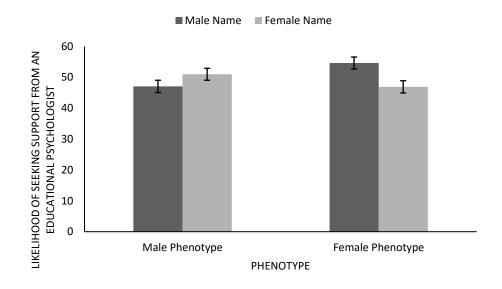
## Controlling for ratings of mental health conditions

To examine whether Vignette Phenotype and Gender had an independent effect on the support seeking outcome variables, the analysis was repeated after controlling for the likelihood ratings for autism, ADHD, and disruptive behavioural disorder. As can be seen from Table 6, after controlling for these factors, the majority of the findings were no longer significant. There was no longer a main effect of Vignette Phenotype for any of the forms of support seeking, indicating that it is the higher estimations of the child presented in this vignette as having a mental health difficulty that is resulting in higher support seeking ratings, rather than an independent effect of the male phenotype.

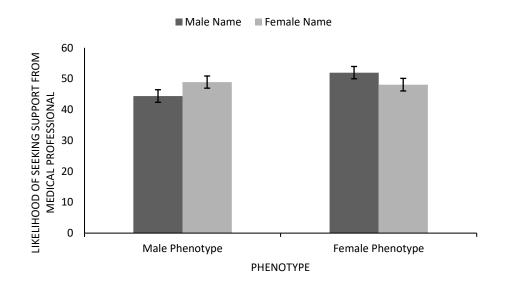
Similarly, when the likelihood ratings were controlled for, there was no main effect of Gender for two forms of support seeking: from within the school or from a medical professional. Interestingly, there was still a significant main effect of Gender for seeking support from an Educational Psychologist (Coefficient =7.71, p=.002) suggesting that if the child depicted in the vignette was male, regardless of how likely the respondent thought that the child had a mental health condition, they rated as more likely to seek support from an Educational Psychologist than if the child depicted was female.

Nonetheless, although reduced in significance, the interaction effects remained even after controlling for the estimations of each mental health difficulty. A significant interaction was found between Vignette Phenotype and Gender for ratings of support seeking from an Educational Psychologist (Coefficient = -11.64, p=.001), and from a medical professional (Coefficient = -8.41, p=.02). For both of these forms of support, the interaction showed that for the male phenotype, the male gender resulted in a lower likelihood of seeking support, whilst for the female phenotype the inverse was found; the female gender resulted in a lower likelihood of seeking support. This can be seen more clearly in Figures 2 and 3. This would suggest that respondents reported being more likely to seek support from outside of the school for the vignettes whereby the gender of the child is in contrast to the presentation. It is possible that when the gender and the phenotype are comparable (i.e. a boy with the typical male presentation, and a girl with the typical female

presentation), respondents indicated that they would be less concerned about the child presented.



*Figure 2.* Graph to show interaction between Vignette phenotype and Gender for likelihood of seeking support from an Educational Psychologist.



*Figure 3*. Graph to show interaction between Vignette Phenotype and Gender for likelihood of seeking support from a medical professional.

## T-tests for 'distractor' vignettes, describing ADHD and separation anxiety

For the distractor vignettes, independent samples t-tests were conducted to compare differences in likelihood/support seeking ratings in male gendered vignettes and female gendered vignettes for each of the conditions. The results of these tests can be seen in Table 7 below.

The majority of results found were non-significant. There was a significant difference in the likelihood ratings of seeking support from an Educational Psychologist for male separation anxiety vignettes (M=66.9, SD=25.1) and female separation anxiety vignettes (M=60.4, SD=27.5); t(287)=2.1, p = .04. However, the significance level was small, and it is possible that this could be a result of the number of analyses conducted rather than a true observed effect.

## Table 7

	Ν		M (SD)		t	df	Sig.	95% C.I.
	Male	Female	Male	Female				
Separation Anxiety								
Likelihood	140	149	87.0 (11.3)	85.7 (13.8)	0.9	281.8	<i>p</i> = .37	-1.6 - 4.3
Within	140	149	82.2 (19.6)	81.0 (21.8)	0.5	287	<i>p</i> =.61	-3.5 - 6.1
EP	140	149	66.9 (25.1)	60.4 (27.5)	2.1	287	p = .04*	0.4 - 12.6
Medical	140	149	67.6 (25.4)	63.9 (26.2)	1.2	287	<i>p</i> =.23	-2.3 - 9.7
ADHD								
Likelihood	150	139	67.9 (20.8)	66.2 (22.0)	0.7	287	<i>p</i> =.49	-3.2 - 6.7
Within	150	139	81.2 (20.3)	81.7 (18.6)	-0.2	287	<i>p</i> =.83	-5.0 - 4.0
EP	150	139	60.9 (28.2)	61.0 (27.1)	-0.04	287	<i>p</i> =.97	-6.5 - 6.3
Medical	150	139	55.2 (28.1)	55.0 (27.1)	0.05	287	<i>p</i> =.96	-6.2 - 6.6

Independent Samples T-Tests for Separation Anxiety and ADHD vignettes

Note. EP = Educational Psychologist. \*Significant p<.05

## Discussion

In accordance with the hypotheses put forward, when presented with vignettes depicting fictional children, primary school educational staff were more likely to identify autism in males than females, and were more sensitive to the male phenotype in comparison to the female phenotype of autism, regardless of the gender described. Furthermore, the interaction showed that the bias against girls was more prominent for the female phenotype. As the vignettes indicated that both the female gender and the typical female presentation can result in an increased likelihood of autism going unrecognised, this provides an insight into one influence on the diagnostic bias against females with autism.

### Recognition of autism in the vignettes

As previously described, research investigating the discrepancy in prevalence rates of diagnosed autism in males and females has resulted in the understanding that there is a bias against females with the condition (Lai et al., 2015). This has been evidenced by the current study, in which, despite providing vignettes describing children with autism, those vignettes which portrayed female children or those with a female presentation, were less likely to have their autism recognised in comparison to their male counterparts.

Although the existence of a diagnostic bias against females with autism was somewhat accepted in the literature, the mechanisms of this bias were largely unclear. Qualitative studies with late-diagnosed women had suggested that there could be a bias at the point of referral (Bargiela et al., 2016). From our understanding, this is the first study attempting to formally test this possibility, and our results have evidenced two likely mechanisms by which this bias occurs. Firstly, by providing respondents with identical vignettes apart from the gender described, and finding that girls were significantly less likely to have their autism recognised, this study directly demonstrates a bias against girls based solely on gender. The reasons for this cannot be formally concluded from the current investigation; however, it is possible that this is due to an expectancy bias amongst respondents. It has been shown that when a disorder occurs more often in one gender, or the features are more stereotypical of one gender, clinicians can often exhibit a diagnostic bias in line with their expectations (Kreiser & White, 2014). The prevalence rates previously discussed and theories such as the 'Extreme Male Brain', in which it is argued that males are biologically more likely to have the condition (Baron-Cohen, 2002), have likely contributed to the belief that autism is more common in this gender. As a result, this stereotype may have shaped responses in the current study such that educational professionals were influenced by their expectation that autism is less likely to be present when responding to a female vignette.

By further demonstrating that the female phenotype is less recognised than the male, regardless of the gender described, this study shows that the female presentation is another mechanism potentially contributing to the diagnostic bias against females with autism. This supports the findings of Bargiela et al. (2016), in their qualitative study with late-diagnosed women with autism. The participants of this study reported that their delay in receiving a diagnosis was partly due to professionals having a poor understanding of how autism may present in females. Of particular note, these women reported that in primary school, teachers interpreted their symptoms as 'shyness' and utilised stereotypes regarding a lack of special interests in mathematics and science as a reason for the girl not having the condition. The symptoms described by these women contributed to the female autism phenotype developed in this study, and our results evidenced their claims that educational staff were less likely to recognise this presentation of autism in comparison to the stereotypical male presentation they also discuss.

It is possible that these findings are the result of the female phenotype being a milder, or more subtle, presentation of autism. As previously mentioned, one of the key diagnostic criteria for autism is deficits in social communication and interaction (APA, 2013), and yet one of the defining features of the female autism phenotype is the ability to camouflage this deficit by mimicking peers and displaying a motivation to socialise (Lai et al., 2015). This ability to camouflage likely makes it difficult for professionals to notice the hidden difficulties these girls are experiencing. In the current study, for example, the child described in the female phenotype vignette displays less obvious social communication and interaction deficits than the male phenotype. Consequently, respondents may have provided lower likelihood ratings for the female phenotype vignette in comparison to the male because the symptoms that define the female presentation are harder to detect.

Further to this, it is important to note that our findings showed that educational professionals were still, on average, fairly sensitive to autism in our vignettes; the average score was 60 out of 100 for the female phenotype and therefore an indication of more 'likely' than 'unlikely'. Despite this, the likelihood drops further to just 54 when the vignette is presented as a female, which is the gender most likely to express this phenotype. Similarly, ratings showed that for this phenotype, educational staff indicated that they were actually 'unlikely' to seek support from an Educational Psychologist or a medical professional, suggesting that if these were real children, their school would not enable them to receive an assessment with a professional who could provide a diagnosis. This would undoubtedly contribute to the observed discrepancy in prevalence rates of diagnosed autism in males and females.

### Alternative interpretations to the findings

Nonetheless, it is also feasible that the current findings were the result of how the vignettes were written. Even if we account for the differing symptoms between the male and female phenotypes, it is still possible that the symptoms described in the vignette for the female autism phenotype were not as severe as the symptoms depicted in the male phenotype vignette. As previously discussed, a considerable amount of time and attention was given to the development of the vignettes in order to avoid this issue and create comparable presentations. Autism experts were consulted on this matter and reported that the vignettes depicted children of comparable severity. Despite our efforts however, it is still possible that the male and female presentations were not equal in terms of severity and subtlety, and this led to the lower autism likelihood ratings observed for the female autism phenotype.

This leads onto one of the limitations of the current study; our conclusions are based on the data from only four vignettes. We could have included multiple descriptions for each condition, and thus reduced the reliance on a small number of vignettes. By including more than one description of the female autism phenotype, we would have reduced the effect of possible differences in symptom severity, improving the reliability of our findings and thus the ability to draw firmer conclusions. Yet, this design may also have resulted in lower recruitment rates and a greater burden on our respondents. The respondents would have had to read and answer more content and questions, resulting in the survey requiring more time and effort. This may have led to a higher drop-out rate, as well as reducing the likelihood of respondents sharing the survey with other educational staff.

## Support seeking & the influence of gender expectations

In regards to the support seeking variables, the findings showed that when the 'likelihood' ratings were controlled for, the effects of gender or presentation on the likelihood of respondents seeking support were no longer significant. This would support the idea that it is the under-recognition of autism in the females presented in these vignettes that is causing any differences in support seeking behaviour. This is a useful finding, as it demonstrates that it is improbable there is an overall bias against girls whereby educational staff are less likely to seek support for females generally in comparison to their male counterparts. Instead, it would indicate that when an educational professional is concerned about a child, they will seek support from various sources; but they seem to be less concerned about girls and the female autism phenotype in comparison to boys and the comparable male presentation. This could be a result of broader sociocultural influences: as explained by Kreiser and White (2014), gender-based expectations might result in symptoms of autism in girls being viewed as more 'normal' for that gender and therefore less concerning. For example, in girls, social difficulties or abnormal behaviour can be perceived as being "passive" or "shy", particularly if she is seemingly managing well (Attwood, 2006). Consequently, teachers and other professionals are less likely to be concerned for these children.

Arguably, the possible influence of socio-cultural expectations is further evidenced by the interactions found in the study, which remained significant even after controlling for the estimations of mental health diagnoses. These interactions showed an inverse relationship, whereby respondents provided higher ratings for vignettes in which the gender and phenotype did not correspond. Research investigating gender stereotypes has shown that teachers often expect boys to be more aggressive or assertive, whilst they expect girls to be passive and easier to manage (Gray & Leith, 2004). For example, Kokkinos, Panayiotou, and Davazoglou (2004) examined the effects of pupil gender on teachers' perceptions of the seriousness of various unacceptable behaviours, and found that teachers rated behaviours such as being sensitive, crying, and being easily disappointed, as more serious in boys, whilst they rated behaviours such as being verbally or physically abusive, as more serious in girls. In line with these findings, respondents in this study may not expect a male child to be passive and anxious, as depicted in the female phenotype vignette, and similarly may not expect a female child to be aggressive with peers, as depicted in the male phenotype vignette. Consequently, when presented with this behaviour, it is viewed as more concerning due to the discrepancy with expectations, and therefore individuals are more likely to seek support for that child.

#### Other conditions in the study

The diagnostic bias against females with autism is further supported by the findings for the other mental health diagnoses investigated in this study. These results showed that educational professionals were more likely to recognise both ADHD and an anxiety disorder in the vignettes presented, regardless of the gender described. Similarly, there was no significant effect of gender on the estimations, indicating that respondents' ability to recognise other mental health diagnoses was not influenced by the gender of the child depicted. This is important as it demonstrates that there is not a bias against one gender more generally, and instead this seems to be specific to autism. As such, this provides further evidence for the suggestion that the female autism phenotype and the stereotypes surrounding autism are influencing the diagnostic prevalence rates. In spite of this, it is worthy of note that both the ADHD vignette and the separation anxiety vignette were based on the diagnostic criteria provided in the DSM-5. Yet, similar to the research on the differing male and female presentations in autism, there is a growing literature which suggests there could also be differing male and female presentations in ADHD (Gershon & Gershon, 2002). Research has shown that girls with ADHD are often more inattentive, rather than impulsive or hyperactive, and display less aggressive and disruptive behaviour than their male counterparts (Quinn & Wigal, 2004). Our ADHD vignette arguably depicts the male presentation of ADHD, and thus it is possible that if we had included the female ADHD presentation described in the literature, we may have observed an effect of gender and/or presentation on the likelihood of the described child having ADHD. This is a potential avenue for future research, which could also contribute to the literature on the differing prevalence rates of ADHD in males and females.

## Limitations

Due to the use of vignettes in this study however, our findings may lack ecological validity. In order to manipulate the variables in this experiment, we were required to use depictions of 'pretend' children, rather than real life examples. Although this allowed for variable control and a direct investigation into the influence of gender and the female autism phenotype, we cannot be certain that these findings reflect what occurs in real school settings, nor if they are a true reflection of educational professionals' behaviour.

On the other hand, it can be argued that the method of this study could have resulted in respondents displaying higher sensitivity to autism, and real-life behaviour may show more bias than our findings suggest. That is, although careful

consideration was taken to hide the autism-focused nature of the study, respondents were still asked to rate the likelihood of a child having a mental health diagnosis, and therefore the respondents were forced to look for potential signs and consider the possibility. However, in real-life, faced with around thirty children in a classroom, it is unlikely that educational professionals will be looking as closely, and the possibility may be less likely to cross their minds. Indeed, it is shown that as the size of classes increase, teachers display less knowledge of their pupils and find it harder to detect problems or specific needs (Blatchford, Russell, & Brown, 2009). As such, one can hypothesise that, in reality, primary educational staff may display a higher level of bias than our study detected, due to a combination of the subtlety of the female autism phenotype and the difficulty noticing individual pupil needs in a class of children.

Furthermore, these results are comparable to the experiences reported by latediagnosed women (Bargiela et al., 2016). By demonstrating similar findings across two differently designed studies, there is increasing evidence to support our conclusions.

To be able to conclusively argue that the respondents were influenced by the female presentation of autism and the gender of the child in the vignette in this study, it would have been beneficial to have a qualitative element to the experiment. Our conclusions are currently based on numbered estimations, and therefore we cannot know what information the respondents used to inform their decisions. It is recognised that educational staff can express stereotypical and/or incorrect assumptions about autism (Bargiela et al., 2016; Crane et al., 2018), and interviews with professionals, parents, and individuals with autism, have shown that there is

variation in the level of autism awareness amongst professionals (Crane et al., 2018). A qualitative element to this study could have provided information on the possible assumptions educational professional hold about autism, as well as their knowledge of the condition in females. This would aid in informing the increased training of educational staff on autism, which is being regarded as a necessity by those with autism and their families (Crane et al., 2018).

Similarly, it is important to note that the sample was limited to primary school educational staff, and thus our conclusions cannot be generalised to other populations. These individuals are key gatekeepers to an autism diagnosis, and an early diagnosis is more beneficial to the child. Consequently, it was important to investigate the diagnostic bias in this population due to the significant impact it could have on diagnosis in female children. Nevertheless, it is acknowledged that this population are not the only gatekeepers to diagnosis, and it is unclear whether others, such as GPs or those in later education, show a similar bias. Indeed, late-diagnosed women and those unsatisfied with the diagnostic process, have noted that GPs often displayed a lack of autism awareness, and failed to recognise the more subtle symptoms of the condition (Bargiela et al., 2016; Crane et al., 2018). This would suggest that GPs are another important population to investigate in regards to the diagnostic bias against females, and future research would benefit from focusing on this population.

Further to this, there are limitations in regard to the possible integrity and reliability of the collected data in the current study. As previously mentioned, only data from respondents who completed the entire survey were included in the analysis. Due to the structure of the questionnaire, we were unable to gain any demographic information on those respondents who dropped out, and therefore it is unclear whether these individuals are significantly different from our final sample. Similarly, as the experiment was completed remotely, there is uncertainty in regards to how carefully the respondents completed the survey. That is, respondents may have varied in how long they spent considering and reading the vignettes, and some respondents may have provided quick ratings without properly considering the questions being posed. To overcome these limitations, future research could repeat the study but ask for demographic information first, and potentially measure the time it takes each respondent to complete the questionnaire. This would then allow for comparisons between respondents who drop-out and those who complete the survey, and also in responses between those who complete the experiment faster than average and those who do not. This would provide a measure of the reliability of the final responses and therefore add further support for the findings.

### Implications for research

This leads onto the implications of the current study. In regards to research, this experiment provides direction for future study, as well as a methodology for these investigations. As previously mentioned, from our understanding this is the first study to attempt to formally test whether there is a bias against females with autism and the mechanisms of this bias. Our findings begin to support this conclusion; however, the current study should be replicated to ensure our findings were not an anomaly. If alternative vignettes were also developed, this would begin to clarify whether our findings were the result of differences in severity between our vignettes. Similarly, the study should be repeated with other populations who act as

gatekeepers to autism diagnosis, such as GPs and educational staff in secondary schools. This would provide an insight into whether the behaviour of these populations are also potentially contributing to the diagnostic bias against females with autism, or whether our findings are limited to primary school educational staff.

Although there are limitations with our study design, the use of vignettes provided an ethical and internally valid method of investigating the mechanisms of the diagnostic bias against females with autism. Consequently, this study provides a method to future researchers hoping to investigate this area. The method can be easily manipulated to improve on other aspects of our design; for instance, potentially compromising on sample size but including multiple vignettes for each condition to improve on reliability. In addition, our study has implications for other areas of research, whereby this methodology could also be utilised in the literature investigating the potential differing male and female presentations in ADHD and the significant differences in prevalence rates of this diagnosis.

### Clinical implications

Clinically, the current study has implications for those girls whose autism is going unrecognised and the primary school staff who potentially contribute to this diagnostic bias. As stated above, a missed diagnosis has a significant impact on the wellbeing of individuals, and can increase the likelihood of experiencing a number of adverse effects. Consequently, it is important that we reduce the rates of undiagnosed autism, and improve our recognition of girls with the condition. By demonstrating two possible mechanisms for this diagnostic bias, the current study provides a method of beginning to tackle the issue. Our findings begin to suggest that primary educational staff may not recognise the female autism phenotype, and thus by

providing improved training in autism and how it may present in females, we may begin to improve referral rates to specialist services for these girls.

The current study also suggests that educational staff may exhibit stereotypical views regarding gender. This has implications for both autism and children more generally. Not only does gender stereotyping of particular diagnoses, such as autism and ADHD, potentially result in missing these conditions in children, but gender stereotyping has been shown to have a wide range of negative implications. It can result in a self-fulfilling prophecy, whereby children conform to the gender roles assigned to them, and underperform in subjects which are viewed as atypical for their gender (Wang, Rubie-Davies, & Meissel, 2018). Similarly, the behaviour of teachers can result in girls forming negative attitudes towards 'male interests' such as computers and mathematics (Siann, Macleod, Glissov, & Durndell, 1990), and children receiving differing levels of feedback and attention, which can impact selfcompetence and self-worth (Gray & Leith, 2004). Indeed, Gray and Leith (2004) found that only 10% of the teachers they surveyed had received any training or discussion on gender issues in their initial teacher training. As the current study suggests that this issue may be prevalent amongst primary school educational staff, we could improve the outcomes for children by including information on these issues in training and courses.

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Part 3: Critical Appraisal

#### Introduction

This critical appraisal reflects on a number of challenges that arose during the process of completing this project. It will first consider the use of vignettes in the project and the different decisions this methodology presented, before commenting on the methodology more generally in regards to the use of quantitative and qualitative approaches. It will then discuss our respondents and the decisions we faced regarding our inclusion criteria, before ending with a reflection on the process of completing a joint project.

## Vignettes

As the project focused around a set of vignettes, it became apparent early on in the research process that their development was one of the most important aspects of the project overall. There were multiple factors which needed to be considered in order to best utilise this methodology and ensure that the study was both valid and reliable. As such, a considerable amount of time went into developing these vignettes during the research process, and I have detailed below some of the challenges we faced.

## Balancing a number of variables

One of the main difficulties we came across during the development process was the substantial number of factors we had to consider and balance against one another. We had to make the vignettes realistic, relatively concise, and not too 'obvious', whilst also balancing the need to include sufficient diagnostic information to test our variables, and standardise the vignettes so that they were comparable enough to test our hypotheses. This resulted in a number of decisions and compromises.

When faced with the diagnostic criteria, it was important to think about how these symptoms might realistically present in a child at primary school. My previous experience of working with children with autism prior to training, followed by the school observations I carried out during my placement at CAMHS, provided knowledge that proved particularly useful for this task. I was able to draw upon examples of children I had observed and worked with, and think about some of the behaviours they showed. However, this process made me reflect on the difficulty teachers must have in noticing the more subtle symptoms of diagnoses such as autism, in the environment and conditions they work in. I was aware that any difficulties would be hidden amongst the needs and behaviour of 20-30 other children in the class, whilst I was also struck by how easily each of the symptoms we had included in the vignette could be explained by other things. This gave me a sense of empathy towards educational staff when faced with the responsibility of potentially 'missing' difficulties in children, as it seems like an almost impossible task considering all the other things they must contend with.

The difficulties teachers face and the reality of their decision-making process also led to reflections on the length of the vignettes. During the pilot, many of the respondents who took part commented on the limited amount of information provided before being asked to make a decision. This made me consider how realistic the use of vignettes was for the purpose of our project. In reality, educational staff will see children almost every day and have the ability to observe them in lots of different scenarios and contexts. They also have the ability to talk to and share thoughts with other members of staff who also know the child. This likely influences the opinion these professionals form on each pupil, and also impacts any subsequent decisions they make about onward referrals or support for that child. Consequently,

teachers likely have a much broader understanding of a pupil than perhaps the vignettes in the study provided.

One the other hand, the decision to compromise on this by keeping our vignettes relatively concise was founded on valid concerns for the project overall. Firstly, we considered the well-established fact that current UK teachers face a significant workload and are already stretched in terms of time and resources (National Education Union, 2018). Consequently, we did not want the survey to be too arduous or time-consuming, as not only would this be unethical on our respondents, but we were unlikely to be able to recruit a sufficient number of teachers willing to complete the entire survey. Further to this, by extending the length of our vignettes we realised it would become more difficult to standardise their content across all the mental health difficulties presented. This would have resulted in a number of confounding variables, and thus limited the conclusions we could draw from our results. Similarly, although respondents in the pilot commented on the minimal amount of information, they also reflected that the children depicted in the vignettes were comparable to pupils they are currently or have previously worked with. As such, I feel that overall, we attained a sufficient balance between the amount of information we provided to the respondents and the ecological validity of that information, because our vignettes were comparable to real-life children.

## Developing the female phenotype

Another aspect which proved challenging when developing these vignettes was the lack of differing criteria for boys and girls with autism. We had decided to use the DSM-5 diagnostic criteria for all the conditions portrayed in the vignettes to ensure both their content and face validity. However, this presented us with some difficulty

when writing the differing male and female autism vignettes as the DSM-5 does not distinguish between the two. We were forced to rely on research which had investigated the differences between males and females, particularly the qualitative information provided by late-diagnosed women in the study conducted by Bargiela, Steward & Mandy (2016), and the extensive review by Lai, Lombardo, Auyeung, Chakrabarti, & Baron-Cohen (2015). However, this brings into question the validity of the female autism vignette in comparison to the others. The other vignettes are based on criteria developed from a long and stringent process of research evaluation on many years' worth of research and findings. In comparison, the research pertaining to the female phenotype is still in its infancy, resulting in ongoing disagreement in regards to some of the differences between the male and female presentations. This made writing the vignette somewhat more difficult as we did not have a set of clear criteria in which to base it upon.

Despite this, in order to investigate teachers' ability to recognise the female phenotype, we had no choice but to use the information currently available. As my review of the literature indicated, there are a number of well-established differences between the male and female presentations, which proved sufficient to write our vignettes. Furthermore, we consulted expert clinicians and researchers during our vignette development, which also aided with this issue. However, as the female autism phenotype becomes more well-defined and evidenced, it would be useful to repeat this research to gain a more valid comparison.

## Methodology

During the pilot we adopted the use of cognitive interviewing to gain feedback on the questionnaire and vignettes. This enabled us to hear respondents' thoughts as they

completed the survey, as well as gain an insight into their decision-making process. This was particularly helpful and resulted in me reflecting on the additional benefit a qualitative aspect would provide to our project. Although our methodology enabled us to manipulate variables and directly test the effect of gender and autism presentation on respondents' ratings of autism likelihood, it was still limited in terms of the conclusions we could draw. By relying on quantitative ratings, we were unable to gain any insight into the reasoning behind these decisions, nor the information used by our respondents to base their ratings.

The consideration to include a qualitative aspect to our project involved a cost-benefit analysis surrounding the additional beneficial information we could gain, versus the increased burden on both our respondents completing the questionnaire, and ourselves when attempting to analyse the results. If we had included additional questions at the end of each vignette which asked about the reasoning behind respondents' ratings, we would have been able to gain further insight into the bias educational staff demonstrate against females with autism. It may have informed us of the symptoms in the male presentation which led to higher ratings, as well as respondents' thoughts on the female presentation and what they were and were not concerned about. Similarly, we could have compared the reasoning for male-gendered vignettes against the almost identical female-gendered vignettes to potentially gain an insight into why respondents display this bias. This would have further validated any conclusions drawn from the project, and potentially provided information which could be used to develop ways of reducing this bias.

Despite these benefits, there were valid concerns about introducing an additional qualitative aspect to the experiment. Firstly, in terms of practicality, we would have had to include these open-ended questions after every rating to ensure

respondents did not determine the focus of the study. This would have significantly extended the length of the survey for respondents; requiring more time and effort. As previously mentioned, we were keen to avoid this due to concerns over response rate, and also the time-constraints of our target population. Another factor we considered came to our analyses. Neither I nor the other trainee had relevant research experience in qualitative approaches. Although we had been provided with relevant teaching on the course, neither of us felt confident in analysing data this way, and we were also aware that our supervisor had more experience in quantitative analyses. Consequently, this felt like a large undertaking that we were unlikely to have the required time or resources for.

However, the primary reason for not including a qualitative aspect to the survey was because we were unable to do it justice within the constraints of this project. Admittedly, when I analysed the results, I found myself asking questions about the responses and wishing I could directly ask respondents more about their ratings and decisions. However, this simply increased my enthusiasm for the potential of future research to investigate the area using a qualitative approach. A separate project utilising this methodology would offer increased flexibility in terms of questioning, and it would focus on the reasoning and decision-making process. A methodological pluralism approach such as this, combining findings from a diverse number of studies, would elucidate the diagnostic bias further.

## Respondents

When first developing our research project, we knew that we wanted to target gatekeepers to autism assessment. This raised a number of questions regarding which group or groups to focus our research on and decisions had to be made regarding our inclusion and exclusion criteria.

## Inclusion of teachers and General Practitioners (GPs)

As this was a joint project, in the initial proposal we had planned on conducting the same experiment on two different populations – teachers and GPs. This was due to the acknowledgement that these two populations represent two of the main gatekeepers for children to be referred to services which can provide assessment and diagnosis for autism. This would have improved the generalisability of our results, as well as providing more information on where the bias against girls with autism was occurring. However, one of the first problems we encountered in the project was the rejection of this initial proposal due to the likely difficulty in recruiting both teachers and GPs – two professions well-known for being stretched for resources and time. It was suggested that we should focus on one population and create two separate research projects using this sample. At the time this felt frustrating; not only did we need to develop ideas for another project, but we had already begun to develop the differing vignettes for both populations, so it felt like we had wasted time and effort in the research process.

Nonetheless, upon reflection I think this was a sensible decision for a number of reasons. In the end we encountered no problems recruiting for our study, as we were able to focus on one population and utilise contacts that both myself and the other trainee had in the education system. This enabled us to gain more respondents than we had planned, which added to the power of each of our projects. I can now acknowledge how difficult it would have been to recruit GPs when neither of us had any contacts in the area, nor methods of recruiting within GP practices. Similarly, as

two separate projects with differing target populations, undoubtedly we would have each focused on our own required samples. Without our combined efforts, it is unlikely we would have recruited as many educational staff as we did, thus reducing the overall power of our research.

#### Inclusion and exclusion criteria

After deciding to target school staff due to their role as gatekeepers to autism assessment, we had to determine our inclusion and exclusion criteria further. When we first began to consider this, I was struck by how many aspects we had to think about and felt overwhelmed as to how we would decide. For instance, we had to consider whether to target primary or secondary school staff, or both; to include solely teachers or other school professionals also; and whether to include only those qualified and employed at the time of the study, or to open recruitment to those individuals in training or those no longer employed in the relevant roles. This required us to balance the need to target individuals who realistically had a role in supporting a child to receive an autism diagnosis, against the need for less stringent inclusion criteria to aid with recruitment and generalisability.

The decision to restrict our sample to primary school staff was based on two aspects. Firstly, as previously mentioned, we recognised the vignettes as one of the most important parts of our research, and the need to standardise these as much as possible to avoid any confounding variables. As a result, we noted that all the vignettes would have to depict a child of the same age. We could not, therefore, include both primary and secondary school staff as a proportion of the respondents may be unaware of how a child of that age behaves, and it would lack in ecological validity. Once we had realised that we could only target primary or secondary school

staff, we made the decision to present a primary school aged child in the vignettes and focus on this population. This was because the literature showed that the gender gap in autism diagnosis is most prevalent during this time (Rutherford et al., 2016), and because of the importance of an early diagnosis previously mentioned (Bryson, Rogers, & Fombonne, 2003). Although this decision limited the generalisability of our results, I think as a first step in investigating the diagnostic bias against females, it was important to focus on a population that has the potential to have the largest impact.

During the development process, I was acutely aware that we referred to teachers as being the gatekeepers to diagnosis, and yet from my own knowledge and experience, I understood that this responsibility in schools was not solely on teachers. Many primary schools have members of staff with further training or responsibility in regards to children with additional needs and these individuals play a key role in liaising with Educational Psychologists and/or outside services for assessments and support. Similarly, Teaching Assistants often spend more time with the children who require additional attention or support - regardless of whether they have any diagnoses – and therefore are in the prime position to notice and raise concerns for a child. As we reflected on these scenarios, it became clear that we needed to extend our inclusion criteria beyond only teachers. In collaboration with respondents from our pilot - who had more experience of the primary school setting it was agreed that the most appropriate target population should be primary school 'educational' staff. That is, through discussions with these respondents, any member of staff in an educational capacity (i.e. they had received some sort of teaching or education training) had a responsibility to raise any concerns about a child to another member of staff. It was recognised that there were other professions within a primary school, such as a Lunchtime Supervisor, or a Receptionist, who have contact with the children but are unlikely to have any educational training and seemingly would not be expected to seek support for a child if required. Not only did this decision feel more inclusive and ecologically valid, but it also enabled us to consider comparisons between different professions within a school to investigate whether those with more specialist training (i.e. SENCO's) show less of a bias.

#### Recruitment

As previously discussed, one of the key concerns raised from our proposal was the possible difficulty we would face in recruiting teachers due to the time constraints they already face. I think this consideration featured heavily when developing our research and impacted a number of decisions. As mentioned, we purposefully tried to keep the survey reasonably concise and simple, so that the research would not be too time-consuming. We also used an internet survey for our design, which aided in terms of flexibility; it provided respondents with the ability to complete the project at a time which suited them best, as well as the option to complete the survey on the go through their smart-phone. This felt important to me ethically; coming from a family of teachers I know the pressures they face, and so I wanted to ensure the questionnaire was not an additional burden on their time and resources.

Despite our concerns however, we faced no difficulties in recruiting and in the end recruited more respondents than we had originally aimed for. There are a number of possible reasons for this. It could be that the care taken over ensuring the questionnaire was relatively short and straight forward increased the likelihood of respondents sharing the questionnaire with colleagues, utilising a snowball sampling method as we had hoped for. Furthermore, the other trainee and I were able to

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combine our recruitment efforts by focusing on one population, and we were aided by extending our inclusion criteria to include other primary educational staff.

Even with these considerations however, we managed to recruit respondents from all over the UK in a matter of weeks. This led me to reflect on the other possible reasons for our recruitment success. It made me consider the relevance of the questionnaire to our target population. Although we did not explain the real focus of the experiment, we did state that it was an investigation related to child mental health. Arguably, this is a popular topic in the media at the moment, with more money and focus being invested in the area. As this population undoubtedly cares about children and their wellbeing, it is possible they felt more invested in research related to this topic, and were therefore more willing to partake in relevant projects.

Nevertheless, concerns over recruitment had been the reason for us focusing on only one population, and had almost resulted in the proposal being rejected. Yet these doubts were unfounded, and our recruitment was one of the easier parts of the research process. Consequently, this caused me to reflect on the knowledge that we cannot be certain of the arising difficulties during research, and thus it proved worthy to go ahead with the project despite our concerns.

#### Joint theses

As previously mentioned, this was a joint project with Fulton (2019). Overall, I found being a part of a joint project advantageous and I enjoyed working alongside another trainee during the research process. There were practical advantages, such as the ability to share the workload and thus reduce the stress which often comes with conducting research. Similarly, we were able to combine our time and resources for

aspects such as recruitment, which enabled us to gain more respondents than perhaps one of us could individually.

Looking back over the entire process however, the aspect that I found most useful was the emotional support I gained from working alongside another trainee, and the availability of a like-minded individual with whom I could problem-solve and share ideas with. As training progresses and more time is dedicated to the thesis over other elements of the course, I realised how easily training can become a source of loneliness or isolation. Yet by completing a joint project, the other trainee and I were forced to keep in regular contact throughout, and we were therefore able to use one another to reflect on the process and any difficulties we were facing individually. Although our supervisor was an ongoing source of support, and he was available to help with any questions, queries, or difficulties, it was useful to be able to ask another trainee first, thus saving us time in the long-term, as well as enabling us to focus meetings with our supervisor on topics that required more support or discussion.

Completing a joint project did not come without challenges or difficulties. One of the primary challenges we faced was early on in the process, when our initial proposals were rejected and we were forced to rethink one of the projects. This meant one of us had to start again and could not undertake the thesis they had originally planned. Arguably, this had the potential to create tension or conflict as we decided which of our projects would be changed and how. However, I feel that this experience set the precedent for how we worked together through the rest of the process; listening to and respecting one another's viewpoints and preferences, as well as ensuring the workload was equally shared.

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Additionally, by working well together, there was a risk that our theses would be too similar and thus fail in terms of stand-alone projects. However, although this was a challenge we consistently faced throughout the process, we were able to continually check in on this and avoid any duplication. Furthermore, following our data collection, our projects naturally separated and thus the research process became more independent. Through the use of our good working relationship we were able to maintain the benefit of having another individual to go to for advice and/or emotional support, even during this time.

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# Appendix A Joint thesis statement

As this was a joint theses with Kate Fulton (Fulton, 2019), I have outlined below our individual contributions to the study for clarification.

# Vignettes

The process of developing the vignettes was split equally. During the first drafts, we divided the number of required vignettes in two and each wrote half, before sharing with the other to edit and re-draft accordingly. This process continued throughout the development of the vignettes, following consultation with our supervisors and the autism experts – we each wrote and edited half before sharing back and forth via email.

# Questionnaire

Following discussions about what questions we would like to ask, Kate drafted the response scales and questionnaire on Word. After we had decided on a finalised version, I put the questionnaire and the vignettes together on Qualtrics.

## Forms

We completed the Low Risk ethics form and the Data Protection form together following a meeting about these with our supervisor. I completed and submitted the request for funding, whilst Kate completed the risk assessment.

# Pilot

We sat down together to draft the cognitive interview used for piloting and decide how many respondents we wanted. I travelled to a primary school and conducted and completed the pilot. I fed the responses back to both Kate and our supervisor and we made edits to the study together accordingly.

## Recruitment

Kate created the advert for social media and posters. We both utilised our own social media for recruitment and both used Kate's advert for this. We also both contacted any schools we knew to aid with recruitment.

# Analyses & Write-up

As our project aims were different, we conducted analyses and write-up separately. I conducted the statistics and analyses for my own project, and wrote up the entirety of the study, including the literature review, independently.

# Appendix B Ethical Approval

## UCL RESEARCH ETHICS COMMITTEE OFFICE FOR THE VICE PROVOST RESEARCH

27<sup>th</sup> June 2018

Dr William Mandy Department of Clinical, Educational and Health Psychology UCL

Dear Dr Mandy,

## **Notification of Ethics Approval**

# <u>Project ID/Title: 12891/001: Investigating the potential diagnostic bias and predictors of teachers'</u> <u>ability to identify Autism Spectrum Disorder</u>

Further to your satisfactory responses to my comments, I am pleased to confirm in my capacity as Joint Chair of the UCL Research Ethics Committee (REC) that I have ethically approved your study until **January 31**<sup>st</sup> **2020**.

## Notification of Amendments to the Research

You must seek Chair's approval for proposed amendments (to include extensions to the duration of the project) to the research for which this approval has been given. Each research project is reviewed separately and if there are significant changes to the research protocol you should seek confirmation of continued ethical approval by completing an 'Amendment Approval Request Form' <u>http://ethics.grad.ucl.ac.uk/responsibilities.php</u>

## Adverse Event Reporting – Serious and Non-Serious

It is your responsibility to report to the Committee any unanticipated problems or adverse events involving risks to participants or others. The Ethics Committee should be notified of all serious adverse events via the Ethics Committee Administrator (<u>ethics@ucl.ac.uk</u>) immediately the incident occurs. Where the adverse incident is unexpected and serious, the Joint Chairs will decide whether the study should be terminated pending the opinion of an independent expert. For non-serious adverse events the Joint Chairs of the Ethics Committee should again be notified via the Ethics Committee Administrator within ten days of the incident occurring and provide a full written report that should include any amendments to the participant information sheet and study protocol. The Joint Chairs will confirm that the incident is non-serious and report to the Committee at the next meeting. The final view of the Committee will be communicated to you.

## <u>Final Report</u>

At the end of the data collection element of your research we ask that you submit a very brief report (1-2 paragraphs will suffice) which includes in particular issues relating to the ethical implications of the research i.e. issues obtaining consent, participants withdrawing from the research, confidentiality, protection of participants from physical and mental harm etc.

In addition, please:

- ensure that you follow all relevant guidance as laid out in UCL's Code of Conduct for Research: <u>http://www.ucl.ac.uk/srs/governance-and-committees/resgov/code-of-conduct-research</u>
- note that you are required to adhere to all research data/records management and storage procedures agreed as part of your application. This will be expected even after completion of the study.

With best wishes for the research.

Yours sincerely

## **Professor Michael Heinrich**

Joint Chair, UCL Research Ethics Committee

Cc: Alana Whitlock

Kate Fulton

# Appendix C Copy of final vignettes

## Vignette 1 – ASD female phenotype, female name

Chloe is a 7-year-old pupil in your class. She is best friends with another girl in the class, Mia, although Chloe does not seem to be friends with any of the other children. You have noticed that Chloe dislikes it when Mia begins to play with the other children, wanting her exclusive focus. Chloe will also copy a lot of Mia's behaviours. Chloe loves meerkats, and has pictures of them over her books, and will often reference them in her creative writing in English. Chloe is a bright student, however she is generally quite nervous and will worry a lot about her work, as well as scare stories she hears from other children. The only times you really have difficulties with Chloe is during lunchtime, particularly in the summer; she suffers from mild eczema so you are required to put cream on her during the summer months, which Chloe becomes very distressed about. You have also been told by the lunch time staff that she is a fussy eater and will leave a fair amount of her food every lunchtime.

## Vignette 1 – ASD female phenotype, male name

Charlie is a 7-year-old pupil in your class. He is best friends with another boy in the class, Mitch, although Charlie does not seem to be friends with any of the other children. You have noticed that Charlie dislikes it when Mitch begins to play with the other children, wanting his exclusive focus. Charlie will also copy a lot of Mitch's behaviours. Charlie loves meerkats, and has pictures of them over his books, and will often reference them in his creative writing in English. Charlie is a bright student, however he is generally quite nervous and will worry a lot about his work, as well as scare stories he hears from other children. The only times you really have difficulties with Charlie is during lunchtime, particularly in the summer; he suffers from mild eczema so you are required to put cream on him during the summer months, which Charlie becomes very distressed about. You have also been told by the lunch time staff that he is a fussy eater and will leave a fair amount of his food every lunchtime.

## Vignette 2 – Separation anxiety, female name

Becky is a 7-year-old pupil who arrives late to your class every day. When she gets to school she is often very tearful and distressed, and in the past you have had to physically coax Becky from her Mum when they enter the classroom. Becky will often complain of sickness, such as nausea or headaches, which you believe is in an attempt to go home. She suffers from mild eczema, which is often used as a reason to stay home from school as Becky will often say her skin is too sore to sit on the classrooms carpet. Becky is often tearful and withdrawn, and even when she is encouraged to play with the other children she will refuse to go to the far end of the playground, stating that she is scared of being taken by a stranger near the gates.

When you have tried to encourage Becky by giving her extra input and sending her on an 'important' errand to another classroom, she became very tearful at the prospect because she did not want to walk around the school alone.

# Vignette 2 – Separation anxiety, male name

Ben is a 7-year-old pupil who arrives late to your class every day. When he gets to school he is often very tearful and distressed, and in the past you have had to physically coax Ben from his Mum when they enter the classroom. Ben will often complain of sickness, such as nausea or headaches, which you believe is in an attempt to go home. He suffers from mild eczema, which is often used as a reason to stay home from school as Ben will often say his skin is too sore to sit on the classroom carpet. Ben is often tearful and withdrawn, and even when he is encouraged to play with the other children he will refuse to go to the far end of the playground, stating that he is scared of being taken by a stranger near the gates. When you have tried to encourage Ben by giving him extra input and sending him on an 'important' errand to another classroom, he became very tearful at the prospect because he did not want to walk around the school alone.

# Vignette 3 – ASD male phenotype, male name

Johnny is a 7-year-old pupil in your class. He loves playing tag and really enjoys being able to play during break time. He tries to join in with the other children but tends to be ignored. If there is any free time in the classroom, Johnny will spend it playing with his Harry Potter cards. There are a couple of boys in the class who love Harry Potter too, but Johnny is the most obsessed with it. He likes the routine of the classroom, but you have noticed that he can struggle moving from playtime where he is engaging in tag, back to the classroom. He is quite a nervous child who will worry a lot about things going wrong. When he gets upset he does find it quite difficult to calm himself down and you have observed that he responds well to quite clear rules and boundaries. He has been involved in a couple of arguments and fights with his peers which you and the other staff have to keep a keen eye on. Generally, Johnny is a fit and healthy child but you have noted that his lunch lacks healthy options like fruit.

# Vignette 3 – ASD male phenotype, female name

Joanna is a 7-year-old pupil in your class. She loves playing tag and really enjoys being able to play during break time. She tries to join in with the other children but tends to be ignored. If there is any free time in the classroom, Joanna will spend it playing with her Harry Potter cards. There are a couple of girls in the class who love Harry Potter too, but Joanna is the most obsessed with it. She likes the routine of the classroom, but you have noticed that she can struggle moving from playtime where she is engaging in tag, back to the classroom. She is quite a nervous child who will worry a lot about things going wrong. When she gets upset she does find it quite difficult to calm herself down and you have observed that she responds well to quite clear rules and boundaries. She has been involved in a couple of arguments and fights with her peers which you and the other staff have to keep a keen eye on. Generally, Joanna is a fit and healthy child but you have noted that her lunch lacks healthy options like fruit.

# Vignette 4 – ADHD, male name

James is a 7-year-old pupil in your class. He is working below expected levels and struggles with his maths and English, which makes him describe school as "rubbish". He can find it difficult to focus during class and will often distract peers or interrupt you when you are giving instructions. You have noticed that he actively refuses to comply with requests and rules. It has become difficult to manage James in the classroom as a result of this, and he has become one of the more challenging pupils in the year group. James prefers to be out of the classroom and engages well in PE. He loves playing tag and says he wants to play sport when he grows up. He can become boisterous with his peers, which has led to other children being hurt accidently, after which he seems genuinely sorry and seems as though he did not really know what he was doing. After break time he can struggle with the transition back to the classroom and will often fidget in his seat. Generally, James is a fit and healthy child but you have noticed that his lunch lacks healthy options.

## Vignette 4 – ADHD, female name

Jade is a 7-year-old pupil in your class. She is working below expected levels and struggles with her maths and English, which makes her describe school as "rubbish". She can find it difficult to focus during class and will often distract peers or interrupt you when you are giving instructions. You have noticed that she actively refuses to comply with requests and rules. It has become difficult to manage Jade in the classroom as a result of this, and she has become one of the more challenging pupils in the year group. Jade prefers to be out of the classroom and engages well in PE. She loves playing tag and says she wants to play sport when she grows up. She can become boisterous with her peers, which has led to other children being hurt accidently, after which she seems genuinely sorry and seems as though she did not really know what she was doing. After break time she can struggle with the transition back to the classroom and will often fidget in her seat. Generally, Jade is a fit and healthy child but you have noticed that her lunch lacks healthy options.

# Appendix D Cognitive Interview Schedule

# **Prior:**

- Stress to the individual that we are not primarily collecting survey data on them, but rather testing a questionnaire that has questions that may be difficult to understand, hard to answer, or that make little sense
- Make clear that although we are asking them to answer the questions as carefully as possible, we are primarily interested in the ways that they arrived at those answers and the problems they encountered. Therefore, any detailed help they can give us is of interest, even if it seems irrelevant or trivial
- Might be helpful to add "I didn't write these questions, so don't worry about hurting my feelings if you criticise them my job is to find out what is wrong with them".

# Introduction

- What do you understand by the term 'vignette'?
- What do you understand by the term 'demographics'?
- Could you tell me what you are consenting to and your rights in regards to this?
- Are there any aspects that you would need clarifying further before you felt happy to agree?
- General question does it read ok? Clear etc.?

# Vignettes

- General feedback on vignette is there anything that is unclear? Do you feel it represents a primary school aged child?
- Do you know what is meant by ADHD/Autism/Conduct Disorder/Anxiety/Depression?
- What information did you use to get to your response?
- What do you understand by 'referring'?
- What language would you use for seeking more professional help for a child with possible mental health difficulties? Would you use the word 'refer'?
- Feedback on rating scales are they easy to use? How do you feel about them and the options?
- How easy/difficult was it to come to your responses? Did you feel the presentations in the vignettes were obvious/ambiguous?

# **Demographics/Experience**

- Do the choices provided fit with your desired response?
- Is each question clearly written?
- For 'years practising' question how did you get to this number?
- What do you understand by 'training on autism'?

• Are the lists comprehensive enough e.g. for 'types of school'?

# Overall

- Overall experience filling it out?
- Layout? Ease of use? Time taken? Repetitiveness?

# Appendix E Copy of final questionnaire given to respondents

## <u>An online study investigating school professionals' understanding of a range of mental</u> <u>health problems in children</u>

Please save or print this information sheet if you would like to keep a copy. Alternatively, you could contact the research team to request a copy.

This study has been approved by the UCL Research Department of Clinical, Educational and Health Psychology Ethics Chair **Project ID Number**: 12891/001

We would like to invite you to participate in this research project. You should only participate if you want to, and choosing not to take part will not disadvantage you in any way. Before you decide whether you want to take part, please read the following information carefully and discuss it with others if you wish. Ask us if there is anything that is not clear or you would like more information.

What is this research about? The purpose of this research is to gauge your knowledge on a range of mental health presentations.

What will I have to do? If you agree to take part, you will be asked to complete an online survey. There will be a series of case studies for you to read followed by questions about how likely you would be to refer the child on to more specialist services. There will then be a series of questions for you to answer about your professional experience and training as well as a few questions about your demographic information.

**Who can take part?** We are inviting any primary school teachers, trainee primary school teachers, or SENCOs to take part in the study.

**Are there any risks or possibility of discomfort?** The risks involved in participating are minimal. If you find yourself becoming distressed during the study, you can choose to stop at any time. If you feel upset or distressed as a result of participation, please contact the research principal investigator who will be able to provide information for accessing resources or services which you may find helpful.

**How will we maintain your privacy and confidentiality?** You will be asked to give some demographic information, such as your age, gender, and ethnicity. All information will be stored confidentially and only the researchers involved in the study will have access or process the data. Participation cannot take place without your agreement. All data will be collected and stored in accordance with the Data Protection Act 1998. If you choose to withdraw from the study, you have the option of also requesting that all data be deleted.

When and where will the study take place? The study will take place at a time convenient to you. The survey will take approximately 20 minutes to complete.

**Will I be compensated for my participation?** The first 162 people to take part in the study will be given £5 to donate to charity at the end of the survey.

What if I have questions about the project? If you have any questions or require more information about this study, please contact the principal investigator or researchers using the contact details below:

**Researchers:** Kate Fulton, University College London, 1-19 Torrington Place, London WC1E 7HE, Email: kate.fulton.13@ucl.ac.uk Alana Whitlock, University College London, 1-19 Torrington Place, London WC1E 7HE, Email: Alana.whitlock.16@ucl.ac.uk

**Principal Investigator:** Dr William Mandy, University College London, 1-19 Torrington Place, London WC1E 7HB, Tel: 020 7679 5922, Email: will.mandy@ucl.ac.uk

If you feel you require any additional support or participation has harmed you in any way, you can contact the principal investigator using the details above for further advice and information

1. I confirm that I understand that my participation is voluntary and that I am free to withdraw at any time and without giving any reason.

2. I confirm that I understand that all data will be confidential and personal details will not be included in reports or publications.

3. I also understand that should the research be published in a journal that requires making the data available, the data will be provided only in a form that preserves the anonymity of all of the participants.

4. I agree to my data being collected, processed and stored according to the Data Protection Act of 1998 and to be destroyed after a minimum of 10 years.

5. I agree to take part in the above study.

- Yes
- No

Thank you for agreeing to take part in this study. You will now be presented with a series of 4 fictional cases of primary school aged children. Please read these carefully before answering the questions below each one. Please also note that there are no right or wrong answers, we are just interested in your views.

#### Vignette 1 – ASD Female Phenotype, Female name

Chloe is a 7-year-old pupil in your class. She is best friends with another girl in the class, Mia, although Chloe does not seem to be friends with any of the other children. You have noticed that Chloe dislikes it when Mia begins to play with the other children, wanting her exclusive focus. Chloe will also copy a lot of Mia's behaviours. Chloe loves meerkats, and has pictures of them over her books, and will often reference them in her creative writing in English. Chloe is a bright student, however she is generally quite nervous and will worry a lot about her work, as well as scare stories she hears from other children. The only times you really have difficulties with Chloe is during lunchtime, particularly in the summer; she suffers from mild eczema so you are required to put cream on her during the summer months, which Chloe becomes very distressed about. You have also been told by the lunch time staff that she is a fussy eater and will leave a fair amount of her food every lunchtime.

# Based on the information above, please answer the following questions. We understand that you have limited information to base your answers, however please answer to the best of your ability.

How likely is it that this child has Attention Deficit Hyperactivity Disorder (ADHD)?

0	100
Extremely unlikely	Extremely likely
How likely is it that this child has an Anxiety Disorder?	
0	100
Extremely unlikely	Extremely likely

How likely is it that this child has an Autism Spectrum Disorder (e.g. autism or Asperger's)?

0	100
Extremely unlikely	Extremely likel
How likely is it that this child has a disruptive behavioural disorder (s disorder or conduct disorder)?	such as oppositional defiant
0	100
Extremely unlikely	Extremely likel
How likely would you be to seek additional support or advice regards school e.g. the school SENCO	ing this child WITHIN your
0	100
Extremely unlikely	Extremely likel
How likely would you be to seek additional support or advice regardi Educational Psychologist?	ing this child from an
0	100
Extremely unlikely	Extremely likel
How likely would you be to recommend that this child has an assessmental health professional?	nent from a medical (e.g. GP) or
0	100
Extremely unlikely	Extremely likel

#### Vignette 1 – ASD Female Phenotype, Male name

Charlie is a 7-year-old pupil in your class. He is best friends with another boy in the class, Mitch, although Charlie does not seem to be friends with any of the other children. You have noticed that Charlie dislikes it when Mitch begins to play with the other children, wanting his exclusive focus. Charlie will also copy a lot of Mitch's behaviours. Charlie loves meerkats, and has pictures of them over his books, and will often reference them in his creative writing in English. Charlie is a bright student, however he is generally quite nervous and will worry a lot about his work, as well as scare stories he hears from other children. The only times you really have difficulties with Charlie is during lunchtime, particularly in the summer; he suffers from mild eczema so you are required to put cream on him during the summer months, which Charlie becomes very distressed about. You have also been told by the lunch time staff that he is a fussy eater and will leave a fair amount of his food every lunchtime.

Based on the information above, please answer the following questions. We understand that you have limited information to base your answers, however please answer to the best of your ability.

Extremely unlikely	100
	Extremely likely
How likely is it that this child has an Anxiety Disorder? 0	100
Extremely unlikely	Extremely likely
How likely is it that this child has an Autism Spectrum Disorder (e.g. autisn	n or Asperger's)?
0	100
Extremely unlikely	Extremely like
How likely is it that this child has a disruptive behavioural disorder (such as disorder or conduct disorder)?	s oppositional defiant
0	100
Extremely unlikely	Extremely like
How likely would you be to seek additional support or advice regarding this school e.g. the school SENCO	s child WITHIN your
0	100
Extremely unlikely	Extremely like
How likely would you be to seek additional support or advice regarding this Educational Psychologist?	s child from an
	100
0	
0 Extremely unlikely	Extremely like
Extremely unlikely How likely would you be to recommend that this child has an assessment free	

## Vignette 2 – Separation Anxiety, Female name

Becky is a 7-year-old pupil who arrives late to your class every day. When she gets to school she is often very tearful and distressed, and in the past you have had to physically coax Becky from her

Mum when they enter the classroom. Becky will often complain of sickness, such as nausea or headaches, which you believe is in an attempt to go home. She suffers from mild eczema, which is often used as a reason to stay home from school as Becky will often say her skin is too sore to sit on the classrooms carpet. Becky is often tearful and withdrawn, and even when she is encouraged to play with the other children she will refuse to go to the far end of the playground, stating that she is scared of being taken by a stranger near the gates. When you have tried to encourage Becky by giving her extra input and sending her on an 'important' errand to another classroom, she became very tearful at the prospect because she did not want to walk around the school alone.

Based on the information above, please answer the following questions. We understand that you have limited information to base your answers, however please answer to the best of your ability.

How likely is it that this child has Attention Deficit Hyperactivity Dis 0	100
Extremely unlikely	Extremely likely
How likely is it that this child has an Anxiety Disorder?	
0	100
Extremely unlikely	Extremely likely
How likely is it that this child has an Autism Spectrum Disorder (e.g.	autism or Asperger's)?
0	100
Extremely unlikely	Extremely likely
How likely is it that this child has a disruptive behavioural disorder (s disorder or conduct disorder)?	
0	100
Extremely unlikely	Extremely likely
How likely would you be to seek additional support or advice regardi school e.g. the school SENCO	ing this child WITHIN your
0	100
Extremely unlikely	Extremely like
How likely would you be to seek additional support or advice regardi Educational Psychologist?	ing this child from an
0	100
Extremely unlikely	Extremely like

How likely would you be to recommend that this child has an assessment from a medical (e.g. GP) or mental health professional?

0	100

Extremely unlikely

Extremely likely

#### Vignette 2 – Separation Anxiety, Male name

Ben is a 7-year-old pupil who arrives late to your class every day. When he gets to school he is often very tearful and distressed, and in the past you have had to physically coax Ben from his Mum when they enter the classroom. Ben will often complain of sickness, such as nausea or headaches, which you believe is in an attempt to go home. He suffers from mild eczema, which is often used as a reason to stay home from school as Ben will often say his skin is too sore to sit on the classroom carpet. Ben is often tearful and withdrawn, and even when he is encouraged to play with the other children he will refuse to go to the far end of the playground, stating that he is scared of being taken by a stranger near the gates. When you have tried to encourage Ben by giving him extra input and sending him on an 'important' errand to another classroom, he became very tearful at the prospect because he did not want to walk around the school alone.

Based on the information above, please answer the following questions. We understand that you have limited information to base your answers, however please answer to the best of your ability.

How likely is it that this child has Attention Deficit Hyperactivity Disorder (ADHD)?

0	100
Extremely unlikely	Extremely likely
How likely is it that this child has an Anxiety Disorder?	
0	100
Extremely unlikely	Extremely likely
How likely is it that this child has an Autism Spectrum Disorder (e.g. autism	or Asperger's)?
0	100
Extremely unlikely	Extremely likely
How likely is it that this child has a disruptive behavioural disorder (such as disorder or conduct disorder)?	oppositional defiant
0	100
Extremely unlikely	Extremely likely
How likely would you be to seek additional support or advice regarding this oschool e.g. the school SENCO	child WITHIN your
0	100
Extremely unlikely	Extremely likely

How likely would you be to seek additional support or advice regarding this child from an Educational Psychologist?

0	100
Extremely unlikely	Extremely likely

How likely would you be to recommend that this child has an assessment from a medical (e.g. GP) or mental health professional?

100

Extremely likely

Extremely unlikely

0

## Vignette 3 – ASD Male Phenotype, Male name

Johnny is a 7-year-old pupil in your class. He loves playing tag and really enjoys being able to play during break time. He tries to join in with the other children but tends to be ignored. If there is any free time in the classroom, Johnny will spend it playing with his Harry Potter cards. There are a couple of boys in the class who love Harry Potter too, but Johnny is the most obsessed with it. He likes the routine of the classroom, but you have noticed that he can struggle moving from playtime where he is engaging in tag, back to the classroom. He is quite a nervous child who will worry a lot about things going wrong. When he gets upset he does find it quite difficult to calm himself down and you have observed that he responds well to quite clear rules and boundaries. He has been involved in a couple of arguments and fights with his peers which you and the other staff have to keep a keen eye on. Generally, Johnny is a fit and healthy child but you have noted that his lunch lacks healthy options like fruit.

Based on the information above, please answer the following questions. We understand that you have limited information to base your answers, however please answer to the best of your ability.

How likely is it that this child has Attention Deficit Hyperactivity Disorder (ADHD)?

0	100
Extremely unlikely	Extremely likely
How likely is it that this child has an Anxiety Disorder? 0	100
Extremely unlikely	Extremely likely
How likely is it that this child has an Autism Spectrum Disorder (e.g. autis	sm or Asperger's)?
0	100
Extremely unlikely	Extremely likely

How likely is it that this child has a disruptive behavioural disorder (such as oppositional defiant disorder or conduct disorder)?

-1	nn
	111
	00

100

0

0	100
Extremely unlikely	Extremely likely
How likely would you be to seek additional support or advice regardin Educational Psychologist?	g this child from an
0	100
Extremely unlikely	Extremely likely

How likely would you be to seek additional support or advice regarding this child WITHIN your school e.g. the school SENCO

How likely would you be to recommend that this child has an assessment from a medical (e.g. GP) or mental health professional?

0	100
Extremely unlikely	Extremely likely

#### Vignette 3 – ASD Male Phenotype, Female name

Joanna is a 7-year-old pupil in your class. She loves playing tag and really enjoys being able to play during break time. She tries to join in with the other children but tends to be ignored. If there is any free time in the classroom, Joanna will spend it playing with her Harry Potter cards. There are a couple of girls in the class who love Harry Potter too, but Joanna is the most obsessed with it. She likes the routine of the classroom, but you have noticed that she can struggle moving from playtime where she is engaging in tag, back to the classroom. She is quite a nervous child who will worry a lot about things going wrong. When she gets upset she does find it quite difficult to calm herself down and you have observed that she responds well to quite clear rules and boundaries. She has been involved in a couple of arguments and fights with her peers which you and the other staff have to keep a keen eye on. Generally, Joanna is a fit and healthy child but you have noted that her lunch lacks healthy options like fruit.

## Based on the information above, please answer the following questions. We understand that you have limited information to base your answers, however please answer to the best of your ability.

How likely is it that this child has Attention Deficit Hyperactivity Disorder (ADHD)?

0	100
Extremely unlikely	Extremely likely
How likely is it that this child has an Anxiety Disorder?	
0	100
Extremely unlikely	Extremely likely
How likely is it that this child has an Autism Spectrum Disorder (e.g. autism	m or Asperger's)?
0	100
Extremely unlikely	Extremely likely

100
Extremely likely
nild WITHIN your
100
Extremely likely
nild from an 100
Extremely likely
Extremely likely a medical (e.g. GP) or
Extremely likely a a medical (e.g. GP) or 100

#### Vignette 4 – ADHD, Male name

James is a 7-year-old pupil in your class. He is working below expected levels and struggles with his maths and English, which makes him describe school as "rubbish". He can find it difficult to focus during class and will often distract peers or interrupt you when you are giving instructions. You have noticed that he actively refuses to comply with requests and rules. It has become difficult to manage James in the classroom as a result of this, and he has become one of the more challenging pupils in the year group. James prefers to be out of the classroom and engages well in PE. He loves playing tag and says he wants to play sport when he grows up. He can become boisterous with his peers, which has led to other children being hurt accidently, after which he seems genuinely sorry and seems as though he did not really know what he was doing. After break time he can struggle with the transition back to the classroom and will often fidget in his seat. Generally, James is a fit and healthy child but you have noticed that his lunch lacks healthy options.

Based on the information above, please answer the following questions. We understand that you have limited information to base your answers, however please answer to the best of your ability.

How likely is it that this child has Attention Deficit Hyperactivity Disorder (ADHD)?

0	100
Extremely unlikely	Extremely likely
How likely is it that this child has an Anxiety Disorder?	100
0 Extract also well'italia	
Extremely unlikely	Extremely likely

How likely is it that this child has an Autism Spectrum Disorder (e.g. autism or Asperger's)?

0	100
Extremely unlikely	Extremely likely
How likely is it that this child has a disruptive behavioural disorder (disorder or conduct disorder)?	(such as oppositional defiant
0	100
Extremely unlikely	Extremely likely
How likely would you be to seek additional support or advice regard school e.g. the school SENCO	ling this child WITHIN your
0	100
Extremely unlikely	Extremely likely
How likely would you be to seek additional support or advice regard Educational Psychologist?	ling this child from an
0	100
Extremely unlikely	Extremely likely
How likely would you be to recommend that this child has an assess mental health professional?	ment from a medical (e.g. GP) or
0	100
Extremely unlikely	Extremely likely

#### Vignette 4 – ADHD, Female name

Jade is a 7-year-old pupil in your class. She is working below expected levels and struggles with her maths and English, which makes her describe school as "rubbish". She can find it difficult to focus during class and will often distract peers or interrupt you when you are giving instructions. You have noticed that she actively refuses to comply with requests and rules. It has become difficult to manage Jade in the classroom as a result of this, and she has become one of the more challenging pupils in the year group. Jade prefers to be out of the classroom and engages well in PE. She loves playing tag and says she wants to play sport when she grows up. She can become boisterous with her peers, which has led to other children being hurt accidently, after which she seems genuinely sorry and seems as though she did not really know what she was doing. After break time she can struggle with the transition back to the classroom and will often fidget in her seat. Generally, Jade is a fit and healthy child but you have noticed that her lunch lacks healthy options.

Based on the information above, please answer the following questions. We understand that you have limited information to base your answers, however please answer to the best of your ability.

How likely is it that this child has Attention Deficit Hyperactivity Disorder (ADHD)?

0	100
Extremely unlikely	Extremely likely
How likely is it that this child has an Anxiety Disorder?	
0	100
Extremely unlikely	Extremely likely
How likely is it that this child has an Autism Spectrum Disorder (e.g. autism	or Asperger's)?
0	100
Extremely unlikely	Extremely likely
How likely is it that this child has a disruptive behavioural disorder (such as disorder or conduct disorder)?	oppositional defiant
0	100
Extremely unlikely	Extremely likely
How likely would you be to seek additional support or advice regarding this of school e.g. the school SENCO	child WITHIN your
0	100
Extremely unlikely	Extremely likely
How likely would you be to seek additional support or advice regarding this of Educational Psychologist?	child from an
0	100
Extremely unlikely	Extremely likely
How likely would you be to recommend that this child has an assessment from mental health professional?	m a medical (e.g. GP) or
0	100
Extremely unlikely	Extremely likely

You have almost completed the survey; we now just need to ask some brief questions about your teaching experiences.

What is your age? (Years)

What is your gender?

Please choose the statement that best describes you:

- I am currently practising as a Teacher
- I am currently training to become a Teacher

• I am trained as a Teacher but no longer practising

• I am another member of teaching staff (e.g. SENCO, Teaching Assistant etc.) I was previously another member of teaching staff (e.g. SENCO, Teaching Assistant etc.) Other (Please specify)

Display this question if: I am currently practising as a Teacher OR I am trained as a Teacher but no longer practising

How many years in total have you practised as a teacher?

### Display this question if:

I am currently practising as a Teacher OR I am currently training to become a Teacher OR I am trained as a teacher but no longer practising

Please choose the option that best describes your teaching qualification

- PGCE (1 year full time or 2 years part time)
- BSc/BA in Education (3 year degree)
- School-centred initial teacher training (1 year full time)
- Other (please specify)

In what type of schools have you practised? Please tick all that apply.

- Mainstream state-funded nursery
- Mainstream state-funded primary school
- Mainstream state-funded secondary school
- Mainstream state-funded sixth form college
- Mainstream independent nursery
- Mainstream independent primary school
- Mainstream independent secondary school
- Mainstream independent sixth-form college
- Maintained special school for children with special educational needs
- Maintained special school for children with Autism
- Independent special school for children with special educational needs
- Independent special school for children with Autism
- Other (please specify)

Have you ever practised at a mainstream school with any of the following? Please tick all that apply.

- Specialist behavioural unit (e.g. nurture group)
- Specialist educational needs provision unit
- Autism Resource Base
- None of the above

#### Display this question if:

*I am currently practising as a Teacher OR I am another member of teaching staff (e.g. SENCO, Teaching Assistant etc.)* 

Where in the UK is your current school located?

- North East
- North West
- Yorkshire and The Humber
- East Midlands
- West Midlands
- East of England
- London

- South East
- South West
- Wales
- Scotland
- Northern Ireland

### Display this question if:

*I am currently practising as a Teacher OR I am another member of teaching staff (e.g. SENCO, Teaching Assistant etc.)* 

How many years have you spent in your current school?

Display this question if: I am currently practising as a Teacher OR I am another member of teaching staff (e.g. SENCO, Teaching Assistant etc.)

What is your primary role in your current school?

- Teacher
- Teaching Assistant
- Headteacher
- Deputy Headteacher
- Assistant Headteacher
- SENCo
- Inclusion Leader
- Phase Leader
- Other (please specify)

## Display this question if:

*I am trained as a Teacher but no longer practising OR I was previously another member of teaching staff (e.g. SENCO, Teaching Assistant etc.)* 

What was your primary role in school?

- Teacher
- Teaching Assistant
- Headteacher
- Deputy Headteacher
- Assistant Headteacher
- SENCo
- Inclusion Leader
- Phase Leader
- Other (please specify)

#### Do you currently teach a class?

- Yes
- No

#### Display this question if:

*I am currently practising as a Teacher OR I am another member of teaching staff (e.g. SENCO, Teaching Assistant etc.)* 

How many children with a diagnosis of Autism Spectrum Disorder are currently in your class?

Display this question if:

*I am currently practising as a Teacher OR I am another member of teaching staff (e.g. SENCO, Teaching Assistant etc.)* 

How many children with a diagnosis of Attention Deficit Hyperactivity Disorder (ADHD) are currently in your class?

## Display this question if: I am currently practising as a Teacher OR I am another member of teaching staff (e.g. SENCO, Teaching Assistant etc.)

How many children with a diagnosis of Anxiety Disorder are currently in your class?

Approximately how many children with a diagnosis of Autism Spectrum Disorder have you worked with throughout your professional career?

Approximately how many children with a diagnosis of Attention Deficit Hyperactivity Disorder (ADHD) have you worked with throughout your professional career?

Approximately how many children with a diagnosis of an Anxiety Disorder have you worked with throughout your professional career?

Did you have any experience of working with children with any of the below diagnoses prior to beginning your teacher training, either in a voluntary or paid capacity? Please tick all that apply.

- Anxiety Disorder
- Attention Deficit Hyperactivity Disorder (ADHD)
- Autism Spectrum Disorder (Autism or Asperger's)
- Disruptive Behavioural Disorder (Oppositional Defiant Disorder or Conduct Disorder)
- None of the above

Do you have personal experience of any of the following e.g. through relatives, colleagues, friends? Please tick all that apply.

- Anxiety Disorder
- Attention Deficit Hyperactivity Disorder (ADHD)
- Autism Spectrum Disorder (Autism or Asperger's)
- Disruptive Behavioural Disorder (Oppositional Defiant Disorder or Conduct Disorder)
- None of the above

#### Display this question if:

I am currently practising as a Teacher OR I am another member of teaching staff (e.g. SENCO, Teaching Assistant etc.) OR I am trained as a Teacher but no longer practising OR I was previously another member of teaching staff (e.g. SENCO, Teaching Assistant etc.)

Have you received any specific training (e.g. CPD courses) on any of the following since obtaining your primary qualification? Please tick all that apply.

- Anxiety Disorder
- Attention Deficit Hyperactivity Disorder (ADHD)
- Autism Spectrum Disorder (Autism or Asperger's)
- Disruptive Behavioural Disorder (Oppositional Defiant Disorder or Conduct Disorder)
- None of the above

#### END OF SURVEY - Please click to the next page to fully submit your responses

We would like to thank you for your participation in this research project. Now you have completed the survey, we would like to request that you do not share any details of this questionnaire to others to ensure any future responses are not invalidated. We thank you for your co-operation with this.

What if I have been affected by this study? If you find yourself feeling distressed or upset as a result of your participation, please contact the research principal investigator or researchers who will be able to provide information for accessing resources or services which you may find helpful.

What if I have questions about the project? If you have any questions or would like to know more information about the study, please contact the researchers using the contact details below:

**Researchers:** Alana Whitlock, University College London, 1-19 Torrington Place, London WC1E 7HE, Email: Alana.whitlock.16@ucl.ac.uk Kate Fulton, University College London, 1-19 Torrington Place, London WC1E 7HE, Email: kate.fulton.13@ucl.ac.uk

**Principal Investigator:** Dr William Mandy, University College London, 1-19 Torrington Place, London WC1E 7HB, Tel: 020 7679 5922, Email: will.mandy@ucl.ac.uk

If you feel you require any additional support or participation has harmed you in any way, you can contact the principal investigator using the details above for further advice and information.

As a further thank you for your participation in our study, we would like to donate £5 to a charity of your choice. If you are interested in this, please pick from the list below and we will donate on your behalf.

- MIND
- NSPCC
- UNICEF