

# Autism identification across ethnic groups: a narrative review

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## Abstract

**Purpose** – *The purpose of the paper is to review autism identification across different ethnic groups. Diagnosis of autism may be missed or delayed in certain ethnic groups, leading to such groups being underserved relative to their needs. This can result in members of such groups being effectively denied essential avenues of support that can substantially improve the quality of life of autistic persons as well as those whom care for them.*

**Design/methodology/approach** – *A literature search for articles reporting autism identification across ethnic groups was undertaken. Data are compared, with a special focus on possible explanations for any inter-group variation.*

**Findings** – *Autism identification appears to be generally lower in minority ethnic groups relative to the majority population. Individuals presenting with autism from minority groups appear to have more severe forms of the condition.*

**Originality/value** – *There are a multitude of potential explanations for inter-ethnicity variation in autism identification, including health care-related factors, broader environmental influences, cultural factors and possible biological differences. Implications for clinical practice and public health include a need to look at means of ensuring equitable access to relevant autism diagnostic and support services across ethnic groups. Further work is required to better understand the belief systems that operate within specific ethnic groups, how this may potentially impact upon autism identification and measures to address the concerns of such groups.*

**Keywords** *Autism, Diversity, Ethnicity, Epidemiology, Pervasive developmental disorder*

**Paper type** *Literature review*

## Introduction

Autism spectrum disorders (hereafter referred to as autism) are lifelong neurodevelopmental conditions associated with atypicalities in reciprocal social interaction and communication, as well as restricted, stereotyped and repetitive behaviours (World Health Organization, 1992). Ethnicity describes the belonging to a certain social group with a common national or cultural tradition (Oxford University Press, 2020). Within minority ethnic groups, people share commonalities and experiences on areas such as diet, religion, migration experience, language, education and health behaviours (Agyemang *et al.*, 2005). Autism appears to be under recognised, misdiagnosed or diagnosed late in many vulnerable and/or disadvantaged groups, including females (Loomes *et al.*, 2017), homeless persons (Churchard *et al.*, 2019) and adults using psychiatric services (Tromans *et al.*, 2018; Brugha *et al.*, 2020). Disadvantages in obtaining a diagnosis may be similarly exacerbated in ethnic minority groups (Mandell *et al.*, 2009), in keeping with disparities observed in other conditions, such as diabetes and hypertension (Kim *et al.*, 2018).

This literature review aims to discuss the current research investigating autism identification across ethnic groups. As current understanding around the influence of ethnicity on autism

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Received 10 March 2020  
Revised 23 May 2020  
Accepted 23 May 2020

identification is limited ([Becerra et al., 2014](#)), it is essential for health-care professionals to develop insight into the presentation of autism across different ethnic groups ([Mandell et al., 2007](#)). Thus, this review is primarily intended for an international audience of health-care professionals involved in autism assessment and diagnosis.

## Methodology

A literature search was conducted for articles reporting and/or discussing autism identification across different ethnic groups, using the PubMed, Medline and Google Scholar databases, from 7-12 January 2020. In keeping with a narrative review design, the authors did not apply strict eligibility criteria ([Ferrari, 2015](#)). Further articles were identified through the ancestry method for already included studies, as well as consultation with professionals with expertise in autism research. Though our intent was to obtain an international perspective, our search was limited to articles published in English language. Though minority ethnic groups vary between or within countries, within the context of autism research, we consider any research on populations outside of the majority ethnic population as minority ethnic for the purposes of this paper. We identified recurrent themes from the articles included in the review.

## Differences in autism identification: findings across ethnic groups

Our review highlighted several differences in autism identification rates across ethnic groups ([Table 1](#)).

A literature review by [Zaroff and Uhm \(2012\)](#) found that whilst autism identification varied greatly across countries, it appeared as if this was predominantly a result of methodological variables, such as the diagnostic methods and criteria used in different studies. Thus, studies should be compared with due caution.

A North American multi-centre study involving analysis of health and educational records of 2,568 8-year-old children found that black, Hispanic or other non-white children were less likely to have documented autism relative to their white peers ([Mandell et al., 2009](#)). Earlier findings by [Kogan et al. \(2008\)](#) showed similar trends when analysing data from the 2005–2006 National Survey of Children with Special Health Care Needs ([Blumberg et al., 2008](#)). For Hispanic and Asian children, this disparity in identification was largely concentrated within those with co-occurring intellectual disability (ID), though in black children the disparity persisted irrespective of the child's intelligence quotient. An additional North American population-based study found higher rates of autism with co-occurring ID among children born to black mothers relative to their white peers, with rates increasing substantially when only those whose mothers were born outside of North America were considered [1] ([Becerra et al., 2014](#)).

A study by [Begeer et al. \(2009\)](#), involving 81 paediatricians each judging a sample of 6 clinical vignettes of child patients from different ethnic backgrounds (European majority – Dutch; European minority; and non-European minority), found that cases of European majority (Dutch) cases were more likely to be judged as having features of autism when compared to their non-European minority (Moroccan or Turkish) peers.

A study in England investigated the impact of maternal ethnicity and immigration on observed rates of autism in their offspring, via retrospective analysis of 428 recorded diagnoses of autism in children in two child developmental centres ([Keen et al., 2010](#)). They observed that mothers born outside Europe had a significantly increased likelihood of having a child with a recorded diagnosis of autism, compared to mothers born in the UK, with mothers of black ethnicity having a significantly higher likelihood relative to white mothers. However, once immigration was controlled for, there was little evidence to support an independent ethnicity-based effect on likelihood of autism diagnosis. A similar

**Table 1** Reported autism identification rates in different ethnic groups across selected studies

Study	Population and setting	Study design	Diagnostic criteria	Autism identification rates <sup>a</sup>
<i>Autism and Developmental Disabilities Monitoring (ADDM) Network (Centers for Disease Control and Prevention, 2019)</i>				
<a href="#">Durkin et al. (2017)</a>	Data for 8-year-old children in 4 surveillance years (2002, 2006, 2008 and 2010), collected as part of the work of the Centers for Disease Control and Prevention (CDC) ADDM Network. 11 US states participated: Alabama, Arizona, Arkansas, Colorado, Georgia, Maryland, Missouri, New Jersey, North Carolina, Utah and Wisconsin	Population-based surveillance study	DSM-IV-TR (American Psychiatric Association, 2000)	2002 Surveillance Year: Non-Hispanic white 0.67% (95% CI = 0.64-0.70) Non-Hispanic black 0.59% (95% CI = 0.54-0.65) Hispanic 0.39% (95% CI = 0.34-0.45) Combination of 2006, 2008 and 2010 surveillance years: Non-Hispanic white 1.32% (95% CI = 1.29-1.35) Non-Hispanic black 1.11% (95% CI = 1.06-1.16) Hispanic 0.80% (95% CI = 0.76-0.84) Confirmed autism cases: White 1.36% (95% CI = 1.29-1.44) Black 0.93% (95% CI = 0.80-1.08) Hispanic 0.90% (95% CI = 0.81-1.00) Asian 0.77% (95% CI = 0.59-1.00) Adjusted autism case counts <sup>b</sup> White 1.42% (95% CI = 1.34-1.50) Black 0.93% (95% CI = 0.80-1.08) Hispanic 0.94% (95% CI = 0.85-1.04) Asian 0.85% (95% CI = 0.66-1.10)
<a href="#">Imm et al. (2019)</a>	Analysis of ADDM network data for children from Colorado and Wisconsin (the USA) for surveillance years 2012 and 2014. The authors used multiple approaches to impute any missing information (health records were more likely to be missing for children of black and Hispanic ethnic groups). Additionally, previous autism case counts were adjusted by adding children who were thought to be likely to have resided in the surveillance region on re-review but could not confirm residency and had a previous autism diagnosis in their records	Population-based surveillance study	DSM-IV-TR	
<a href="#">Mandell et al. (2009)</a>	The study population was all 2,568 meeting autism case definition as defined by the ADDM network for the 2002 study year. 14 US states participated, including Alabama, Arizona, Arkansas, Colorado, Georgia, Maryland, Missouri, New Jersey, North Carolina, Pennsylvania, South Carolina, Utah, Wisconsin and West Virginia	Population-based surveillance study	DSM-IV (American Psychiatric Association, 1994)	Odds ratios: White (ref) 1.00 Black 0.79 (95% CI = 0.64-0.96) Hispanic 0.76 (95% CI = 0.56-0.99) Asian 0.91 (95% CI = 0.52-1.56) Other 0.65 (95% CI = 0.43-0.97)
<i>National Survey of Children with Special Health Care Needs (Centers for Disease Control and Prevention, 2015)</i>				
<a href="#">Jo et al. (2015)</a>	Data collected from the 2009-2010 National Survey of Children with Special Health Care Needs (NS-CSHCN), a random-digit-dial telephone survey. The study population included 2,729 US-based children (3-17 years) with an autism diagnosis	Telephone survey	Asking parents if child has been diagnosed with autism by a health-care professional	Non-Hispanic white 1.53% Non-Hispanic black 1.04% Hispanic-English 1.41% Hispanic-other 0.52%
<a href="#">Kogan et al. (2008)</a>	Data collected from the 2005-2006 NS-CSHCN. The study population included 2,088 US-based children (3-17 years) with an autism diagnosis	Telephone survey	Asking parents if child has been diagnosed with autism by a health-care professional	Non-Hispanic white 1.00% Non-Hispanic black 0.81% Non-Hispanic other 0.68% Hispanic 0.55%

(continued)

Table 1

Study	Population and setting	Study design	Diagnostic criteria	Autism identification rates <sup>a</sup>
<i>Other Studies</i> <b>Becerra <i>et al.</i> (2014)</b>	Children born in Los Angeles County with a diagnosis of autism at ages 3-5 years from 1998-2009	Populated-based surveillance study	DSM-5 ( <a href="#">American Psychiatric Association, 2013</a> )	<i>Crude rates of autism diagnosis:</i> White (US born) 0.63% White (Foreign born) 0.66% Black (US born) 0.43% Black (Foreign born) 0.91% Hispanic (US born) 0.44% Hispanic (Foreign born) 0.36% Asian (US born) 0.64% Asian (Foreign born) 0.64%  In combining the 2007 and 2014 data sets, 31 adults with autism were identified, none of whom were from an ethnic minority. However, there was a small minority of minority ethnic respondents to the survey and the authors recommend that this finding be interpreted with caution
<b>Brugha <i>et al.</i> (2009), McManus <i>et al.</i> (2016)</b>	The 2007 and 2014 iterations of the England-based Adult Psychiatric Morbidity Survey, involving 16-64-year-old adults living in the community. Involved a two-phase design, whereby autism quotient ( <a href="#">Baron-Cohen <i>et al.</i>, 2001</a> ) score would determine likelihood of being invited to the second phase, involving ADOS assessment ( <a href="#">Lord <i>et al.</i>, 2000</a> )	Population-based prevalence survey	A score of $\geq 10$ on ADOS assessment	White 1.12% Black or African American 0.87% Asian 1.04% Hispanic 0.67% American Indian or Alaskan Native 0.67% Native Hawaiian/Pacific Islander 0.62%  Two or more races 1.06% Caucasian 1.07% Asian 0.93% Black 1.16% Indian, Maori or Polynesian 0.27% Indigenous 0.46%
<b>Dickerson and Dickerson (2018)</b>	Children based in Texas, USA. Data was obtained from the Texas Education Agency Division of Research for 1,225 districts for the 2013-2014 academic term.	Populated-based surveillance study	DSM-IV-TR <sup>c</sup>	White 2.07% (95% CI = 1.83-2.34) Black (non-Somali) 2.77% (95% CI = 2.31-3.31) Somali 3.08% (95% CI = 2.16-4.38) Hispanic 1.25% (0.87-1.79)
<b>Fairthorne <i>et al.</i> (2017)</b>	Children born to all women in Western Australia from 1994-2005. Surveillance data was obtained from the Midwives Notification System and the Western Australia Birth Register ( <a href="#">Government of Western Australia, 2020</a> ), as well as the Intellectual Disability Exploring Answers Database ( <a href="#">Petterson <i>et al.</i>, 2005</a> )	Retrospective cohort study	DSM-IV and DSM-IV-TR	White 2.07% (95% CI = 1.83-2.34) Black (non-Somali) 2.77% (95% CI = 2.31-3.31) Somali 3.08% (95% CI = 2.16-4.38) Hispanic 1.25% (0.87-1.79)
<b>Hewitt <i>et al.</i> (2016)</b>	This study, entitled the Minneapolis Somali Autism Spectrum Disorder Prevalence Project, used previously established methodology used by the CDC ADDM network. The study population was 7-9-year-old children who had one parent or legal guardian living in the city of Minneapolis, the USA	Population-based surveillance study	DSM-IV-TR	White 2.07% (95% CI = 1.83-2.34) Black (non-Somali) 2.77% (95% CI = 2.31-3.31) Somali 3.08% (95% CI = 2.16-4.38) Hispanic 1.25% (0.87-1.79)
<b>Keen <i>et al.</i> (2010)</b>	Case notes of 428 UK-based children diagnosed with autism within two centres (Lambeth Borough and Wandsworth Borough) over a 6-year timeframe	Retrospective case-note analysis	Autism diagnostic interview-revised ( <a href="#">Lord <i>et al.</i>, 1994</a> ), Diagnostic Interview for Social and Communication	<i>Annual Incidence of Autism by Maternal Ethnicity (per 1,000):</i> Lambeth Borough: White 0.11; Black 0.90; Asian 0.67 Wandsworth Borough: White 0.49; Black 1.88; Asian 0.60

(continued)

Study	Population and setting	Study design	Diagnostic criteria	Autism identification rates <sup>a</sup>
<a href="#">Levaot <i>et al.</i> (2019)</a>	Retrospective analysis of clinical and demographic characteristics of 318 Bedouin-Arab and Jewish children evaluated in a Southern Israel-based autism centre	Retrospective case-note analysis	Disorders ( <a href="#">Wing <i>et al.</i>, 2002</a> ) and ADOS DSM-5	Bedouin-Arab 0.26% Jewish 1.55%
<a href="#">Mahajnah <i>et al.</i> (2015)</a>	Retrospective analysis of clinical and demographic characteristics of 200 Jewish and Arab children evaluated in two North-western Israel-based child development centres from 2008-2013.	Retrospective case-note analysis	DSM-IV	Jewish 0.43% Arab 0.38%
<a href="#">Xu <i>et al.</i> (2018)</a>	Data collected from the US-based National Health Interview Survey ( <a href="#">Parsons <i>et al.</i>, 2014</a> ), involving in-person household interviews of adults pertaining to a randomly selected child (3-17 years) within the household.	In-person survey	Asking parents if child has been diagnosed with autism by a health-care professional	Non-Hispanic white 2.76% (95% CI 2.39-3.13) Non-Hispanic black 2.49% (95% CI 1.69-3.29) Hispanic 1.82% (95% CI 1.42-2.22) Other 2.48% (95% CI 1.77-3.19)

**Notes:** With the exception of [Brugha \*et al.\* \(2009\)](#) and [McManus \*et al.\* \(2016\)](#), all studies were focussed on child populations; <sup>a</sup>Findings detail identification rates as a percentage value unless otherwise stated; <sup>b</sup>Including confirmed autism cases with missing race/ethnicity data imputed and additional likely autism cases excluded because of missing residency information; <sup>c</sup>However, to be recognised as having autism in the study, a child meeting DSM-IV-TR criteria would also need to be considered as displaying educational deficits and be in receipt of special education and related services

association has been observed between immigration and psychosis, suggesting the possibility of selective immigration of individuals with such conditions (Keen *et al.*, 2010).

However, an Australia-based study (Fairthorne *et al.*, 2017) found that children born to immigrant mothers were approximately 40% less likely to receive an autism diagnosis. This may reflect the differing immigration policies of Australia and the UK. Equally, there may also be an inequality of access to assessment and diagnostic services for immigrant ethnic groups relative to non-immigrant groups, the nature of which may vary according to the specific country, ethnic groups and health-care systems concerned (Keen *et al.*, 2010). However, an ethnicity-based difference in identification rates was observed with indigenous mothers being approximately half as likely to have a child with an autism diagnosis compared to their non-immigrant Caucasian peers. The authors suspected that this might be related to indigenous people within Western Australia often living in remote areas, with reduced access to diagnostic services.

There is mixed evidence as to whether ethnicity affects the age at which autism assessment is sought. In a North American-based study, Mandell *et al.* (2002) found that Caucasian children received an autism diagnosis at an average age of 6.3 years, compared to 7.9 years for African American and 8.8 years for Hispanic children. Suggested factors contributing towards the later average age of diagnosis in Hispanic children relative to their Caucasian and African-American peers have included language barriers, less awareness of autistic features and a reluctance to seek professional support unless having severe difficulties (Chaidez *et al.*, 2012). Additionally, African-American children required three times the number of visits over three times as long as white children before receiving an autism diagnosis, though white children tended to commence the assessment process at an earlier age. Jo *et al.* (2015) also observed a similar pattern of later autism diagnoses among minority ethnic groups. However, Jang *et al.* (2014), in studying Caucasian, African-America, Hispanic and Asian ethnic groups, found no significant difference between groups with regard to the age at which caregivers would first report concerns.

### Possible explanations for inter-ethnicity variation in the recognition or diagnosis of autism

The literature suggested a multitude of potential explanations for inter-ethnicity differences in autism identification, broadly falling into the categories of health care, environmental, cultural and biological (Table 2).

#### *Health care*

Ethnic minorities often receive reduced access to or quality of health-care services than non-minority groups, because of inequalities such as discrimination or a lack of insurance (Nelson, 2002; Gourdine *et al.*, 2011). One factor that could underlie observed disparities in autism identification across ethnic groups may be referral biases among health professionals and institutional racism (Gourdine *et al.*, 2011). Professionals may be more likely to attribute social and communication problems to an individuals' ethnic background, which would lead to under-diagnosis of autism in minority groups, resulting in individuals being denied support services (Billstedt *et al.*, 2011). Ratto *et al.* (2016) evaluated the diagnostic experiences of Latino and white mothers of autistic children within the USA. There were no differences in the average age at which mothers raised concerns about their child, yet Latino families experienced a delay in diagnosis relative to their white peers.

Biases may also exist within diagnostic tools. Although diagnostic tools such as the autism diagnostic interview-revised and Autism Diagnostic Observation Schedule (ADOS) generally increase the quality and consistency of autism diagnostic assessment (Risi *et al.*, 2006), such tools may be biased towards the ethnicity and context of tool developers, alongside the validation/normative population. In spite of cultural variance across



**Table 2** Potential explanations for observed inter-ethnicity variation in autism identification rates

Category	Examples
Health care	Health-care professional bias Lack of awareness of health-care service availability within certain ethnic groups In-built bias related to autism diagnostic tools Access to health-care facilities Geographical-/ethnicity-based bias in related research literature Patients and caregivers descriptions of symptoms Lack of complete health care or educational records Methodological variation across studies (e.g. diagnostic methods and criteria)
Environmental	Different environmental exposures in certain ethnic groups Pre-natal environmental exposure (e.g. maternal vitamin D deficiency during pregnancy) Family migration to areas with more services for people with autism Different rates of immigration Differences in socio-economic status Language difficulties Parental education level Living in remote areas
Cultural	Ethnicity-based belief systems, such as wariness of obtaining a diagnosis and cultural understanding of neurodevelopmental conditions Greater social stigma within certain ethnic communities Cultural norms and expectations (e.g. eye contact, language, social skills) Language, particularly descriptions of early presentation Fictional portrayals of autistic persons in various forms of media
Biological	Maternal age Reduced/increased genetic susceptibility in certain ethnic groups Higher rates of parental consanguinity in certain ethnic groups

populations, [Carruthers et al. \(2018\)](#) showed universality in autism quotient screening tool items that are predictive of autism amongst children from India, Japan and the UK. Acceptable or excellent discrimination across all three geographies was found in 28 items and key indicators included “he/she enjoys social chit-chat”; “he/she knows how to tell if someone listening to him/her is getting bored”; and “he/she finds it difficult to work out people’s intentions”. Others appeared more prone to cultural bias, such as spontaneity in behaviour, one-sided conversation style, understanding of humour and enjoyment of social occasions.

Additionally, norms and expectations differ across ethnic communities, including features such as eye contact, language and the development of social skills, influencing the emphasis patients or caregivers place on differences observed within these domains ([Perepa, 2014](#)). [Wilford \(2012\)](#) discussed the importance of incorporating cultural differences in diagnostic tools for autism, highlighting how a lack of cultural awareness from health-care professionals could impact on diagnostic decision-making. Thus, assessment tools and diagnostic instruments may need to be adapted depending on the ethnic group of the individual being assessed ([Carruthers et al., 2018](#)). [Wilford \(2012\)](#) highlighted the importance of awareness of the cultural norms, perceptions and social structures of minority ethnic populations, detailing how black South African children behaved very differently to their white peers. For example, eye contact expectations vary within cultures; in Zulu cultures, it is considered rude for a child to look into the eyes of an adult speaking to them.

### Environmental

Different trends in environmental exposures across ethnic groups may contribute to variance in autism identification. Such exposure may take place in the prenatal period, for example, a lack of Vitamin D in pregnant mothers who typically wear clothes that cover their

entire bodies (Levaot *et al.*, 2019). Living in remote areas and/or regions where health-care resources are scarce could also impact the likelihood of having autism identified. There may be less incentive for diagnosis seeking in such settings, because of reduced availability of post-diagnostic support (Fairthorne *et al.*, 2017). Another factor is socioeconomic status, particularly in countries lacking a system of universal health care (Rai *et al.*, 2012; Durkin *et al.*, 2017), and this would disproportionately impact ethnic groups within which higher rates of socioeconomic deprivation exist.

In a North American study, schools were identified as the most important source of diagnosis for African-American children with younger mothers and those mothers with fewer than 12 years of education. It was also highlighted that the high rates of cognitive impairment (in 68% of cases) demonstrate that diagnostic and service rates are not capturing a potentially large number of children who have higher cognitive functioning (Yeargin-Allsopp *et al.*, 2003).

### *Cultural*

Cultural differences, religious beliefs and family traditions are all factors that affect the “minority experience” of autism (Heer *et al.*, 2012). Differences in cultural understanding of neurodevelopmental conditions, languages spoken and parental education all impact autism recognition among minority ethnic groups (Bailey and Arciuli, 2020). The knowledge and awareness of autism within ethnic minority populations influences ethnic parents’ recognition of autism and seeking of diagnostic assessment, thus impacting identification rates (Bailey and Arciuli, 2020).

Dickerson and Dickerson (2018) demonstrated that language difficulties possibly impact receipt of a diagnosis, finding that autism prevalence estimates were significantly lower for white children from non-English speaking homes compared to English speaking counterparts. Indeed, a survey of families of children with autism described English proficiency as an important barrier to diagnosis within the Latino community (Zuckerman *et al.*, 2017). Autism is considered a “new word” in many languages and generally perceived as a foreign condition affecting mainly white populations (Fox *et al.*, 2017). Patients and caregivers from different ethnic groups may also describe their symptoms and experiences differently to health-care professionals, impacting on the likelihood that such features are deemed consistent with a diagnosis of autism (Mandell *et al.*, 2007). Language differences may lead clinicians away from an autism diagnosis, for example, Latino mothers have been reported as more likely to raise initial concerns about temperament (Ratto *et al.*, 2016). Language difficulties and parental education level in certain ethnic groups could impact the ability of caregivers to assert themselves sufficiently to obtain an autism assessment and/or be sufficiently familiar with the condition to recognise it in someone they know.

Belief systems may contribute to observed identification rates. For example, perceptions of persons with autism as being dangerous or a fear of being identified by wider society as autistic, may be more prevalent in minority groups, contributing to a delay in seeking assessment (Burkett *et al.*, 2015). Stigma surrounding autism may be a factor in observed differences in identification rates across ethnic groups. Burkett *et al.* (2015) conducted observations and in-depth interviews with 28 African-American family members of autistic children. Family members cited widespread stigmatisation of disability within the African-American community, promoting a culture of delay or avoidance of seeking assessment or professional input. Stigmatisation of autism also appears prevalent in Arab communities (Khowaja *et al.*, 2015). Additionally, Arab families often view mental health services as being insensitive of Islamic values, contributing to a reluctance to engage (Al-Krenawi *et al.*, 2009).



The hidden nature of autism in some populations leaves room for misconceptions, which subsequently perpetuates poor knowledge, awareness and negative cultural beliefs about autism within ethnic communities (Burkett *et al.*, 2015). However, Pruchno *et al.* (1997) suggested that many African Americans accept their roles as a caregiver for a family member with a disability more readily, reporting lower levels of depression, anger and hostility in this role. Dilworth-Anderson and Anderson (1994) found that African Americans may perceive unique benefits and satisfaction from care giving, which may stem from their cultural experiences, social support networks, church participation and the perception that a disabled child is a gift from God (Gourdine *et al.*, 2011).

Levaot *et al.* (2019) compared the characteristics of Bedouin-Arab and Jewish children referred to a Southern Israel autism clinic, reporting that referral rates from the Jewish group (21 per 1,000) were nearly six times higher than from the Bedouin-Arab group (3.6 per 1,000). Though the proportion of referred patients receiving an autism diagnosis was very similar (73% vs 74%), Bedouin-Arab children were significantly ( $p < 0.01$ ) more likely to be characterised as having more severe autism, requiring a more substantial degree of support. The authors suggested that Bedouin-Arab children with milder manifestations of autism were less likely to come to the attention of health-care professionals compared to their Jewish peers. This finding is supported by another Israeli-based study, which found that Arab patients presented with more severe manifestations of autism relative to Jewish persons, as well as a higher prevalence of ID (Mahajnah *et al.*, 2015).

### **Biological**

In contrast to the previously discussed factors, which would likely principally impact autism identification rates, biological factors are more likely to impact on the true prevalence of autism. It is conceivable that individuals from certain ethnic groups may have genes that confer a greater tendency towards the clinical manifestation of autism relative to others.

Additionally, higher rates of parental consanguinity, such as in the Arab-Israeli population, may also contribute to increased autism prevalence, particularly for severe forms of the condition or where there is co-occurring ID (Mahajnah *et al.*, 2015). Ethnic groups associated with increased maternal age (>35 years), such as affluent westernised groups, could also be at an increased risk of autism in their offspring, particularly those without co-occurring ID (Leonard *et al.*, 2011).

### **Conclusions**

This narrative review has summarised the literature on autism identification across different ethnic groups. Autism identification generally appears to be under-represented in ethnic minorities when compared to the majority ethnic group. Potential explanations fall into health care, environmental, cultural and biological barriers to autism identification, which are likely to interact.

Health-care factors include widely held professional views and unconscious biases, which can significantly affect autism diagnosis, possibly more so in minority ethnic groups. Social and communication difficulties can be misattributed to ethnic background, contributing to bias in referral to diagnostic services and during diagnostic assessment (Begeer *et al.*, 2009). There is a lack of knowledge of minority ethnic group cultural norms among health-care professionals (Fong and Lee, 2017; Bailey and Arciuli, 2020). Autism diagnostic tools may be biased, having been validated in majority ethnic populations (Wilford, 2012). Additionally, diagnostic practices vary widely (Penner *et al.*, 2018) and further efforts to standardise assessment while providing guidance pertaining to ethnic group norms would help in addressing this. Patient- and caregiver-related factors can also present barriers to autism identification, and certain groups may have greater difficulties accessing diagnostic services because of language difficulties (Dickerson and Dickerson, 2018), cultural beliefs,

autism stigma (Burkett *et al.*, 2015) and the nature of symptoms reported to health-care professionals (Ratto *et al.*, 2016). In terms of environmental factors, disproportionate socio-economic disadvantage in ethnic minorities remains a key issue (Rai *et al.*, 2012), as well as living in remote areas (Fairthorne *et al.*, 2017).

## Limitations

This paper has several limitations. Excluding non-English language articles could have overlooked relevant evidence published in foreign languages. The preponderance of North American studies identified is likely to affect international generalisability, though it is important to note that the overwhelming majority of mental health publications in general come from the Western countries, with under-representation in areas such as Arab countries (Afifi, 2005). As with any narrative review, the quality is affected by its constituent studies. The research retrieved was predominantly focussed on child and adolescent populations, with a lack of data on adults, in keeping with trends observed in autism research more generally (Edwards *et al.*, 2012).

## Recommendations

Based on the findings of this narrative review, we make several recommendations for clinical practice and future research, which would improve autism identification in minority ethnic populations.

### *Clinical practice recommendations*

Regarding clinical practice, recommendations relate to curriculum and training of professionals, development of screening tools and assessments. There is a clear need for health-care professionals to be educated about the presentation of autism across ethnic groups. Professionals in a diagnostic role should be supported to develop their understanding of cultural differences in the presentation of autism in minority ethnic populations. As such, it is recommended that professional bodies and service providers review their curriculum, training needs and provision to ensure that training is amended to be diverse, e.g. by including specific examples of diagnostic criteria in different ethnic groups. It is imperative that training is offered to all staff, not only new entrants.

One approach to redressing the socio-economic disadvantage experienced by minority ethnic groups would be universal screening for autism across all children, as previously recommended by the American Academy of Paediatrics (Zwaigenbaum *et al.*, 2015). Another one of the identified issues was a lack of services in more remote areas (Fairthorne *et al.*, 2017). As such, building infrastructure for autism assessment and post-diagnostic support services is imperative.

Further to the need for cultural sensitivity within the assessment and diagnosis process, Fong and Lee (2017) highlighted the need for culturally sensitive interventions for patients, whose needs can be best met when addressed with respect to their socio-cultural contexts. Preliminary research has indicated promising outcomes, with Lopez *et al.* (2019) using a randomised-controlled trial design to highlight how culturally informed parent education interventions for Latino parents of autistic children improved outcomes, including access to services, social communication and the quality of life of the family unit. A final recommendation is the promotion of diversity within public awareness campaigns and in characters within fictional media, such as film and television (Tharian *et al.*, 2019). This would aid recognition of autism in minority ethnic people in both the general public and clinicians. Throughout this process, it is essential to consult with the particular ethnic group, to help avoid any offensive stereotypes or condescending messages (Nwankwo and Lindridge, 1998).

## Research recommendations

We recommend that future autism prevalence studies record ethnicity data on their subjects using methodology previously validated in large-scale surveys (Tromans *et al.*, 2019; McManus *et al.*, 2016). Genome-wide association studies may be able to illuminate whether certain inherited genetic variances associated with autism are more prevalent in specific ethnic groups (Robinson *et al.*, 2015). If individuals within certain ethnic groups are indeed found to have a greater propensity to developing autism, such knowledge can help inform future resource allocation for autism services. Research findings regarding cultural differences in the presentation of autism should be incorporated into screening and assessment tools. Qualitative research examining autism-related belief systems and diagnostic assessment experiences of individuals and their families within ethnic groups is vital. Such research will help inform approaches to ensuring equitable access to diagnostic and support services across ethnic groups, improving the lives of autistic persons and their caregivers, irrespective of ethnic group status.

## Note

- 1 Rates of autism with co-occurring ID (per 10,000 births): black (US-born mother): 6.3; white (US-born) 5.2; black (foreign-born) 12.9; and white (foreign-born) 5.5.

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## Further reading

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