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Seen but not heard: School-based professionals' oversight of autism in children from ethnic minority groups

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ABSTRACT

Previous studies have shown that ethnic background hinders clinician detection of autistic features in children from non-western minority groups. The use of a structured instrument during evaluation of these children can reduce the risk of hindered detection. The aims of the current studies were to establish the extent of school-based professionals' involvement in detecting autism and to replicate earlier findings of autism detection amongst school mentors. Results showed that school-based professionals were reported to be the first to suspect autistic features in 20% of children later diagnosed with autism. Additionally, school-based professionals refer to autism more often when judging children from majority than children from minority groups. However, using a structured instrument did not eliminate this bias. Providing these professionals with culture-sensitive education may help maximise their involvement in detecting autism amongst children from *all* ethnic backgrounds.

1. Introduction

An autism spectrum disorder (ASD) is a complex lifelong neuro-developmental condition with detrimental effects on one's social functioning. An ASD is characterised by deficits in social interaction and communication as well as unusually narrow interests and activities (American Psychological Association (APA), 2013). The early identification – and diagnosis of ASDs is vital for implementing early interventions which are essential for the well-being of individuals with an ASD (American Academy of Pediatrics (AAP), 2001; Bryson, Rogers, & Fombonne, 2003; Rogers & Vismara, 2008). However, various factors may hamper the detection of ASD symptoms. For example, female gender (Begeer et al., 2013) and low-income (Mandell & Palmer, 2005) are associated with delayed identification. Ethnic background may also complicate the detection of autism. It has, specifically, been shown to delay the detection of autistic features in paediatricians (Begeer, El Bouk, Boussaid, Meerum-Terwogt, & Koot, 2009). However, like most deviant behaviour, autism is often first detected by adults in the child's environment who *subsequently* consult a paediatrician for evaluation (Verhulst & Koot, 1995). Besides parents, school-based professionals are likely to play a role in the detection of psychological problems in children. However, research to date has not investigated school-based professionals' ability to evaluate symptoms of autism in young children. The aim of the current study was firstly, to establish the extent to which school-based professionals contribute towards the

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detection of ASDs in school-aged children and secondly, to examine the influence of children's ethnic background on school-based professionals' perceptions of autistic features.

Children from ethnic minority groups are under-represented within institutions treating autism (Begeer et al., 2009). In particular, minority children in the Netherlands (Moroccan and Turkish) are found to be under-diagnosed with autism in comparison to their native counterparts. This problem may be linked to health-care professional's perceptions of autistic features amongst ethnic minority-group children (Cuccaro & Wright, 1996), as well as their education, which may have been tailored to represent the majority culture (Betancourt, Green, Carrillo, & Park, 2005). However, a simple checklist, asking health-care professionals to consider the likelihood of a number of mental-health disorders, including autism, eliminated biased paediatricians' perceptions (Begeer et al., 2009). Presumably, this checklist encouraged paediatricians to consider the possibility of autism as an explanation for the symptoms as opposed to overemphasising explanations such as cultural differences or problems related to immigrant status. Access to mental-health care for children from ethnic minority groups may thus be hindered by biased clinical judgments. This conclusion is in accordance with other research reporting minority-related discrepancies in public health-care (van Ryn & Burke, 2000; van Ryn & Fu, 2003), and specifically with regards to ASDs (Mandell et al., 2009; Shattuck et al., 2009; Thomas, Ellis, McLaurin, Daniels, & Morrissey, 2007). The detection of ASD symptoms may be increased by using culture-sensitive assessment (El-Ghoroury & Krackow, 2012) or the use of structured instruments (e.g. Honigfeld, Chandhok, & Spiegelman, 2011; Robins, Fein, Barton, & Green, 2001).

The idea that structured instruments facilitate objectivity during the diagnostic procedure is not new; the efficacy of such measures is favourable across the board of diagnostic categories (e.g. Hirschfeld et al., 2000; Reijneveld, Vogels, Hoekstra, & Crone, 2006). Research shows however, that there is great variability in screening and evaluation of children amongst professionals in health-care, with greater tendency to rely on spontaneous judgement as opposed to structured instruments (Sices, Feudtner, McLaughlin, Drotar, & Williams, 2003). Spontaneous judgement may be influenced by choice of diagnostic strategy and knowledge, both of which are related to experience as a health-care professional (Elstein & Schwarz, 2002). Variability in evaluation methods is also likely to be reflected in school environments where there is currently no standard practice for screening of mental-health development (Weist, Rubin, Moore, Adelsheim, & Wrobel, 2007). These findings suggest that (particularly inexperienced) health-care professionals' current evaluation techniques are subject to biases which may influence children's outcomes.

To date, bias towards children with an ASD from ethnic minority groups has been shown only in paediatricians. How other professionals compare to paediatricians is yet to be determined. Receiving an ASD diagnosis can be a long and arduous process. Professionals filter patients along the way thereby managing access to help (Verhulst & Koot, 1995). Alongside paediatricians, general practitioners, psychiatrists and psychologists are involved in the filtering process. These professionals however, are second and even third 'filters'. By the time a child has reached one of these professionals, he has already passed through a *community* filter. Parents are often the first to raise the alarm at a community level but other adults are also in a position to do this. The most significant of these are school-based professionals. Teachers for example, regularly observe and interact with children from an early age and are reliable and accurate informants on their behaviour (Kerr, Lunkenheimer, & Olson, 2007; Verhulst, Dekker, & van der Ende, 1997). School-based *health* professionals are also present at most schools. Amongst them are school mentors who, in the Netherlands, are responsible for monitoring both academic progress and social-emotional well-being of children. The role is, in many respects, comparable to that of the school counsellor in the USA (see Keys, Bemak, & Lockhart, 1998). These professionals are in an optimal position to recognise problematic behaviour early in development and initiate the process of diagnostic assessment where necessary (Zwaanswijk, Van Der Ende, Verhaak, Bensing, & Verhulst, 2005). A recent report addressing school mentors' responsibilities indicated their main tasks as 'evaluating pupils' and 'visiting and liaising with teachers in lessons' (Vrieze & van Gennip, 2007). These descriptions suggest that school mentors work continuously and collaboratively with school teachers to manage problems expressed by children at school.

Research investigating the involvement and accuracy of school-based professionals in detecting ASDs is scarce and non-existent regarding potential ethnic bias in ASD detection. However, Mandell and Palmer (2005) reported education-related spending to be positively associated with ASD prevalence in the USA. The authors hypothesised that this may be related to the contribution of school-based professionals who are able to recognise ASD symptoms in children. The attitude and approach of school-based professionals are thus of great interest for examination. As a *first* and frequent point of contact for children, their objectivity and accuracy is imperative in early identification of ASDs and specifically amongst children from ethnic minority groups.

In the current study, we aimed to determine the number of children for whom ASD is first detected by school-based professionals *and* to compare the age at first detection of an ASD by school-based professionals vs. other ASD detection sources (Study 1). A large national sample of individuals with an ASD was utilised to do this. Once we established the *extent* of school-based professionals' contribution to identifying ASDs in study one, we then examined their *objectivity* when judging children with an ASD from various ethnic backgrounds (Study 2). In doing so we aimed to replicate earlier findings in a sample of paediatricians (Begeer et al., 2009), and also to directly compare our findings with school-based professionals to those of paediatricians. An analogue design was used to examine school-based professionals' perceptions of ASD symptoms in relation to ethnicity. School-based professionals' judgments were measured with an open question (spontaneously) and a checklist (structured instrument). Children from minority groups were expected to elicit fewer *spontaneous* references to ASD than children from the majority group. However, *structured* ratings of ASD were not expected to differ between child from ethnic minority groups and those from the majority group.